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UNIVERSITY OF ALBERTA

UP BY THEIR OWN BOOTSTRAPS: REDEFINING DISABILITY THROUGH EMPOWERMENT AND COMMUNITY-BUILDING

BY
RENE ROBERT GADACZ

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE
OF DOCTOR OF PHILOSOPHY

DEPARTMENT OF ANTHROPOLOGY

EDMONTON, ALBERTA

SPRING, 1990

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled UP BY THEIR OWN BOOTSTRAPS: REDEFINING DISABILITY THROUGH EMPOWERMENT AND COMMUNITY-BUILDING, submitted by RENE ROBERT GADACZ, in partial fulfilment of the requirements for the degree of DOCTOR OF PHILOSOPHY in ANTHROPOLOGY.

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In Memory of
Leroy Thompson (1934-1986),
"Godfather" of the Alberta
Disabled Consumer Movement

ABSTRACT

This thesis describes the independent living/disabled consumer movement and the organizational strategies by which disabled people pursue the goal of integrated community living. The development of an independent living philosophy is part of the (disabled) consumer ethic that has emerged over the past decade. The disabled consumer and citizen is no longer the passive patient or client of treatment and services as under the charity and medical ethics, but has become empowered to participate in decision-making processes within the production-provision/consumer relationship.

As discussed in this study, empowerment is a developmental and transforming process constructed through action at both the individual and collective levels. Empowerment is defined as the ability to develop community structures; it is both the means and outcome of independent and integrated community living. Empowerment is at the core of community-building and, indeed, of "social movement." Social movement in turn refers to the motivations, attitudes, and abilities essential in playing a conscious and active role in the reform and reconstruction of one's social and political environment. The thesis discusses how empowered disabled citizens collectively attempt to produce new patterns of action in order to reconfigure the power structures that have historically been the source of their oppression, and to secure their self-determination.

Central to the disabled consumer independent living model is therefore an ecological perspective that focuses on the social structure, or social environment, in which disability occurs and in which disability is produced and maintained. Personal and collective self-determination involves the process of overcoming what are socially and culturally defined physical and mental "handicaps." Issues of human rights, equality rights, and reasonable accommodation in employment, housing, transportation, etc., thus concern revitalizing the concept of personhood. It is personhood that is seen ultimately as the basis of community life.

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Chapter 1

Introduction: Process and Action in Redefining and Decategorizing Disability

Perhaps it is unthinkable to conclude that modern society has no need for people with physical and mental impairments. This conclusion, however, is often reached by disabled people themselves. According to David Lepofsky, a Toronto lawyer,

> Disabled people in our society are a substantially numerous and substantially disadvantaged minority. Their experience is typified by unemployment rates that are radically higher than those that would be acceptable to anyone in the mainstream of society. We are concerned when unemployment goes from 7 percent to 10 percent for the mainstream. For disabled people, there is [sic] data that shows unemployment to be from 50 to 80 percent. The data also indicates [sic] that they are disproportionately impoverished and welfare dependent (Parliamentary Forum on the Status of Disabled Persons 1988: 7).

At the same time, those individuals who try to lead what may be called conventional lives tend to repress their pariah status and the patronizing attitudes of the able-bodied, and to internalize the values of the so-called normal or straight world. Autobiographical accounts repeatedly emphasize this (e.g. Kleinfield 1979, Vash 1981, Zola 1982, National Parliamentary Forum on the Status of Disabled Persons 1988, Secretary of State of Canada 1989). Writes Doreen Demas, a disabled student living in Winnipeg,

> All of a sudden I realized that in some ways I felt really different, that I wasn't like everybody else. I think I went all through school with that attitude -- that feeling

> of inferiority. So I think for a while I put all my efforts into being normal. Until one day I realized, normality was accepting myself for what I was. Once I broke out of that I found things so much easier. I've learned how to feel comfortable around people (Coalition of Provincial Organizations of the Handicapped 1987d: 60-61).

Personal accounts such as Doreen's are at the same time embarrassing and encouraging. On one hand, they are reminders of what little progress has actually been made towards the reintegration and "normalization" of disabled people; on the other hand, they are testimony to the patience and persistence of people attempting to extricate themselves from the tangled web of the politics of disability. Increasingly, however, disabled people are facing a choice between accepting the marginal existence in which they find themselves, and actively confronting and changing the social and economic life imposed on them.

Disabled people and those with whom they interact -- rehabilitation and medical professionals, service agency personnel, employers, and others -- are caught in power relationships that provide, as the case might be, little opportunity for self-determination or many chances for wielding direct power (Stubbins 1988: 22). Disability, of course, means many things. As examined in this dissertation, disability is a socially created category rather than an attribute of individuals. At the same time, disability is a formal administrative category that not only determines the rights and privileges of large numbers of people, but one that is also tied to concepts of control and responsibility (Stone 1984). Disability is "big business," notes Stubbins (1988: 22-23), one that provides health care practitioners, researchers, the prosthetics and pharmaceutical industries, insurance companies, and even academics with respectable livlihoods. It is those with political or economic interests in disabled people that define the problems, the agenda, and the social reality of disabled persons in ways that almost always serve their own interests more closely than those of their clients or cases. Indeed, definitions of disability themselves both reflect and are an outcome of political and economic interests.

Medical and rehabilitation technology has come a long way in solving the problems of a great variety of physical impairments by creating compensating or alternative ways of getting around, communicating, and of self-care so that only the most severely disabled might still require the intensive or long-term care of institutional settings (Stubbins 1988: 24). Significantly, much less progress has taken place in enabling disabled persons to become reinvolved in mainstream social and economic activities. In a way, advances in technology have transformed the central meaning of disability from a strict concern with physical aspects to an intense search for meaning in contexts of social isolation, under- or unemployment, and a bewildering number of imprisoning environmental barriers. The essence of disability, of course, is the social and economic consequences of being different from the "majority" (Ainlay, et. al. 1986). Being disabled, like being female rather than male, black rather than white, old instead of young, is regarded as a symptom of oppression and disadvantage. Disadvantages, however, inhere primarily in social relationships and structures (Stubbins 1988: 24). Indeed,

> Are the deaf, deaf; are blind persons really sightless? Or is it the social setting we place them in? In their social relations they communicate, they "see"..... We place them in specific social relations that make them deaf, an unwarranted and unjustified expectation on our part. We evaluate their abilities for them (Alberta Committee of Disabled Citizens 1981b: 14).

Disability, then, can be viewed as a particular kind of relationship between a person with a physical or mental impairment and the social and physical environment around him or her. This relationship can be characterized as a dominant-subordinate one, with able-bodied persons generally having power over those with impairments. This power relationship is manifested by the able-bodied with respect to imposed definitions (for example, saying that disability is intrinsic to the person rather than a feature of social relationships), control of the environment, and in the determination of the kinds of treatment, services, amenities, and programs deemed appropriate to the needs of disabled people. These characteristics of the relations between the disabled and able-bodied have tended to persist across time and space, specific individuals, and individual differences (Eisenberg, et. al. 1982). In fact, they are learned role relationships built into the structure of our institutions and our society. If power involves a relationship in which some people can constrain, coerce, and determine the behavior of others (with or without their conscious participation), then clearly the power of medical and rehabilitation practitioners and specialists resides in their credentials, ideology, authority, their roles as "experts" on disability, and in their control over access to program and welfare benefits and other similar scarce resources.

Power, of course, need not be conceived of only as brute force. In the modern state, an important source of power is the knowledge and techniques generated by science -- medical, clinical, or otherwise. This kind of power is not easily identified as emanating from economic and monopolistic sources, since it appears as neutral technical and scientific information (Foucault 1973, 1980). Medical, clinical, and rehabilitation practitioners may not be consciously aware of how their choices of techniques and treatments are tied to power considerations (Stubbins 1988: 26). Foucault's contribution has been to show the nature of that link in terms of the influences exerted on these practitioners by dominant political and ideological interests, and by the influence they in turn exert on their "clients" in carrying out their assigned duties. Information is one power resource used in exerting these influences. Disabled people, for example, may know far less about those with whom they interact than vice-versa. Until very recently, most disabled people knew practically nothing about the personnel, agencies and organizations under whose care they found themselves. By contrast, practitioners and specialists (and even their lowly assistants) get to know a great deal about the personal lives of disabled individuals, including very intimate details.

Not until the 1970s and 1980s were disabled persons a self-conscious constituency in the sense that medical practitioners or other kinds of "experts" are (Kallen 1989: 147). They depended a great deal on the latter for information, and to some extent still do. Indeed, because the technical and practical knowledge needs of professionals and disabled people are different, most disabled people still find themselves poorly situated to be aware of how their own interests might in fact be compromised. With respect to power and power relations between those who are disabled and those who are not, a related concern has to do with the "set of practices" (i.e. what Foucault calls the discursive formation) that gives coherence and rationality to what clinical and rehabilitation practitioners do. This set of practices (embodied in the medical/rehabilitation model that I discuss in Chapters 2 and 3) tends to reduce disability problems to dimensions and procedures that lie within relatively narrow technical disciplines and specializations. In fact, the moral problems arising from the status of disabled persons in society have increasingly been transformed into technical issues, somehow to be resolved by clinicians, scientists, and technocrats (Stubbins 1988: 29, Conrad and Schneider 1980).

Questions thus arise as to who mediates among competing claims to expertise in the field of disability, whether hegemonic control by one or another profession is justified in terms of the needs of disabled people, who determines those needs, and who should define the scope of the expertise required to deal with those needs. Bourdieu's (1977) notion of "field" as the locus of competitive struggles for the monopoly of symbolic capital among agents is probably applicable to the issue of professional leadership and supremacy in the field of disability. These questions get to the heart of what the status of being disabled means to the people who live it: impairment or social disadvantage, poverty resulting from personal deficit or from the socio-economic structure, isolation from stigma and deviance or socially sanctioned meaning, powerlessness or lack of social competence, and so forth.

Thus, whether one is personally blamed for one's impairment, labelled deviant and deemed socially incompetent, or whether one's powerlessness, poverty, and social and physical isolation is attributed to social structures really depends on who, e.g. which profession or which group in society, does the defining (Illich 1976, 1977).

Medical, rehabilitation and other kinds of experts have power over clients as well as over disabled individuals as a collectivity. These experts focus on certain features concerning the problematics of disability and they conceal or ignore others. Similar processes are probably also at work in such areas as law, economics, politics, or, really, wherever special interests are at stake (Stubbins 1988: 29). Whatever the origins of the current state of affairs regarding the status (or lack of it) of disabled people, it is likely that few medical and rehabilitation practitioners, social policy planners, or legislators have had much voice in creating it (ibid.). Nevertheless, as health care and social policy "experts" intervening in the lives of real people they have considerable influence (and interest) in maintaining and extending it (Stone 1984, Gritzer and Arluke 1985).

There is a widening gap, however, between the ideology and culture of professionals, experts, and that of disabled persons. Not surprisingly, there is disagreement over what the "problem" of disability is or with whom it lies. Much more specifically, there is serious disagreement over whether physical or psychological differences among individuals are more crucial than the shared social, political, and economic disadvantaged status of disabled people. Pierre Majeau, a human relations psychologist who also happens to be disabled, makes the point succinctly:

> A prerequisite for the social integration of a disabled individual is social and economic independence, which supposes access to gainful employment.... A basic requirement for real integration of disabled persons into the economic life of Canada is access to quality education as part of a regular education system rather than special

> schools or a parallel system. In my opinion this is the real key to integration (Parliamentary Forum on the Status of Disabled Persons 1988: 8).

It is likely that disabled people recognize, as perhaps do medical professionals and others, that both groups live in a socially constructed world that impacts on them differently, providing them with diverse values. There is recognition of the fact that knowledge is socially conditioned and as such contains or expresses social and political interests (Stubbins 1988: 32, Berger and Luckmann 1967). It is therefore entirely reasonable to expect that the interests, beliefs about the sources of social and economic disadvantages experienced by disabled people, and solutions to these urgent social policy issues should differ so markedly between disabled people and others in society who think they "know better."

In the following pages I offer a summary of my research focus, interpretations, and conclusions that explain the interests and objectives of action-oriented disabled people, and the kinds of solutions they have undertaken in order to realize their goals of community integration, full citizenship, and uncompromised personhood. An elaboration of the theoretical issues and an explanation of my research methodology, aspects of which are also briefly mentioned below, appear in their own sections later in this chapter.

The Research Problem Defined

This is an interpretive-theoretical study of the process of individual and collective empowerment in the context of what is called the "disabled consumer movement," or as it is sometimes called, the "independent living movement." The central problem I want to address is how an historically excluded and abused collectivity can emerge from a context of powerlessness to pursue its vision of integrated community living and a meaningful social life. The underlying thesis of this study is that in the specific ways action-oriented disabled individuals have empowered and organized themselves to try to reintegrate themselves into community life, there is an intuitive grasping on their part of the fact that social structures and categories are the outcome of learned, conscious, and patterned interactions between people. Thus, the various grassroots structures and organizations disabled people are creating represent not only empowering efforts to consciously structure the contexts of their own existence, but they represent efforts to build a kind of community in which they, and others, can participate more meaningfully.

I offer the independent living/disabled consumer movement as an illustrating example of what I think is occurring on a larger and wider scale: Conscious action to renew social structure, build community, and achieve meaning in social life involves trying to overcome by various social, legal, and political means a large number of imposed language, cultural, gender, homophobic, age, and other "handicaps" -- not only physical or mental ones. Thus, the dis-integration and de-contextualization of disabled people from community and social life is not fundamentally different from what is experienced by certain language, religious, ethno-cultural, gender, age, and many other stigmatized minorities. I posit that what disabled people are trying to accomplish can be clearly understood as part of a much larger context of social reform movements and community-building in which a great number of minorities are involved.

My study is interpretive-theoretical in the sense that I locate or anchor the activities and events of action-oriented disabled people, as recorded by them in their own research and position papers, in a theory-rich macro context. I specifically draw from the materials of the Alberta Committee of Disabled Citizens and the Coalition of Provincial Organizations of the Handicapped. While they do not claim to be representative of the interests of all disabled Canadians, these organizations are nevertheless recognized by many as the most powerful of voices of disabled citizens on disability issues.

My interpretation of the meaning of disability and my discussion of the disabled consumer movement and its independent living model (Chapters 2 and 3) is elaborated in a detailed discussion of social movements, the processes of domination in post-industrial society, and the role of empowerment in social movement (Chapter 4). In Chapters 5 and 6, I link the disabled movement's independent living model to a discussion of the movement's broader organizational strategies and to its more specific empowerment solutions and innovations. Some of the key supporting human rights and public policy concerns and interests of disabled consumers from the point of view of community-building are outlined in Chapter 7. Finally, in Chapter 8 I conclude with a brief discussion of the implications of the movement for a greater understanding of community-building; in this context I also consider the political economy of consumerism.

What I have tried to develop, then, is an approach that is inspired and guided by the field material (i.e. the documents), but that moves rapidly towards a meta-theory of consumer action in the field of disability. Moreover, my motivation in writing the dissertation this way was to develop links between consumer action, the process of empowerment, and the on-going social construction of human rights as they pertain to disabled people. Empowered consumer action, as I realized after studying the briefs and reports that disabled people themselves produced, was the key to understanding the efforts of the independent living/disabled consumer movement in trying to stimulate and participate in the development of anti-discrimination laws, equality rights legislation, and public policies that would enable disabled people to pursue independent living lifestyles and achieve re-integration into the larger social community.

The independent living/disabled consumer movement as I discuss it in this study is a contemporary social reform movement that is also concerned with revealing the processes by which the bodies and identities of disabled individuals have become objects on which various systems of domination have converged. Essentially contentionist in approach, its social policy reform and human rights goals have been described as integrationist in outlook (Kallen 1989: 45, 157). The movement has recognized, for example, efforts to medicalize and psychologize the social and private realm of individuals for what they really are (Derksen 1980: 1-2): To displace conflict, to neutralize and drain individuals of all potential for protest, and to "rehabilitate" bodies and minds to more completely internalize a specific kind of rationality upon which modern social and cultural reproduction is supposedly based. The over-all goals of the movement, then, are to challenge and end these efforts of domination, to reclaim "expropriated" bodies, and to reappropriate the "spoiled" identities that are a result of well-intentioned but generally ineffective medical and rehabilitation practices, misguided public policies and programs, bad laws and legislation, and paternalistic attitudes. In effect,

> The heart-and-soul of the self-help consumer group is the individual citizen determined to take charge of his own lifestyle and decision-making. He/she is prepared to recognize his/her own physical limitations and at the same time wishes to share in the responsibility of solving common community problems faced by all disabled persons (Simpson 1980: 7).

What are disabled people doing to accomplish these goals? One of the strategies of the independent living/consumer movement has been to try to reinterpret the meaning of disability by constructing counter-images of "the disabled," and by rejecting the very assumptions upon which normative definitions of disability are built. For activists in the disability field, it is not disability or the disabled individual that ought to be the focus of attention, but rather the social environment and social structures in which disability occurs, and which continue to produce and maintain the disability category. The movement, for example, has been relatively successful in raising awareness of the effects of the quality of working life, the politics of health and welfare administration, and the state of the physical environment on the overall physical and mental health of people in general. From this ecological perspective, then, to demedicalize and deconstruct disability is also to work towards social and cultural change.

The movement is called the disabled consumer movement for the reason that consumerism, for disabled persons, means participation in the decision-making processes within the service provider/client relationship. The disabled person is the poor deserving cripple under the charity ethic; he or she is the patient and the client under the medical and professional ethics. The consumer ethic that has emerged over the past decade or so "is the first of the ethics to be defined by disabled individuals themselves" (Derksen 1980: 11). A person who defines him- or herself as a "consumer" is not the passive recipient of treatment, services, and programs, but identifies him- or herself as central in his or her own production. As disabled people themselves claim, because of their experience of living with a mental or physical impairment, they not only know better than anyone else what their needs are, but they are in a better position to determine just how those needs are going to be met. The goal, that of independent living, thus means

> the ability to examine alternatives and make informed decisions and direct one's own life. The ability requires the availability of information, financial resources, and peer group support systems. Independent living is a dynamic process, it can never be static. A person's physical, emotional and social environment and subsequent needs are continually changing and evolving (Michael Huck, COPOH 1987d: 19).

Accordingly, the Coalition of Provincial Organizations of the Handicapped made it clear that,

> WHEREAS there is a fundamental need to ensure that disabled consumers are directly involved in the planning, evaluating and monitoring of community services related to their needs;

> BE IT RESOLVED that COPOH call upon the appropriate federal/provincial authorities to enact legislation that requires meaningful direct involvement of consumers in planning, evaluating and monitoring roles in community delivery systems...... (Resolution A 5.80.7, COPOH 1985c: 22).

To consume services and goods is not only to reproduce oneself, but also the exchange relations within which those services and goods are produced. As I will show in later chapters, the independent living/disabled consumer movement rejects what it considers is a false opposition between production and consumption. As disabled consumer activists point out, people should be directly engaged and implicated in the production of their own health, learning, and growth. In advocating the reassertion and regaining of control over the context and circumstances of this reproduction, the movement's consumer ethic represents a critique, not an outright rejection, of capitalist market and production relations that are an integral part of medical and rehabilitation practice, program administration, and service provision. As I hope to show in an appropriate context, disabled consumers do reject outright the notion that people have no worth apart from their ability to sell their labor.

In efforts to reintegrate themselves into society and community life and to place themselves squarely within the production and exchange process, a specific strategy adopted by disabled people has been to develop organizational structures that are designed to provide workable alternatives to existing ones. Alternative and innovative structures include personal support networks called Joshua Committees, self-help groups, service brokerage systems, Independent Living centres, consumer organizations or committees, and coalitions of consumer organizations. These will be discussed in the appropriate chapters below. According to disabled consumer activists, current structures and institutions do not enable disabled people to live independently, to prove their participatory competence or autonomy, or to demonstrate (or even realize) their capacity for self-determination. Instead, the existing normative and shared relevance structures of society are said to encourage and promote the marginalization, isolation, dependency, and powerlessness of disabled (and able-bodied) people.

It may seem paradoxical that the process of social reintegration and community-building involves the creation of parallel or alternate* structures, yet the paradox is resolved in the understanding of the importance of these structures on a number of levels. It is important to point out that disabled people do not envision themselves a parallel, alternative, or separate society; change and reform are sought within the existing social order. On one level, these new mediating structures are viewed as "permanently temporary," or as a kind of "half-way house" (cf. Kallen 1989: 38). Their purpose is to bridge or to connect existing services, programs, and opportunities to the specific needs of disabled individuals by relaying pertinent information and knowledge about "how the system works." In a number of cases they may fill a gap where presently nothing exists at all. The Coalition of Provincial Organizations of the Handicapped is explicit in stating, however, that

> Those who espouse the independent living philosophy do not wish to segregate services for disabled citizens..... The emphasis is upon having citizens with disabilities access services from mainstream service delivery systems. Independent living centres [for example] operate as

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* Kallen (1989: 39, 46), drawing from the work of others, distinguishs between "alternate" and "parallel" types of minority organization. The former are typically associated with revitalization movements, while the latter are associated with contentionist/social reform movements (such as the disabled consumer movement). These are not mutually exclusive however. Because there is sometimes literally nothing in the greater society that answers to the needs of some disabled people, true "alternate" structures can, and do, emerge. This does not mean that disabled people are organizing themselves along the lines of a separate society or sub-culture. In this study I will use the terms interchangeably.

> transitional centres which serve to facilitate the integration of disabled persons into the community..... Once perfected these can be integrated into mainstream community service delivery systems..... To do otherwise would retard, not further, disabled citizens' objective to full participation in Canadian life (COPOH 1987d: 35).

As means to certain ends, the new structures such as self-help groups, so-called independent living centres, etc., reduce ignorance, isolation, and dependency by expanding awareness and understanding on the part of individuals, bring people into contact with one another, and serve to demystify the disabled person's social and political environment. They are temporary in the sense that once individuals have learned to access "the system" and to find their way around in it, they are assumed to be reintegrated. At the same time, these new structures and those involved in them may stimulate the further development of generic community services and programs by making explicit what is lacking, and in so doing these mediating structures could either become obsolete or develop into something more formal.

At another level, personal support networks, self-help groups, consumer organizations and so forth represent contexts, or sites, for the production and exchange process, i.e. learning and support. It is suggested that these parallel or mediating structures facilitate the development of social learning and participatory skills because they bring together the skills and knowledge of fellow disabled persons, specialists in clinical rehabilitation and community development, qualified attendants, volunteers, and others. Not only can disabled individuals learn what is available and how to access community services and programs in these contexts, but by associating with peers, sympathetic professionals, and volunteers they can learn the motivations and interaction skills that are necessary in gathering and assessing information, determining their own needs, and making their own decisions. Skills and knowledge are acquired only in the context of living life, not by being told what to do by so-called experts.

At a deeper level, then, these networks and structures are significant not only for what they are, but for what they mean. Support networks, self-help groups, independent living centres, and consumer coalitions represent new ways of interacting for disabled individuals. These parallel or mediating structures bring all kinds of disabled people together, often for the first time. They serve to unify rather than to isolate or alienate, and are thus the foundation, or the structural elements, of the community-building process. While providing valuable services and contexts for learning certain skills and an organizational base for empowerment as well as the politicization of disability, they are organized on the assumptions that disabled people are not only fully capable of being directed by their own conceptions of their own identities, but that they also have a <u>right</u> to determine their own actions.

A rather important implication of the meaning of these new structures and organizational initiatives that directly relates to the central thesis of my study, which I elaborate in the next section, is that they represent the idea of the duality of structure, that is, that institutions, organizations, and social categories are what people make them, literally, to be. Community, then, is likewise what people make it to be.

Theoretical Orientation

One of the most significant developments in the history of both sociology and anthropology was the insight that society is made and imagined, that it is a human artifact rather than the expression or reflection of some underlying natural order (Touraine 1981: 31, Unger 1987: 1). On a somewhat different level this insight also came to inspire the great social philosophies of liberalism, socialism and, of course, communism. These philosophies held out the vision of a society in which people could become empowered to free their practical, everyday, and even intimate relationships from oppressive and imposed roles and hierarchies. If it is indeed possible to somehow reinvent or rebuild society and community, as social scientists and those who are involved in contemporary social movements are convinced it is, it should be done without bringing back old dependencies and dominations. Ideally, it should even be possible to construct a social world where individuals do not have to give up their society-making powers, or to have them (once again) appropriated by others (Unger 1987: 1-2).

Yet, neither sociology nor anthropology seem to have developed the idea of "society as artifact" in the fullest possible way. On the one hand, theories in both these social sciences have continued to compromise the notion that society is constructed and imagined by trying to come up with law-like explanations of organization and behavior. On the other hand, there has been a movement away from the search for comprehensive social or historical laws, regularities and generalizations, towards another extreme altogether -- one that views society as being comprised of an endless number of competing and conflicting individual or group interests (Ortner 1984: 151). The difficulty with this kind of empirical and positivist anthropology and sociology is that it still lacks the means with which to address the institutional and imaginative assumptions on which interests, conflicts, and so on, are based. There is, in other words, still the tendency to take the existing framework and structure of social life for granted, thereby giving it a semblance of a priori authority and necessary pre-existence. In this respect positivist social science is still conceptually far away from the idea of society as artifact (Unger 1987: 2).

What is needed is an approach that does not diametrically oppose the distinctions between agency or practice, and the institutional frameworks and structures in which it occurs. Such an approach would include the institutional and organizational arrangements and preconceptions that help shape conflict and competition, for example, over the control and use of resources (Ortner 1984: 146-150). It is resources, such as symbolic and economic capital, governmental power, technical expertise, and so on, that enable some to determine what others can and cannot do, and that structure roles and hierachies.

In turn, the social framework can be seen as comprised of legal rules, for example, that use property rights as an instrument of economic distribution, and legal or constitutional arrangements that provide for the representation of vested interests, and so on (Unger 1987: 3).

Thus, while preserving for analytical purposes the distinction between agency and structure, it is recognized that the institutional frameworks and models of social and community life provide the basis by which people define their interests and conflicts, and interact with each other. At the same time, these frameworks and models have to be seen as being not merely the crystallized outcomes of routine activities and resolved conflicts. Until the assumptions that underlie institutional and organizational structures are made explicit, there is the risk that the routine activities and behavioral regularities that generate the structures will be confused with "general laws" of social organization.

It should be possible to make statements about society-making and community-building that do not depend on general laws or on preordained sequences of forms of social, political, or organizational life. It should also be possible to question the notion that structures are structures in the sense that they always have the same relation to the practices that they influence (and provide the context for), and to the constraints that in turn shape them. I would like to argue that it is possible -- through some type of conscious process -- to both diminish the power of structures to impose constraints on people's interaction, and to minimize the distinction between structure-preserving and structure-transforming practices. Social movement, or empowerment, may in fact be this process.

Important, then, is that process by which institutions, structures, and preconceived beliefs and models of society come to be consciously and actively redefined. Less entrenched and more revisable sets of arrangements and beliefs should empower disabled people, for example, individually and collectively. What is at the center of this process of empowerment or social movement is the view that the various contexts of social life can come apart and consciously be remade (Unger 1987: 80 ff, Berger and Luckmann 1967: 61). Social movement is therefore the process by which freedom from dependence and dehumanization is sought by attempting to diminish the sometimes negatively experienced effect of rigid hierarchies and categories based on such things as age, gender, color, physical ability, etc., that can severely constrain people in their social and other kinds of interactions.

Thus, human and equal rights movements are recognized as expressions of general efforts, on the one hand, to break from constraining gender, age, ability, etc., categories, and on the other hand, to attain more complete control over the structural and relational contexts of social life from which categories, designations, and labels emerge and in which they are maintained (Unger 1987: 6-17, 144-150). Human rights movements are, in this respect, a very good illustration of the tendency to swing between being structure-preserving and structure-transforming activities, with the end (logical?) result that structures are neither fully preserved nor totally transformed. What movements such as the disabled consumer movement face is the "failure" of structures, in Unger's words, to entirely prevent or assist in their own revision. This is at the same time both the problem and opportunity for individual and collective empowerment, and represents the challenge facing the disabled community.

Empowerment is that developmental and learning process that some disabled people are involved in when they build and actively participate in the community structures of their own creation.* This

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* Empowerment is a construct used by some social scientists and others who deal with the issue of powerlessness of so-called minority group members, for example, the poor, women, the disabled, blacks, and others (Powell 1987, Boyte and Riessman 1986, Rose and Black 1985, Freire 1984, Rappaport, et. al. 1984, Lieberman, et. al. 1979, Solomon 1976). The concept has been used freely with such terms as coping skills, mutual support, community and

process is the essence of what I refer to as social movement. In becoming empowered consumers, disabled persons learn to overcome deeply internalized expectations of powerlessness, alienation, and self-blame, to deal with the frustrations of inequities in the distribution of resources, and to counter social and political intimidation. As a learning process, empowerment means learning general action skills that are useful in playing a more conscious and assertive role in the on-going social construction of one's social and political environment, that is, structures. Indeed, I define empowerment as the learned ability to form, develop, and maintain community structures that harness the energies of people in order to achieve desired results (Figure 1).

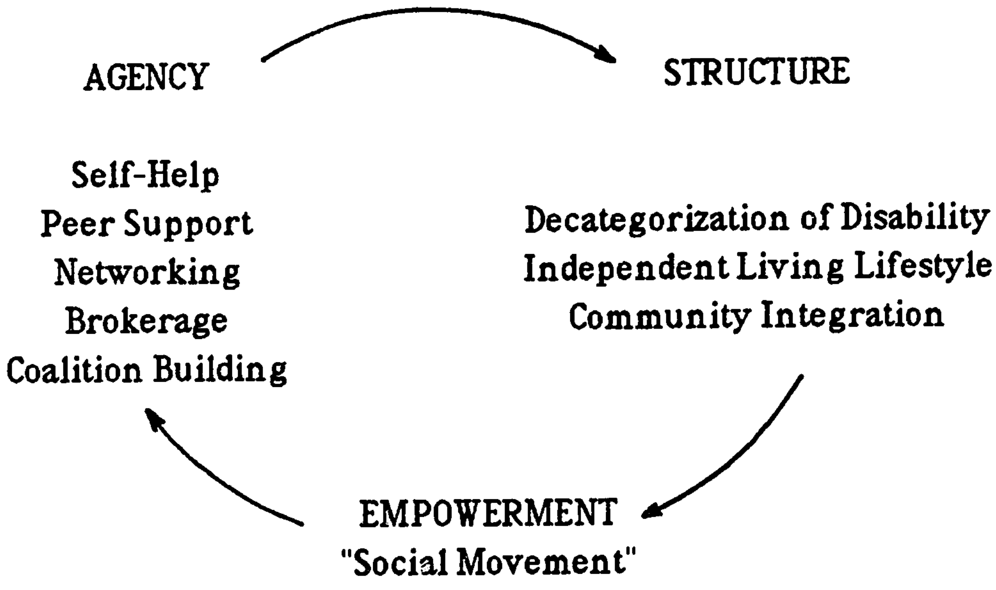

Figure 1. The Community-Building Process

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grassroots organizing, citizen participation, and so on. It is hard to define: It can be a mechanism or process that describes the interactive and highly subjective relationship of individuals and their social environments. It can also be understood as an internalized attitude and/or as an observable behavior; it may mean either a sense of control, or actual control over events and circumstances (or both) for individuals.

What of the relation between agency (or action) and structure? The process of empowerment entails gaining an understanding of how social and political institutions work, and this includes grasping the fact that structures consist of on-going sets of learned interactions. Power structures, structures of domination, social categories, and social designations are thus correctly understood as the outcome of interactions that are mediated by material and non-material resources, and that are contingent on following socially accepted rules of conduct. Acquiring and manipulating resources, trying to change the rules, and so intervening in the flow of action almost ensures that some kind of change in interaction and structure will follow.

This is a formidable task for disabled people because it requires a critical and analytical understanding of what rules and resources are crucial in reproducing the asymmetrical community and institutional power relations that are the outcome, so to speak, of negative stereotypes, labels, and designations. The next step is to put this understanding to use: To produce new patterned and reciprocal interactions in an attempt to reconfigure or redesign community and institutional power structures which have been, historically, the source of oppression of disabled people.

My theoretical orientation to the problem of "breaking" from imposed categories, "rebuilding" community, and "redesigning" power structures from the perspective of the disabled consumer movement is inspired in part by the work of Roberto Unger (1987) and Alain Touraine (1977a, 1981), but mainly by the work of Anthony Giddens. Using an expression possibly borrowed from Piaget, Giddens calls his approach the theory of structuration. The theory is presented in fairly systematic form in The Constitution of Society (1984). Drawing from the work of such classical social theorists as Durkheim, Weber and Marx, and analyzing the contributions of structural-functionalism, positivism, contemporary Marxism, and even interpretive sociology (e.g. symbolic interactionism, ethnomethodology, dramaturgy), Giddens earlier prepared the way for a more comprehensive theory of action (1976, 1977, 1979).

In one of his earliest works, Giddens (1976) discussed what were then new theoretical currents emerging from a critique of the orthodox consensus model formulated decades earlier by Talcott Parsons (e.g. 1937, 1951). The consensus model had been increasingly called into question not only by Marxists and conflict theorists, but also by symbolic interactionists, ethnomethodologists and other "micro" sociologists, and by anthropologists (e.g. Sahlins 1976, Bourdieu 1977). While Giddens agreed to an emphasis on the subjectivity of actors, he still considered interpretive social science too close to the orthodox consensus model in its approaches to the problems of normative meaning to be useful for the analysis of power phenomena, on both micro and macro levels (1976: 51-53). He likewise criticized some post-structuralists (Foucault, Derrida) for almost totally eliminating (decentering) the individual (to get away from an over-emphasis on the conscious actions of individuals), and favoured instead "a recovery of the subject without lapsing into subjectivism" (Giddens 1979: 39-40, 44, 1987a: 205-207).

According to Giddens, then, a more balanced approach is a conceptualization of social structure that does not ignore the capacity of individuals for reflection and action, but that also does not conceive of structures as totally independent from them. This, for example, led him to place the temporality and spatiality of human action (and therefore of all social phenomena) at the heart of his approach (1979: 53 ff, 1984: passim). This means that the extension and reproduction of social actions and systems is specified in terms of time-space distanciation, that is, the extent to which action is face-to-face and involves physical presence/absence.

His rethinking of the idea of social action also includes a new approach to the concept of power (1979: 91-94, 1984: 14-16). Giddens attributes power to the transformative potential of all action, thus not restricting power to the mere ability to act or the wielding" of power. Instead, he proposes a composite view of power as the capability to use resources in the sense of transformative capacity at the level of interaction, as well as in the sense of domination at the structural level of existing institutions and systems. A clearer relationship between action and intentionality is therefore developed in Giddens' action theory. Intentionality is seen as the capacity for self-reflective control and evaluation of one's own behavior. Action is thus no longer merely the execution of pre-formed intentions or of the automatic realization of internalized values and motives. Now, action is conceived as having a multiplicity of motivations, making it possible to attribute more than one motive to every action (Giddens 1979: 58-59, 1984: 6-7).

In Giddens' framework, intentionality and reflexivity are linked together processually in a way that provides a useful cognitive dimension to action theory. A cognitive dimension to social action is rather useful in discussions of the reproduction of interactions, structures, and institutions. Among other things, it introduces the possibility of <u>conscious</u> innovation and change in social conduct (something the structural-functionalist as well as the positivist models of social action are often silent on). The key notion is the over-all contingency of social and cultural reproduction, and an emphasis on the individual's ability to reflexively monitor his or her own motivations and actions, and thus to "make" society.

Giddens does not, of course, ignore the limiting power of existing structures. Despite the creative actions by what seem to be "transcendental" actors, the approach recognizes the fact that social structures are not produced out of "thin air," but in any given instant are both reproduced and transformed. What his approach tries to overcome is the often one-sided conception of action as restricted by existing structures, precisely the kind of one-sidedness that continually gives rise to such typical oppositions as structure and agency, micro and macro approaches, or even voluntarism and determinism which Giddens rejects (1984: 139-144). Giddens' solution is therefore the idea of the <u>duality of structure</u>, the key notion in structuration theory (1979: 69 ff, 1982: 36-39, 1984: 25-28). This is the notion that structures have a two-fold nature that both makes action possible and restricts it, that structures are both the medium as well as the result of practice. Essentially, structures "exist" in manifest form only when they are instantiated in actual social practice. Another way of putting it is that structure presumes the idea of an "absent totality"; the concept of structure is finally understood as constituted and contingent.

Structuration theory bridges or links action and structure together in a number of useful and important ways. For instance, it connects an interpretive and active notion of agency to the concept of an "absent" structure. To study structure is therefore to study the ways in which knowledgeable individuals go about producing patterned and recurrent interactions. It also links face-to-face systems of interaction with impersonal, institutionalized, and "extended" kinds of interaction on the basis of temporality and physical presence. Time-space is useful to distinguish between the kinds of interactions that can occur among individuals (the micro level) and between groups or more complex organizations (the macro level). Finally, structuration theory emphasizes action as "a stream of actual or contemplated causal interventions" and "the practical realization of interests." "To make a difference" or "to have acted otherwise" (phrases Giddens uses to refer to the transformative capacity of power) is to transform some aspect of a continuous flow of events, and suggests that the interventions undertaken by individuals are somehow within their control.

In what way is Giddens' approach to social action useful in understanding the activities of action-oriented disabled people and others? First, Giddens rejects any theory which ignores time and space by separating statics from dynamics. In his approach to action, an interdependence of structure and action must be predicated upon grasping the temporal and spatial aspects inherent in the constitution of all social interaction. Second, Giddens rejects both the deterministic attempts to get behind the "backs of actors," as in functionalism and structural Marxism, and the excessive voluntarism that ends up neglecting the structural context, as in contemporary action theories. Third, and most importantly, Giddens tries to mediate the dichotomy between subject and object by assigning a prime role to the knowledgeability of actors in producing and reproducing their society, while at the same time not denying that they must use societal properties in the process.

Perhaps the most useful aspect of Giddens' approach is his image of society as a continuous flow of conduct, rather than as a series of separate or discrete acts. Structuration, then, is ever a process, never a product. Directly pertinent for the central thesis of my study is Giddens' idea of the dialectic of control, which means that individuals can get "in on" this process to influence, even alter, the flow of social conduct in order to "make a difference" in social life (Giddens 1979: 145-150, 1984: 14-16). The implications of a practical and political kind for the empowerment process, social movement, and community-building are that it is not a given that a dominant individual or group has total or absolute control over the direction and flow of conduct, though they of course try to (and try, too, to make it appear as if they do). Individuals and groups thus have a share in building the social world and the communities in which they live and can rebuild them differently if they so choose, and go about it in the knowledge that they can.

The Concept of Community

As I outlined above, the task disabled citizens have set for themselves, namely their goal of integrated and independent community living through empowerment, is one that involves the construction of mediating or alternative structures. Clearly, present social and community structural arrangements are anathema to the realization of the overall goals of action-oriented disabled people. With specific reference to Giddens' concept of the duality of structure and the dialectic of control, it is also recognized that the struggle to "reconfigure" the categories of society (part of the social structure and part of community life) is the struggle to learn how those categories are constructed in the first place and how they are maintained. The community-building process, from this perspective, entails learning how to simultaneously build up and tear down existing structures. To successfully achieve the goal of independent living also means "teaching" society to rethink some of its fundamental organizing principles, while at the same time learning how to go about doing so.

It is appropriate at this point to try to define the term, or concept, of community and to tie it to the thesis of this study. The concept is acknowledged as a rather important one in social science theory, but at the same time is an elusive and difficult one to clearly define. Used as a descriptive and as an evaluative term, we have such phrases as community politics, community action, community development, community building, and so forth. Perhaps the meaning intended to be communicated by these stock phrases relate to a sought-after rootedness, cohesion, belonging, and attachment -- the opposite of alienation, isolation, and the loss of attachment that is apparently part of the crisis of modern mass society. Community has thus been linked to locality, to identity of functional interests, to a sense of belonging, to shared cultural ideas and values (e.g. ethnicity), and as an alternative to a highly organized and bureaucratized way of life characteristic of modern mass society that simultaneously fragments and segments people's lives.

The idea that community is "founded upon man conceived in his wholeness," that is, "in which men were to be met by other men in the totality of their social roles" as somehow distinct from the "segmentation of the person in modern urban society" is itself rooted in the social and political theory of the late 18th and 19th centuries (e.g. Rousseau, Hegel, and Marx; Plant 1974: 16-17, and Nisbet 1970). This is also a theme that was central in the works of such contemporaries as Ferdinand Tonnies (his Gemeinschaft/Gesellschaft distinction), Emile Durkheim (mechanical/organic solidarity), and Max Weber (substantive/formal rationality). Continuing in the so-called typological tradition were the works of Louis Wirth (on urbanism), Robert Redfield (the folk society and folk-urban continuum), Howard Becker (the sacred/secular distinction), and others (Lyon 1987: 18-26).

The move from communal to associational forms of organization, from Gemeinschaft to Gesellschaft, mechanical to organic solidarity and so on, thus represented a loss of community, a way of life, and an ethos. In turn, this loss became "a necessary condition of the emancipation of the self-conscious, self-directing individual" (Plant 1974: 31) that laid the foundation for a (liberal) utilitarian individualism as a prerequisite for industrial capitalism. According to Marx, of course, the problem of the fragmentation of society and of the personality was seen as part and parcel of industrial capitalism that replaced the communal virtues of cooperation and fraternity with those of conflict, competition, and the cash nexus. Interestingly, division of labor, social class, and interest groups were early recognized as both the outcome of the disintegration of community as well as a means of reorganizing or reorienting community along different but no less satisfactory lines. Thus, the appeal to the values of community was a critique of industrial capitalism at the same time as it provided the impetus and thus a positive basis for new kinds of interaction and organization.

It is doubtful whether community in the nostaligic sense ever existed at all, and it is doubtful whether a return to the rigid status groups of feudal society or a rural lifestyle was ever desired. The attempt to regain community can be seen, in its appropriate historical context, as the attempt to recapture some sense of the wholeness of human nature that purportedly was lost (in a territorial and psychological sense) in urbanization, market society, industrialization, growth of bureaucracies, and specialization. In other words, the notion of community as it was invoked in the social theory of the 19th and 20th centuries can be better understood as a means of trying to make sense of a rapidly changing world and to come to terms with it. In particular, one of the central problems of social theory was (and still is) the "reconciliation" of the tension (dialectic?) between the communitarian tradition that stresses identity of interests, cooperation, and a sense of identity communally mediated, and the individualistic (liberal) tradition that stresses personal freedom, autonomy, self-direction, contract, and private property (Plant 1974: 34, and passim).

Community, then, is an ideal form or type of organization, just as Gemeinschaft/Gesellschaft-type relations, mechanical/organic solidarity, and so forth are themselves hypothetical, extreme constructs existing for the purpose of comparison with the real world (Lyon 1987: 7). According to Lyon (1987: 16), "the community is obviously no longer a self-contained, self-sufficient, homogeneous village, but neither has it become an impotent group of unrelated, alienated, anonymous residents with little or no local ties." The community, then, is a problematic and lies somewhere in between. It is the term's seeming looseness and imprecision that makes it so useful and flexible.

In this study I use the term in much more of a relational and psychological sense than in a geographical, spatial, or geo-political sense. Among its many dimensions of meaning, I do not refer to community as a small closely-knit rural community, as the communal life, and certainly not as a neighborhood in the urban context. Rather, as a kind of counterpoint to centralized authority in political, economic, and social life, I refer to the non-territorial community as an interactional field within which various forms of interaction take place that emphasizes the social-psychological elements of community. Community is a therefore a setting, a node of the macro-system, as it were, in which individuals link themselves to each other and to the larger society. From this perspective, Sarason (1974: 153) notes that,

> The psychological sense of community can have many referents, ranging from a family or a gang to a professional organization with members across the nation. I shall use the concept of referents to mean those groupings (families, fellow workers, friends, neighbours, religious and fraternal bodies) which give structure and meaning to our daily lives and whose quality and force are in some ways a function of the legal-political-administrative entity: the city, town, or village. It is that entity in which these groupings are embedded.....

To Sarason's functional legal-political-administrative entity might be added the state, for it is in relation or juxtaposition to the state that communities of interests, values and ideas, purpose and goals, etc., often form. Depending on one's point of view, the state is an arbiter, mediator, or coordinator of interests -- or is an obstacle to their expression and realization. In a relational and psychological sense, then, I suggest that the importance of the idea of community lies primarily with its organizing value, and in its enabling (empowerment) sense, as a process for learning and contributing to the knowledge of its members. The notion has to do with particular qualities and dimensions of social experience. I must agree with Sarason that community is "one of the major bases for self-definition and the judging of external events" (1974: 157).

The issue of community action, community-building, community development, and so on is therefore one of citizen participation, self-realization, and the fulfillment of needs both in an ontological and instrumental sense. Indeed, the liberal view of community and community-building places a great deal of emphasis on participation--

> The individual citizen has ceased to have any sense of his being personally involved: he no longer feels that he is able to identify himself with any organized body..... The main question then is how to promote greater flexibility in large scale institutions and to increase their systematic contact with the population or, to put it differently, how to transform formal democracy so that it becomes a living democracy. <u>Conscious participation of the population in the development of their own community</u> and readiness to share responsibility are essential if that transformation is to take place (United Nations statement on community development, <u>op</u>. <u>cited</u> in Plant 1974: 59, emphasis added).

From an action perspective, the community-building process involves the amelioration or transformation of structural conditions that limit, restrict, or otherwise destroy both the relational and psychological sense of community. From the perspective of disabled people, and I am sure others, nothing is as morally hideous and destructive to the psychological sense of community as segregation -- either in the form of involuntary institutionalization, specialized services and programs, rehabilitation therapies, labelling, or architectural/physical barriers. Different in form but similar in impact, attitudinal and physical barriers prevent full participation in community life. As disabled citizens themselves write,

> We expect the same treatment in respect to the dignity and integrity of all other human beings who happen to dwell on this planet called earth.... We are persons. We have specific needs, which, once met, can only lead to the public good. But to meet these needs without consultation, co-operation and on-going participation by the disabled is to not recognize our personhood.... And to say this, is to say that persons who happen to have a physical disability do not meet the criteria of using existing community services, but rather, need special segregated

> services. To not be able to gain services and the like through existing community services wherever possible, is equivalent to admitting that we are not persons (Alberta Committee of Disabled Citizens 1981b: 39-40).

The "quest for community" with its call for participation and personhood is therefore a conscious learning and structuring process, one that seeks to reaffirm and ensure a democratic "culture of participation" not only in name, but in reality.

Research Design and Methodology

My primary association has been with the Edmonton-based Alberta Committee of Disabled Citizens (ACDC), which I initially contacted in late 1984. The Alberta Committee was founded in 1972 under the name Alberta Committee of Action Groups of the Disabled, and provincially now represents a coalition of smaller, local, consumer groups of the disabled. By late 1985 I had made a commitment to focus solely on the concerns of disabled people. Until that year, however, my intention was to conduct research with two other organizations on the social construction of equality rights. Section 15 of the Canadian Charter of Rights, pertaining to the equality rights of individuals, was coming into force on April 17 1985, and I was eager to document the groups' reaction to this historic event, and their preparation for legal and political action to pursue the social and economic benefits of equality.

A series of semi-structured interviews (tape-recorded and transcribed) were conducted over a period of several months in 1985 with the leadership of the three organizations, which included the Alberta Committee. These interviews focused attention on the issues, problems, experiences, and events that were directly related to (then) current and on-going political and legal events, and what they meant to the groups. In addition, the interviews were also an opportunity to explore such philosophical issues as the relationship between rights and duties, the meaning of individual responsibility, the role of government in society, and so forth. The difficulties of organizing, maintaining membership, and legitimate collective representation were also the subjects of discussion. In all, approximately six hundred pages of transcribed interview material was generated. It quickly became apparent that maintaining a realistic research pace with three organizations was going to be impossible. In view of the theoretical and substantive complexity of some of the issues, it made more sense to make a commitment to one organization.

It was the interviews with the Alberta Committee and the follow-up unstructured interviews and impromptu talks throughout 1985 and 1986 that eventually led me to a decision regarding both my research focus and my theoretical orientation.* References to brokerage systems, Joshua Committees, Independent Living Centres, the development of an independent living philosophy and model, the consumer ethic, and so on, personally intrigued me: Here was evidence of social action and organized social movement such as I had not heard of or seen before. My earlier reading of the work of Alain Touraine (1977a, 1981) and that of Giddens (1984) convinced me that I could attempt an interpretive analysis of what the Alberta Committee and other organizations that are part of the independent living/disabled consumer movement had accomplished (and what they were still trying to do), by linking the literature on structuration theory with that on social movements.

Significantly, it was also at the Alberta Committee's annual general meeting in Calgary in September 1986 that I heard Henry Enns from COPOH (Coalition of Provincial Organizations of the Handicapped) cite the work of Paulo Freire and talk about the process of empowerment. To the best of my knowledge, Enns neither developed his comments nor did he publish them. The key concept that subsequently helped me formulate links between structuration, social movement, and community-building on both micro and macro levels was of course

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* I elaborate on my fieldwork methodology in Appendix 1, Item 1.

that of empowerment. With reference to the independent living/disabled consumer movement in Canada, a recent study by Kallen (1989) has also linked social movement activity to empowerment. Kallen suggests that the movement is a reform movement organized around "instrumental/empowerment types of goals" (p. 45), and that it is "predicated on the goals of empowerment" (p. 157). Possibly because it is outside the scope of her study, Kallen does not expand on the meaning and significance of empowerment. I elaborate on the concept in this study, and suggest that the empowerment process, synonymous with social movement, is central to discussions of social and cultural change in general, and community-building in particular.

To this end, the data I gathered during the 1985 to 1987 field seasons with the Alberta Committee consisted of organizational histories, formal briefs and submissions, reports and summaries of annual general meetings past and current, newsletters, pamphlets, quarterly as well as annual reports (or year-end summaries), press releases, and dozens of research papers produced by sub-committees (responsible for such areas as human rights, the Native disabled, building standards and accessibility, transportation, public relations, etc.). Of particular use, of course, were the position papers, research reports, formal briefs and submissions produced by the staff, board members, and researchers at the Alberta Committee. These were the documentary source materials (listed in the "unpublished and primary sources" section of the bibliography) that came to constitute my primary data. It is primarily from the Alberta Committee and COPOH materials that I draw inferences about empowerment and the disabled brand of consumerism. In Appendix 1, Item 1, I also discuss more fully the usefulness and limitations of textual and documentary source material.

The Alberta Committee made possible access to material produced by individuals at COPOH as well as at the Calgary Association for Independent Living (CAIL). COPOH, headquartered in Winnipeg, represents a national cross-disability coalition of some 85 provincial consumer organizations claiming a total membership of approximately

30,000 disabled Canadians. CAIL is represented by the Canadian Association of Independent Living Centres (CAILC, Toronto) at the national level. I likewise found helpful numerous federal, provincial, and municipal government and government-sponsored reports. They include Obstacles (publication of the Special Committee for the Disabled and the Handicapped, and the Standing Committee on the Status of Disabled Persons, 1981-1987), the (Alberta) Premier's Council on the Status of Disabled Persons (see Appendix 5, Items 1 and 2), the Premier's Council on Future Health for Albertans, and the Edmonton City Council Citizens Task Force for Physically Disabled Persons (see Appendix 4, Item 1), among many others.

As I briefly outlined in the explanation of my research focus earlier in this chapter, this is an interpretive-theoretical study of empowerment and community-building in the context of the independent living/disabled consumer movement. I distinguish my approach from the customary descriptive-interpretive ethnographies. Descriptive-interpretive studies have often been conducted in social worlds that are largely devoid of written documents, that is, in "oral" cultures. Yet, even when done in literate settings, e.g. urban areas, complex society, organizations, and so on, there has been a tendency in ethnographic writing to treat the situation as if informants were non-literate (Hammersley and Atkinson 1983: 127 ff, Smith 1984: 59).

Thus, what about written and other materials produced by informants or the people themselves that the anthropologist is studying? Hammersley and Atkinson (1983: 129 ff) noted the importance of produced written documents and other materials that are integral to the work and activities of the people the ethnographer is studying. They encourage the use of "inside" written accounts, and note that even the early use of the term participant observer itself referred to the generation of such documents as diaries, letters, autobiographies, bulletins, records, etc., by informants. They are thus correct to identify such inside accounts as social products, as the results and products of socially organized activities, and that it is not enough to view these accounts simply as a source of data (1983: 137).

As social products, such "native texts" are themselves significant for the interpretive and interactional work that went into their production (Smith 1974). With reference to the materials I gathered and with which I worked, I see these documents as not only a reflection of a particular social and political reality, but "of" a social structure that has necessitated, indeed, demanded their production (Smith 1984). Being socially and culturally constituted, their contents are of course biased. But the importance of this bias is in what it means, namely that it represents social/political resistance and challenge, and efforts at image-building. The biases are themselves data; they are a kind of window into a people's social and political reality largely formed or constituted by others than themselves. These self-produced materials emerge from what may be called microsituations, yet at the same time they are the undeniable product of macrosystems (Marcus 1986: 169, n. 6, Marcus and Fischer 1986: 77-110).

The kind of understanding of the activities and documents produced by disabled people that I want to obtain is one that sheds light on what these produced materials mean in the context of self-conscious social and cultural change. Historically, of course, the spatial and temporal isolation of disabled people prevented them from gaining social and politically useful knowledge; it was this isolation that kept them from learning and developing any kind of participatory competence. Participatory competence is obviously related to knowledge, and the uneven distribution of knowledge among individuals and groups across society has in the past (and to some extent still does) placed considerable constraints on the range of practices and interactions disabled individuals have been competent to perform.

Following Giddens, then, the significance of these self-produced research reports, position papers, briefs and submissions, and so on lies precisely with the fact that their production is an intentional, self-conscious, and self-reflexive activity. According to the Alberta Committee of Disabled Citizens (1982c: 4),

> Consumer monitoring and research efforts are beneficial to the community as a whole and serve an important social feedback system to appropriate authorities. Evolution of the consumer movement into a dynamic, informed source creates a valuable resource available for use by officials and service providers..... Government has the opportunity to use this pool of knowledge.... as a basis for <u>information,</u> as a means of <u>input</u> for the development of legislation, policies and programs affecting disabled consumers, as an independent method of <u>monitoring</u> programs to ensure needs are met. [original emphasis]

The production of this information and knowledge represents the "learning" process in action, something that is at the core of social movement, or empowerment. Empowerment means obtaining knowledge and learning how "the system" works, in order to resist it, work upon it, and operate within it -- "to make a difference," in Giddens' words. It is the collection and processing of information in particular that is integral to the reflexive monitoring of action in Giddens' sense, and indeed, that is understood as a key element of the empowerment process. The disabled movement's development of peer support groups, networks, coalition and other enabling or action structures -- especially consumer organizations like the Alberta Committee of Disabled Citizens -- serves to focus and distribute relevant knowledge and information that is initially structurally circumscribed.

Disabled consumers attach a great deal of significance to the production of information and the monitoring process. Defined as "the process of forming an impression of how all aspects of the social environment is affecting the individual," monitoring is also the process "of facilitating system accountability through acquiring, evaluating and relaying information" (Alberta Committee 1987e: 6, 19). To monitor, to "prepare needed briefs in the consultation process," and to "conduct ongoing research into issues and alternatives related to the lives and image of persons with disabilities" are the articulated goals of the

Alberta Committee, and, indeed, are part of the organization's mandate (Alberta Committee 1988a).

Position papers, research reports and other self-produced materials -- even though they are the end product -- may thus provide valuable insights into the interpretive and interactional work that went into their production. It is these end products that perhaps provide the most direct evidence for Giddens' notion of duality of structure and dialectic of control.

Summary

The challenges for individuals with disabilities are complex and far-reaching. On one hand, the individual is part of a unique community labelled the disabled community. On the other hand, the individual is also part of a much larger community comprised of its own socially- and culturally accepted practices and structures. For many individuals, the community they are part of may also be defined in cultural, ethnic, religious, gender, or aboriginal terms. In addition to the community a person may belong to, there also exists different sectors in which he or she participates or is involved with. These include the public, private, commercial, institutional, political, professional, and so on. These different aspects of community present challenges to disabled people with respect to role identity, isolation, segregation, access to services, and meaningful citizenship (Alberta Committee 1989)

Historically, disabled individuals have been viewed from a "we-they" perspective. This we-they dichotomy has enabled the creation of systems, programs, and attitudes which have permitted inequitable treatment because disabled people were considered different. Countless policies (all well-intentioned, of course) have been written that have underlined and emphasized individual differences, and that have helped create and reinforce certain categories and labels. Service delivery and professional care systems have likewise been created that focus and depend on the existence of disabilities. This in turn has led to segregated "different" services and programs (including institutionalization), and public response to people with disabilities has all too often been reflected and supported by policies and legislation. Even language -- terms such as crippled, suffering from, victim of -- has served to make labels and categories more real than they really are, and have prevented the individual from being seen as a whole person with his or her own needs, strengths, weaknesses, and desires. These and related issues are discussed in greater detail in Chapter 2.

Of course, while non-disabled people have held the we-they perspective, so too have many disabled people. The constant focus on disability has made it difficult to break out of that particular social category. The consequence has been that the disabled person, the service provider, policy maker and legislator, and even other citizens have often worked at cross-purposes to each other (Alberta Committee 1989). They have not been systematically linked together in planning and creating healthy, integrated, and supportive communities. Excluded from mainstream community life, the end result has been an insidious segregation and marginalization that is the direct consequence of unthinking barrier-creating attitudes of indifference, over-protection, or as is sometimes the case, outright discrimination.

Citizens with distinctive physical and mental limitations have been mobilizing their talents and political will under the banner of the independent living/disabled consumer movement. The philosophy of consumerism and the independent living model have both evolved from years of personal experience with living with disabilities, and reflect the belief in the rights of individuals to take control of their own lives. Common social concerns, the disabled individual's determined sense of responsibility, and his and her right to be directly involved in the community/legislative decision-making and planning processes, has resulted in the emergence of hundreds of local, regional, and national cross-disability groups and organizations (there are some 700 disability groups in Alberta alone).

What have also emerged are a significant number of parallel, alternative, or mediating structures which create the integrative environments in which organizational and structural innovation and experimentation (i.e. learning) can occur. Following Giddens' idea of the duality of structure, peer supports groups, brokerage systems, independent living centres, and so on are both the medium and the outcome of new interaction patterns among disabled and non-disabled people. What makes these new structures significant is that they represent empowering or learning efforts by action-oriented disabled people to <u>consciously</u> restructure the contexts of their own lives. No less significant for an analysis of the empowering efforts of the disabled community, of course, are the self-produced materials that literally document this conscious and reflexive community-building activity.

Chapter 2

Fact Into Fancy: From Disability To Handicap

I stated in Chapter 1 that the central thesis of my study is that the ways in which people interact with one another generate the social categories and structures they come to share and in which they further participate. Social categories and structures, then, are simultaneously the means and the outcome of the actions and activities of people. With respect to the independent living/disabled consumer movement, my purpose in this study is to document the efforts of action-oriented disabled people to structure the contexts of their own existence and to ensure their participation in the larger community. This structuring process, moreover, is a conscious one, and implies that if structures are made, they can be unmade or remade.

Part of the process of achieving the goal of independent living and community integration thus involves re-examining what disability in fact is, and redefining it. Like all social categories and designations, disability is a social construction -- both a product of social, economic, and political relationships, and the means by which these relationships are sustained. In this chapter, I examine the meaning of disability and attitudes towards so-called disabled persons. I also examine the ways in which disability is a basis for social action, and what the consequences have been for disabled persons.

Disability, as defined by the World Health Organization (1980), is the temporary, prolonged, or permanent reduction or absence of the ability to perform or engage in certain roles and daily living activities. An impairment, on the other hand, which causes the disability, is an actual psychological, physiological, or anatomical defect in the physical and mental functioning of the body, caused perhaps by trauma or disease. These definitions are very broad, and include physical and mental conditions which might both be temporary and permanent; they also include those which may be of limited significance as well as those which are of immense consequence to the lives of people affected or involved.

Who are the disabled, or, more appropriately, who is considered disabled in Canada? According to Obstacles, the 1981 report of the Special Committee on the Disabled and Handicapped, approximately 2 million Canadians (just under ten percent of the total population) are physically or mentally disabled in one way or another, at any given point in time (Appendix 2, Items 1-5, taken from the Canadian Health and Disability Survey 1983/84, detail important aspects of the Canadian disabled population). Based on the 1986 Census of Population, however, 13.2%, or over 3,300,000 Canadians reported some level of disability (the Census showed a total population of 25,309,330). More recently, Statistics Canada has identified 5.2% of Canadian children aged 0 to 14 as having some disabling condition. Among the adult population aged 15 to 64, 21.4% report some level of activity limitation, rising to 45.5% of those 65 years of age and over (see Table 1 below). Table 2, which follows, provides data on the disability rate in the provinces and territories in Canada.

More precise breakdowns are difficult to make, because there are disabilities that, for many individuals, are directly related to the aging process (as Table 1 shows), and because some illnesses or impairments progressively worsen. The general aging of the Canadian population, increased air, water and chemical pollution, poor exercise and dietary practices and so forth, are constantly creating new and complex situations out of which multiple impairments, and therefore multiple categories of impairment, may arise. Disabilities arising from work accidents may be a major factor as well.*

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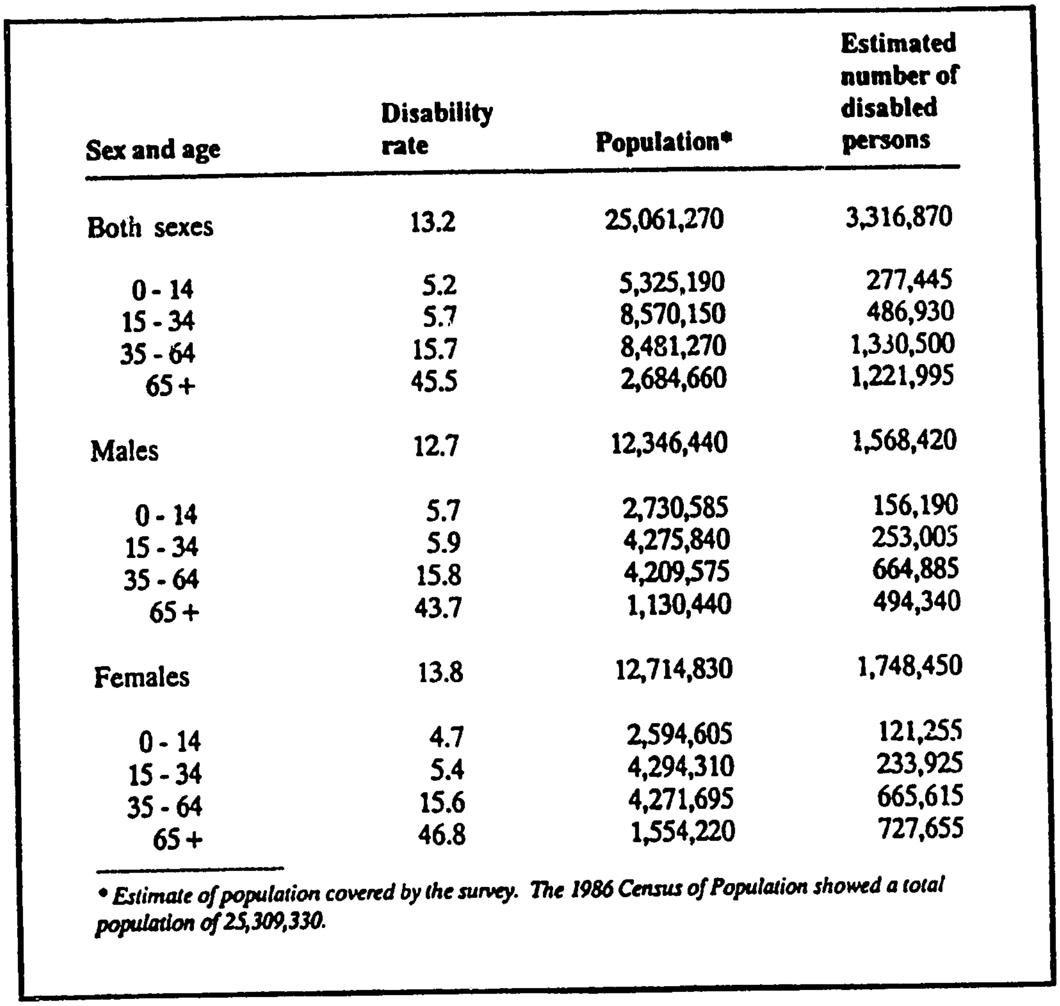
* One source suggests there are some one million industrial injuries every year in Canada, half resulting in compensable accidents, with a significant number of permanent disability cases, and that on average there is a fatal industrial accident every two and a half



Sex and age	Disability rate	Population*	Estimated number of disabled persons
Both sexes	13.2	25,061,270	3,316,870
0 - 14	5.2	5,325,190	277,445
15 - 34	5.7	8,570,150	486,930
35 - 64	15.7	8,481,270	1,330,500
65 +	45.5	2,684,660	1,221,995
Males	12.7	12,346,440	1,568,420
0 - 14	5.7	2,730,585	156,190
15 - 34	5.9	4,275,840	253,005
35 - 64	15.8	4,209,575	664,885
65 +	43.7	1,130,440	494,340
Females	13.8	12,714,830	1,748,450
0 - 14	4.7	2,594,605	121,255
15 - 34	5.4	4,294,310	233,925
35 - 64	15.6	4,271,695	665,615
65 +	46.8	1,554,220	727,655

** Estimate of population covered by the survey. The 1986 Census of Population showed a total population of 25,309,330.*

Table 1. Disability Rates in the Canadian Population [from the Addendum, May 31 1988, HALS, by Statistics Canada, page 3]

Any given definition of "disability" is indeed complicated by the reality of multiple impairments and physical and numerous social/environmental causes, and is at best only a partial definition. According to the HALS 1986/87 (Health and Activity Limitation) survey -- the first post-censal survey conducted as an integral part

---

hours during the Canadian work week. The title of a documentary entitled "Every Twelve Seconds" (CBC) refers to the frequency with which Canadian workers are disabled on the job: every 12 seconds, 5 a-minute (Parliamentary Forum on the Status of Disabled Persons 1988: 34).

of a census operation, and the foundation of StatsCan Disability Database Program -- two-thirds of the disabled population aged 15 and older had more than one type of disability. Not surprisingly, the prevalence of multiple disabilities increases with age; in the disabled population aged 15 to 34, 45.5% reported having more than one disability, increasing to 76.0% in the population aged 65 years and older (see Figure 2).

			Disabled Persons	
	Disability rate	Total	In households	In institutions
CANADA	13.2	3,316,870	3,069,595	247,275
Nfld.	13.1	73,105	69,605	3,500
P.E.I.	14.7	18,450	17,490	960
N.S.	16.9	145,720	139,675	6,045
N.B.	15.5	109,105	103,265	5,840
Que.	11.3	727,740	663,245	64,495
Ont.	13.9	1,263,220	1,167,400	95,820
Man.	15.7	160,865	150,855	10,010
Sask.	13.9	137,515	127,015	10,500
Alta.	11.9	279,425	258,780	20,645
B.C.	13.8	395,115	365,790	29,325
Yukon	8.8	2,040	1,990	50
N.W.T.	8.9	4,570	4,485	85

Table 2. Disabled Persons in Households and Health-Related Institutions, Canada, Provinces and Territories [from the Addendum, May 31 1988, HALS, Statistics Canada, page 4]

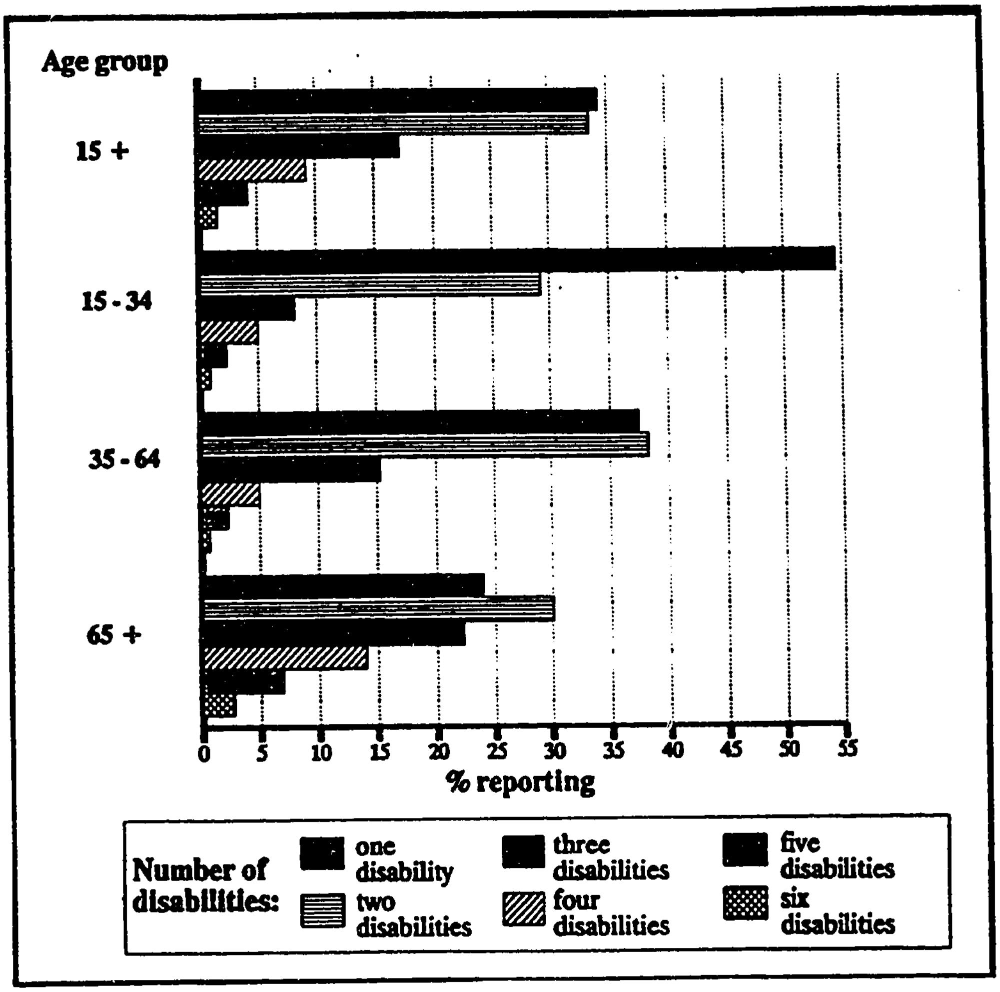


Figure 2. Percentage of the Disabled Population Aged 15 and Older Reporting Multiple Disabilities [from the Addendum, May 31 1988, HALS, Statistics Canada, page 7]

These national data with respect to disability rates and the correlation between age and multiple disabilities compare readily with those of the province of Alberta and the city of Edmonton. With respect to Edmonton, the city's population was 571,506 according to the 1986 civic census. According to estimates published in the Canadian Health and Disability Survey 1983/84, and estimates based on that survey, approximately 10.5% (all ages and gender) of the

Edmonton metropolitan population, or just under 60,000 people, are physically disabled in some way. This estimate is slightly lower than the provincial average of 11.9% and is also below the Canadian national average of 13.2%, as reported in the Survey. The differences may be due to the age structure of Edmonton's population, which tends to be younger than both the provincial and national averages, and that the city's economy is not based on heavy industry, manufacturing, or resource extraction.

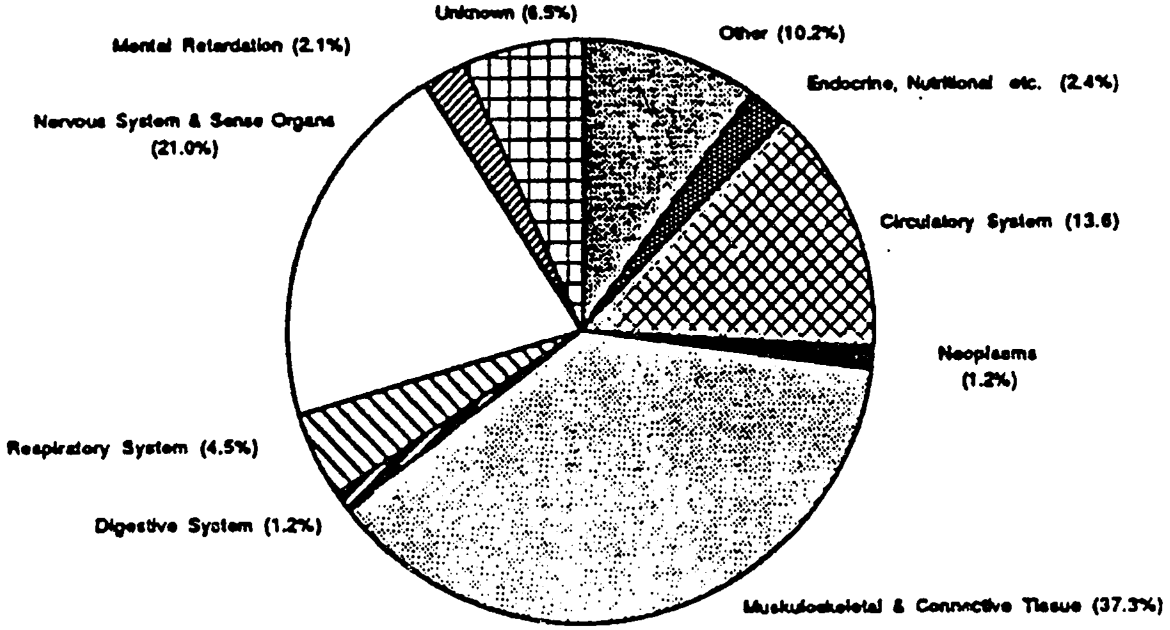
	Male		Female		Both	
Age Groups	%	Number	%	Number	%	Number
All Ages (<14)	6.9	4085	5.4	3086	6.4	7447
0-4 years	5.1	1195	4.3	975	4.7	2168
5-9 years	7.9	1491	5.9	1075	6.9	2559
10-14 years	8.0	1352	6.1	991	7.1	2353
All Ages (15 >)	10.5	23522	11.5	26582	11.0	50068
15-24 years	3.2	1706	3.8	2116	3.7	4033
25-34 years	4.5	2970	5.3	3341	4.9	6323
35-54 years	9.5	6092	9.2	2392	9.4	11957
55-64 years	24.1	5271	25.9	5973	25.0	11233
65 years >	41.7	7794	40.2	10565	4.3	18124

Table 3. Population of Disabled Children and Adults in Edmonton by Gender and Age Group, 1986 (estimated; figures will not add due to rounding) [compiled from Edmonton Social Services, Housing and Social Planning Branch 1987: 17-18]

While a breakdown by age cohort is not available for Edmonton, Edmonton Social Services (1987: Tables 3.3 and 3.4) estimates that disabled adults (ages 15 and older) comprise roughly 9% of the city's total population (11%, or 50,068 persons, of the city's adult population). Disabled children (ages 0-14 years) represent an estimated 1.3% of the city's total population, or 7,447 individuals (Table 3, above). Edmonton Social Services' estimates are based on provincial statistics. As Table 3 indicates, rates of physical disability in Edmonton vary with age and gender (as do the national data). They are usually higher among younger males than females, though the reverse is true among older people. Given that disability rates increase with age, the disability rate among adult women exceeds that among adult men for the reasons that women tend to live longer than men, and that women comprise just slightly more than 51% of the total population.

According to Edmonton Social Services (1987: 23), the rise in the rate of disability among children across all age groups and then a drop in the rate in during early adulthood (15-24 years of age) is attributed to the prolonged, though temporary, character of some disabilities. The three most common disabilities for children, which often disappear in early adulthood, are allergies, asthma, and bronchitis. As well, the statistics in Table 3 include children with vision or hearing trouble, when these conditions are not corrected by appropriate aids and devices.

Unfortunately, there are no statistics available describing the Edmonton (or province of Alberta) disabled community regarding the types or causes of disabilities that its members experience. Figure 3 below (originally prepared by Edmonton Social Services 1987) is based on national statistics (Appendix 2, Item 5). As Figure 3 indicates, the largest group of physically disabled adults in Edmonton experiences problems with musculoskeletal and/or connective tissue. This group is followed in size by persons experiencing difficulties with their nervous system and/or sense organs. Other physically disabling conditions among adults include respiratory system and digestive system problems, endocrine or nutritional difficulties, neoplasms and tumors. 10% of the disabled adult population is afflicted by "other" or multiple disorders, while 6.7% have "unknown"



Prepared by Edmonton Social Services, Housing and Social Planning Branch, 1987.

Figure 3. Distribution of Disabilities by Disabling Condition (Edmonton, Disabled Adult Population) [from Edmonton Social Services 1987, Figure 2, page 21]

or unidentified conditions. According to Edmonton Social Services, 2.1% of Edmonton's disabled population is also mentally disabled, compared to 3% of all Canadians. In Figure 3 above, learning disabilities, mental and psychological impairments are included under the category "mental retardation."

Categorization by cause and by type of disability (e.g. impairments) is largely by convenience, not necessarily by convention. The medical and scientific literature, for example, often distinguishes between four basic kinds of impairments (admittedly simplistic), of which main examples might include:

1. Muscular-skeletal and motor impairments may be caused by encephalopathies, or diseases or trauma of the brain, brought on by sudden cerebrovascular disturbances. Myelopathies, or disease or

trauma of the spinal cord may result in paralysis, paraplegia or quadriplegia. There are arthropathies, or diseases of the joints resulting from arthritis or rheumatism. Diseases of the muscles, or myopathies, can be acquired (e.g. poliomyelitis) or congenital (e.g. muscular dystrophy). Debilitating diseases such as multiple sclerosis, cerebral palsy, and Parkinson's, whose origns are still a matter of intense research, can affect all or any aspects of the physiology.

2. Sensory impairments may be visual, auditory or communicative. Visual difficulties may range from slight to severe, from the necessity of using corrective lenses to legal blindness. These conditions could result from birth, accident, or age. Auditory impairments range in similar fashion, and could be either congenital or acquired. Speech and language difficulties also vary in nature and intensity, and like visual and auditory impairments, can occur as a result of brain trauma or other cerebrovascular disturbances.

3. Organic impairments may or may not result in significant disability, but are no less the "cause" of stigmatization than the impairments just mentioned. These include, among others, such chronic invalidating illnesses as cancer, diabetes, epilepsy, cystic fibrosis and heart conditions. Obesity, "bad breath," and body odors may also be organic in origin, and are socially and culturally tolerated to varying degrees.

4. Mental and psychological impairments vary significantly, ranging from severe mental retardation (e.g. mongolism or Down's Syndrome) to mental illnesses such as schizophrenia, mild psychoses (e.g. depression), anorexia nervosa, and learning disabilities. Chromosome disorders, metabolic disturbances and neurological disorders may be among the congenital (organic) causes, while foetal infection, toxic poisoning, and accidents are among possible leading socio-environmental causes, some of which pose increasing threats to future generations of the unborn. Disfigurement due to accident (e.g. occupational, recreational, etc.) resulting in physical impairment could likewise cause depression, anxiety and so forth.

What should be acknowledged about these impairments is the considerable extent to which some of them overlap, are interrelated, or are points on a continua. A particular cause or a number of causes may give rise to one or several impairments, or disabling conditions (Appendix 2, Item 5), which can vary in nature and intensity. In and of itself this is not remarkable since it is recognized that the body is an interrelated whole. A stressful lifestyle, for example, in combination with a host of other things may cause a stroke or an anyorism, which could result (not uncommonly) in partial paralysis, spasms, incontinence, speech difficulties, and mental depression. Yet, the person, suffering a number of impairments, each of which varies in nature and intensity and is experienced differently (Appendix 2, Item 4), will probably be regarded as simply disabled, either physically or mentally.

Given the complex nature of impairments as causes of, or providing the conditions for, disability, it is probably more helpful to describe the nature of disability with respect to the ability or inability of a person to perform certain functions that are common and customary to most people. Each function might call for the individual to use a different part or parts of his or her body. The Health and Activity Limitation Survey used what is called the "functional limitation approach" through the use of "activities of daily living" (ADL) questions (first established in the Canadian Health and Disability Survey, 1983-84), and so focused on five physical disabilities (see Figure 4 below, and Appendix 2, Item 2):

> Mobility -- walking 400 metres without resting, moving from room to room, walking up and down a flight of stairs, carrying a 5 kg. object for 10 metres, standing for long periods (20 minutes);
>
> Agility -- dressing or undressing oneself, cutting toenails, grasping or handling objects, cutting food;
>
> Sight -- reading ordinary newsprint, seeing someone from 4 metres with or without glasses;

Hearing -- ability to hear what is being said in conversation with other people, with or without a hearing device;

Speech -- ability to speak and be understood.

The category "Other" in Figure 4 includes learning disabilities, emotional and psychiatric difficulties because of developmental delay. Statistics Canada considers the concept of time as a parameter in defining all these disabilities. The limitation had to be of a minimum of six months' duration; only those individuals whose condition had limited or would limit their activities for more than six months were included in the survey.

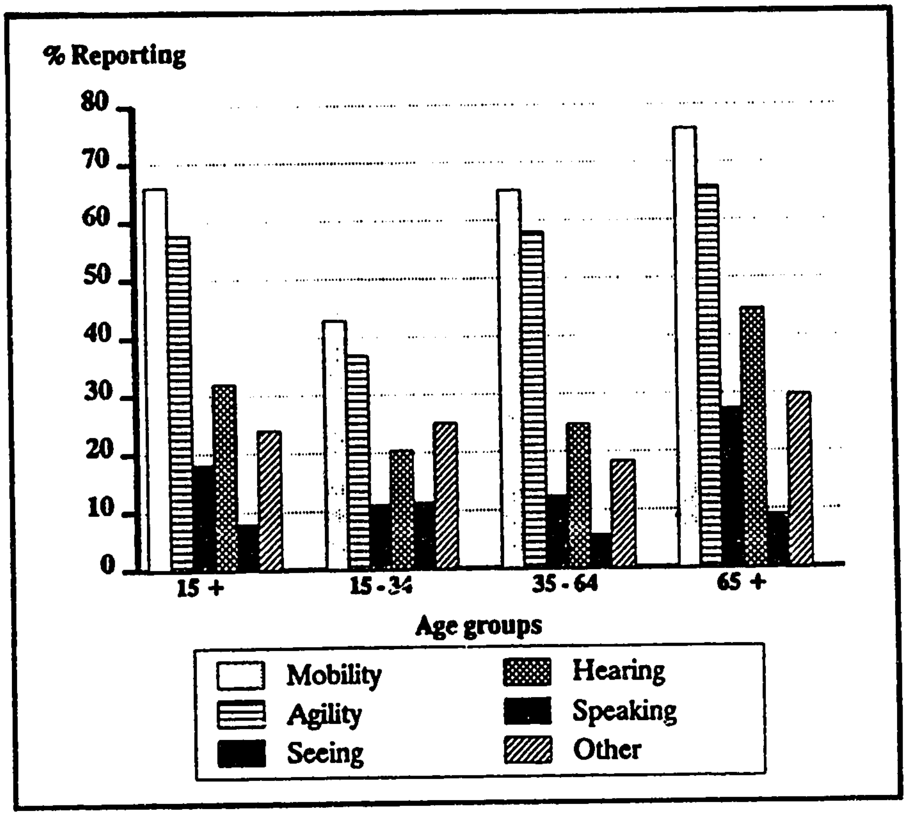


Figure 4. Nature of Disability by Age Group for the Adult Population, Aged 15 and Older [from the Addendum, May 31 1988, HALS, Statistics Canada, page 9]

Again, there are no data for the Edmonton disabled population with regards to the distribution of kinds of disability; the number of individuals with mobility, agility, and other difficulties must be estimated from national data. According to Edmonton Social Services, nearly 66% of all disabled adults (about 33,725 people) have a mobility problem. Over 54% of disabled adults report agility problems, and so on. Table 4 provides data on the distribution of kinds of disablity by [illegible] gender that are reasonably reliable, and as complete as ca[illegible]ted given the lack of original (local) survey data.

Type	Total Disabled	Mobility	Agility	Seeing	Hearing	Speaking	Mental Handicap	Nature Unknown
Both Sexes								
All ages	51,670	33,725	28,154	6,986	13,377	2,444	1,752	4,154
15-34 years	10,356	4,954	4,142	970	1,756	1,101	1,074	1,599
35-54 years	11,957	7,244	6,173	1,090	2,305	473	391	1,399
55-64 years	11,233	7,928	6,627	962	2,662	261	180	820
65 years and over	18,124	13,183	10,835	3,842	6,412	2,082	279	279

Source: Prepared by Edmonton Social Services, Housing and Social Planning Branch, February 1987.

* Percentages used for these calculations are from Canadian Health and Disability Survey, 1983-1984.

Table 4. Nature of Disability and Age Group (Edmonton, Disabled Adult Population) [from Edmonton Social Services 1987, Table 3.5, page 25]

The Social Meaning of Disability Statistics

Given the complex nature of impairment and disability with respect to etiology and causes, and the difficulties in reporting, measuring, and describing such data, broad definitions of impairment and disability such as those suggested by the World Health Organization (noted at the beginning of this chapter) have at least two advantages. First, they draw attention to a whole range of even relatively minor or temporary conditions, rather than just the severe or chronic ones. Secondly, by inviting an awareness of physical disability at this level, the possibility is created for disabled individuals to define their conditions, difficulties, and abilities themselves. In addition, adopting these broader and more general definitions with respect to both breadth and orientation than what purely medical definitions offer, allows for the possibility of social analysis. These distinctions are therefore important. The medical model of physical disability, which helps generate descriptive statistics like those in the above tables and figures, would proceed sequentially as follows (Edmonton Social Services 1987: 11):

Etiology ⟶ Pathology ⟶ Manifestation

While perhaps adequate from a bio-medical point of view, this model includes neither the reaction of individuals to their condition(s), nor the reaction of other people to the condition of the individuals. At the same time, the model does not address the consequences of the interaction between these two variables upon affected individuals, upon other people, or, ultimately, upon society. As the World Health Organization has recognized, these considerations are vital since they concern the social consequences of illness, disease, and accident. It is these social consequences that impact on an individual's functional abilities or inabilities to perform tasks required by the social roles an individual either has, desires to have, or is prevented from attempting.

I have reluctantly devoted the first few pages of this chapter to a presentation of some descriptive statistics in an attempt to give an idea of what kind of descriptions and labelling are involved, and to illustrate the numbers of individuals caught in the process. I say reluctantly because my intention is not to further reify the disability category by identifying who the disabled are. Concern should be with the social significance of an individual's given condition (Edmonton Social Services 1987: 12). Statistics such as those I have selected for presentation above that purport to describe a group of people or to categorize individuals in certain ways do not, and cannot, address issues relating to the social construction of disability and its consequences. This suggests that a somewhat different view of disability should be adopted (Edmonton Social Services 1987: 12):

Disease,
Illness, or → Impairment → Disability → Handicap
Accident

These distinctions now make it possible to start to look for and recognize the differences between conditions that may impair an individual, those that disable, and those that handicap. Impairments become physical disabilities when adequate corrective action (e.g. human or technological intervention) is either unavailable, inaccessible, or not pursued for other reasons. While impairments represent disturbances at the organ or system level, disability might be (loosely) thought of representing disturbances at the level of the person. A near-sighted individual, to give a simple example, becomes disabled only when adequate corrective lenses are not worn. The notion of disability thus arises with a measure of "failure in accomplishment" or "gradation in performance"; this makes it possible to distinguish relative degrees of the severity of disability.

Under some social conditions, however, even adequate corrective measures may not be enough to prevent existing physical disabilities from becoming real handicaps. The near-sighted individual in the example above, even with corrective lenses, may still not qualify for a pilot's license. Specific social parameters or rules have, in this example, been established around the person's physical impairment and/or disability over which he or she has no control, and about which he or she has no say.

Handicaps are therefore to be considered primarily the socio-cultural and environmental consequences of an individual's impairment. They are based on a person's assumed inability (the disability) to fulfill social roles, and are "set up," consciously or unconsciously, to actually prevent his or her access to the various structures and institutions of society that are generally available or accessible to others. Handicaps also curtail or prevent participation in the life of the community on an equal level with others. It is not so much the actual physical or mental condition that is the key to understanding the position of the disabled in society and the dynamics of their interactions with the rest of society, but rather society's perception of that condition and its reaction to it. "Fact," in other words, is turned into "fancy." An individual will be as handicapped as society makes him or her out to be, even with minimum impairment.

Handicaps should be understood as <u>imposed</u> structural constraints. There are really no agreed-upon objective categories of impairment and disability (not even "purely" medical or statistical ones), despite clever attempts to make them seem that way. Any category or definition will reflect the social and political philosophy dominant at the time it is created. Also, disabled individuals themselves distinguish between, and experience, relative degrees of intensity and severity of their impairments (Appendix 2, Items 3 and 4).

It is also worth noting that the severity and degree of impairment and disability an individual experiences depends on how certain, primarily dominant, <u>social</u> and <u>institutional</u> expectations are met. From the perspective of the individual, single all-purpose definitions of specific disabilities are the least useful. More useful are a range of definitions that relate to the incidence or prevalence of certain physical and mental conditions to specific needs that arise from them, the point being that differing conditions and needs of individuals require a range of programs, services, and therefore of planning efforts. Definitions ultimately are important because it is when they are used as entry points to programs or as a basis for claims to social aid and income benefits that their wording and interpretation become crucial -- both from the point of view of the disabled individual <u>and</u> from that of the administrator (Brown 1977: 8-20, and especially Stone 1984).

Clearly, any definitions and categories that are created would be meaningless without input from disabled individuals themselves. This, of course, has hardly ever been the case. It is precisely over the construction of definitions and the imposition of structural constraints that conflict has emerged. It is difficult to escape the conclusion that the disability category is not only socially created, but, as something that can be manipulated, also serves as an excellent (though somewhat insidious) administrative and political tool.

Image into Stigma: The Body as Vehicle of Meaning

I would now like to turn to a brief background discussion of attitudes towards disability and the disabled; a general discussion of how disability emerges as a shared social designation follows. Attitudes towards and so, too, actions against the diseased, the injured, and the disabled have varied greatly across time and space. Often based on perceptions of illness or disability, resulting attitudes and treatments have ranged from complete rejection and ostracism, to semi-deification and the awarding of special privileges and honors.

In the militaristic society of ancient Sparta, as in the China of only several decades ago, for example, physically malformed infants were killed at birth. Homer, the Greek epic poet, was blind and was venerated, and in fact in classical Greece pensions were awarded to blind persons as a matter of right. Yet the deaf in ancient Greek society were considered disabled and "incomplete." In ancient China, the visually impaired could be meaningfully engaged as musicians, poets, story-tellers, soothsayers, teachers and as scholars; there was obviously a place for them in society. Begging was still a possibility, of course, but high political office was not out of the question for the aspiring. In Egypt the priests of the temples taught simple rehabilitative skills to physically incapacitated veterans and civilians. In India, the degree of tolerance of certain kinds of disability was (and perhaps in some areas may still be) related to caste position.

Caesar's military success in what is now western Europe was not hampered because of his epilepsy (the "sacred disease"), now referred to as a hidden disability. In other societies, the presence of such symptoms as hallucinations or epileptic episodes was often considered "proof" of the ability to communicate with supernatural powers, and qualified some for the prestigious social role as shaman or medium. In medieval Europe, however, epileptics were deemed potential witches and qualified instead for the stake. On balance Western society might be described as having a truly schizophrenic attitude towards the sick and disabled. Sometimes disabilities are "seen," and at other times overlooked and apparently irrelevant:

> Nor do we remember that Lord Byron had a club foot and Alexander Pope had curvature of the spine. Elizabeth Barrett Browning was a paraplegic. Milton was blind when he wrote Paradise Lost. Beethoven was deaf when he wrote the Ninth Symphony, Nietzsche was a syphilitic, and Dostoevsky was an epileptic. Edison was deaf, and Freud spent the last sixteen years of his life wearing a prothesis on his jaw. To speak of these men and women as handicapped seems a contradiction in terms (Gliedman and Roth 1980: 29).

Historically, a fundamental change in perception and attitude in the Western world toward the disabled (one that has persisted to this century) seems to have occurred when very large numbers of injured persons returning from the Crusades resulted in institutional intervention for the first time. The Church helped create asylums for them, the earliest example (13th century) and probably the most famous of which was the "House of the Three Hundred" in Paris, a kind of hospital (an institution, incidentally, that has a long history outside Europe). That short term solution eventually became the long term answer in Western society for the question of where to put and what to do with disabled people. Of course, prevailing notions about the etiology of disease or disability significantly influence the degree as well as the nature of social prejudice directed towards the afflicted.

Outside of injury in holy war, it became a firmly held Judeo-Christian ethic (dominant until this century) that physical defect is a just compensation for sin, where the visible defect provided insight into a person's inner moral and spiritual defects. Visibly ill, malformed or crippled individuals were said to be cursed by the Devil or possessed by him, and so were feared, persecuted and, in the extreme, tortured. As the sick individual became personally held responsible for his or her illness, as was the case from the Middle Ages onward, social awareness of the individual tended to become more marked, attitudes more ambivalent, and actions more drastic.

Thus, the physical segregation, institutionalization and social isolation of the disabled, the mentally-afflicted and others was well under way by the Middle Ages. The lazar houses (leprosariums) of 14th and 15th century Europe are well known; the *Narrenschiff* (ship of fools) of about the same period was the solution of some European riverine communities to deal with "vagabond madmen" (Foucault 1965: 7-8). Under James I in England, vagabonds or rogues were actually branded with the letter R, and sometimes V (Bauman 1987: 44). Often reduced to begging and therefore to poverty, and so *because* of their poverty, the "immoral," "lazy" and "unworthy" were increasingly confined to hospitals, workhouses and, more often that not, to prisons. This trend became prevalent in the 17th century and a good part of the 18th century in most European countries. These places of confinement served as punitive and reformative institutions for the criminal, the poor, sick, and the insane alike (Stone 1984: 29-41; 51-55).

Through "discipline," or forced labor and corporal punishment, these unfortunates were "taught" to once again become worthy, moral and work-loving. Yet even in the 18th century it was recognized that these institutions were not a solution, for "the hospital [as an example] is an anachronistic solution that does not respond to the real needs of the poor and that stigmatizes the sick in a state of penury" (Foucault 1973: 44). The hospital, it is interesting to note, is considered the "prime model involved in the early phases of the mushrooming of carceral organizations," which are, incidentally (though not coincidentally), closely associated with the rise of Western absolutist and nation-states (Giddens 1985: 182-197).

What marked these developments as a crucial turning-point in attitudes and actions towards "the sick" as constituting a biological/social category was not just physical segregation, but that for the first time <u>the body</u> itself seems to have become a <u>social</u> object upon which an increasingly concerted integrative and manipulative efforts of particular systems of domination were focused (Foucault 1980: 55-62). The body, whether of positive or negative connotation, was seen as something to be controlled, neutralized, and (preferably) deprived of its potential to menace, in whatever way feared, the system; hence the Great Confinement, that is, the rise of the workshop, prison, and hospital (Foucault 1965: 38-64, 1977: 135 ff, 1980: 166-182), and later, the factory.

Sequestration (Foucault's term) as a means of physically neutralizing and disciplining the body also occurred at about the same time such socially constructed categories and distinctions as "the deviant," the "normal," and the "pathological" began to appear. The processes of depersonalization and marginalization as a function of stigma and "deviance," described below, with which most disabled individuals are probably familiar, clearly had their origins in the events of the 16th, 17th, and 18th centuries.

For the last two hundred years, then, the meaning of illness and physical and mental disability has been specifically related back to the social and political structure with increasing intensity, and with the focus on the biological/physiological etiology of any particular affliction shifted elsewhere. Contemporary images of and attitudes towards disabled, mentally handicapped, and sick individuals are, it is suggested, traceable to the melting away of the pre-18th century medical dualism of health/sickness, and in its place, the gradual emergence in the 19th century of the dualism of normal/pathological, one that has since become established at the very center of all medical reflexion (Foucault 1973: 34-36). Society's initial reaction to the AIDS (Acquired Immune Deficiency Syndrome) epidemic, including carriers of the HIV (human immunodeficiency) virus, illustrates Foucault's point perfectly (e.g. Schilts 1987, Social Research 1988).

It is the process of the typification of human differences (in the Schutzian sense, cf. Schutz 1967) and the translation of the subsequent (culturally- and socially-specific) typologies into structures of interaction that probably comes closest to providing an understanding of the dynamics involved in the historical shifts in perception mentioned in the previous paragraphs. The creation and recognition of meaningful differences in both the physical and social worlds is of course basic to the human cognitive and learning processes. It is a way of organizing our experiences into some interpretive scheme (by way of forms or recipes, in phenomenological terms), but as is the case in organizing perceptions, not only will some differences be highlighted from the perceptual horizon while others are suppressed, but not all individuals will treat the foreground differences equally either (Merleau-Ponty 1963: 68 ff).

The process by which supposedly neutral impairments are transformed (by observers and ultimately by the person him or herself) into, first, a particular disability and then into a handicap, involves (a) selectively shifting the focus away from the cause or causes, (b) selectively differentiating among the impairments (e.g. most visible to least visible, most to least severe, etc.), (c) lumping together all impairments by not differentiating among them at all, and (d) ignoring social setting and social interaction. Put simply, an image of the individual is literally created by cognitive processing, one that may conform to previously constructed meaningful types and categories. The crucial point is that the image of disabled person is thus abstracted from the confusing background differences (those seen but unnoticed) by the selection of salient differences (those seen and noticed), which are evaluated (positively, negatively or neutrally) by way of normative construction.

Once abstracted, the image is conferred on the person (a one-way process), and may become further socially approved and socially distributed (i.e. learned). Important here is that the individual, so abstracted, has ceased to be female, a mother, Native, a Liberal back-bencher, or an Edmonton Oilers hockey team fan. Much like racism, ageism, and sexism, the person's attributes (impairments) are globalized to their whole being, rather than perceived as only a facet of their physical being. The individual has been depersonalized, an effective way as any to sequester or marginalize them within their own community and society.

Thus, like all perceptual phenomena, the differences between human beings that are either noticed or suppressed will depend on both what is relevant in a particular time and place, and on the kind of interaction taking place between individuals. As Douglas (1970: 37) pointed out, human interaction can only be adequately explained in reference to the situational context in which it takes place (her "principle of the integrity of the situation"). So-called relevance structures of human differences that focus attention on some differences and directs it away from others are, moreover, socially, culturally, and historically distributed and maintained. It is also important to recognize that although individual relevance structures do not exist completely apart from categories that are socially derived and approved (assumed to be shared in time and space), the relevance structures that determine how individuals react and respond to differences in the interactional context of the immediate moment are to some degree also personal in nature.

Foreground differences, or those which are relevant or salient for particular kinds of social interaction, are also positively or negatively evaluated, and therefore cognitively stratified or hierarchically arranged. Since the interpretive schemes which organize perceptions of these foreground differences include cognitive (i.e. what is) as well as normative (i.e. what ought to be) constructs, the relevance structures that help maintain an assumed shared sense of reality thus imbue perceived differences with a kind of moral value and significance (Berger and Luckmann 1967: 104-116). Interpretive schemes are clearly normative constructions. It is worth remembering, I think, that while it is the human body that constitutes the perceptual horizon from which foreground differences are selected, any positive or negative valuations or moral judgements (that is, images) that are conferred or imposed upon the bodies of individuals also have social consequences for them.

Though the cognitive and perceptual processing of human body differences is universal, it is when particular human differences are evaluated negatively and imbued with negative moral meaning that the basis for stigma is created; stigma as a distinctly social phenomenon is a special case in the typification of difference. Goffman's (1963) classic study of this phenomenon remains unsurpassed, and he offers this definition: Stigmatized persons possess an attribute that is deeply discrediting, and are viewed as less human because of it (ibid., 3-4). Human differences singled out for negative emphasis include what Goffman would call abominations of the body (i.e. physical deformities), blemishes of individual character (i.e. homosexuality, drug and alcohol addiction), and tribal stigma (i.e. race, religion, ethnic origin).

As Goffman suggests, stigmatization tends to lead to the "master status," the attribute that dominates the perception of the entire person, which has the social effect of neutralizing positive qualities and "spoiling" the identity of individuals (Kallen 1989: 52-55). The "normal" and the "stigmatized" as designations are, above all, perspectives that reflect social and cultural processes. As such, analysis of stigmatization can be carried out from either a symbolic interactionist perspective (e.g. Goffman's approach), or from more of a structural-functionalist perspective in which roles, norms, and motivational structures play a greater part in achieving an understanding of how stigmas are generated as well as maintained (Kallen 1989: 29-30, 51-52, 56-57).

Stigma into Deviance: Perceptions into Actions

Shared social designations are eventually "translated" into actions. That complex of relationships that exists between the human body and the social collectivity constitutes a critical dimension of consciousness in all societies, and provides a basis for action (Comaroff 1985: 6). As Douglas (1970) has noted, among others (e.g. Bourdieu 1977, Turner 1967), the human body, as a natural symbol for conceptualizing about social identity, provides not only numerous objective physical signs, but is the basis for assigning quite arbitrary subjective values and meanings to it that, over time and space, assume an objective and "true" reality. In fact, the "body" and the "social collectivity" always exists in a mutually constitutive relationship. Moreover,

> [T]he body is not merely capable of generating multiple perceptions; it also gives rise to contradictory ones. Thus, within corporeal confines, physical stability coexists with physical transience, stasis with disease and degeneration.

> It is hardly surprising, then, that as biological metaphors come to represent sociocultural realities, they signify not merely relations and categories but also contradictions in everyday experience; it is very common, for example, for sociocultural conflicts to be apprehended in terms of the archetypical metaphor of contradiction, [in this case] physical disease (Comaroff 1985: 8, cf. Sontag 1978).

Both Sontag's (1978) short but rather insightful study, and Turner's (1967) more general approach, actually beg the notion of the "duality of the body" (pace Giddens 1984), which is to say that the body is both the medium and the outcome of social interaction. Its objective physical signs are not only deeply implicated in its production and reproduction, but they have little or no meaning outside of social action. The body as natural symbol may indeed generate contradictory perceptions or confusing and unexpected signs ("what is") that fall outside of or between existing cognitive categories or types ("what ought to be") that are not readily interpretable or understood. Their subsequent resolution and interpretation may therefore reflect a transformation of not only society, but of the body and its signs as well.

Sontag draws attention to disease metaphors in political philosophy, citing, for example, such analogies between disease and civil disorder or moral decay in the body politic, ethnic groups and cancerous growth or mortal gangrene, radical surgery and repression, and so forth. Treatment has distinct "military" and repressive overtones. Going even a little further,

> Early capitalism assumes the necessity of regulated spending, saving, accounting, discipline -- an economy that depends on the rational limitation of desire. TB [tuberculosis] is described in images that sum up the negative behavior of nineteenth-century homo economicus: consumption; wasting; squandering of vitality. Advanced capitalism requires expansion,

> speculation, the creation of new needs (the problem of satisfaction and dissatisfaction); buying on credit; mobility -- an economy that depends on the irrational indulgence of desire. Cancer is described in images that sum up the negative behavior of twentieth-century *homo economicus*: abnormal growth; repression of energy, that is, refusal to consume or spend (Sontag 1978: 63).

People, of course, suffer and die from tuberculosis and cancer. Are these metaphors of the time accidental? I think it unlikely that they are. Foucault's transformation of the health/sickness dualism into the normal/pathological one noted earlier very likely coincides with the rise of industrial capitalism, representing a changing society and therefore a very different valuation of both body and person. It has been argued, for example, that with a growing emphasis on personal initiative and competitiveness, productivity, ability, and achievement (a kind of social Darwinsm) in the context of the rise of industrial capitalism in the 18th and 19th centuries, the unemployable such as the sick, injured and the old became defined, *de facto*, as totally unproductive and thus dependent.

In the context of the rational and depersonalized factory system (see, for example, Smelser 1959: 274 ff), in which productivity and efficiency are highly valued, it is the worker that became defined as one of the most important factors of production. Kinloch (1979: 105-124) outlined the process of segmentation and differentiation in the capitalist mode of production, one which over time generated, in the framework of his conflict approach, role-specialized minority identities and groups, based on physiological, behavioral and other criteria. Some of these groups thus came to be defined as "functionally superfluous" (Apter 1971: 87-100, see also Stone 1984: 41-51), though the point is precisely that they are no longer so.

In an even more recent version of this perspective, internal regionalization (Giddens' (1985: 120, 182-197) term for sequestration), and the simultaneous creation of *deviance* as a social and political category is thought to be a part of the growth of state administration, surveillance, and direct supervision (e.g. bureaucracy) over an increasingly differentiated society (Giddens 1984: 151-153, Bauman 1987: 45-48), and may be considered part of the solution to problems of system coordination and reproduction, that is, social control. Giddens suggests that concepts like normality and deviance make little sense outside the context of the administrative state, and indeed, outside the context of the transformation of urbanism, the development of a mobile labor force, and industrial capitalism. All of this, of course, raises the interesting possibility that as the face of capitalism and the relationship between people and technology as factors of production change (and as the nature of production itself changes), so might old stigmas and stereotypes of human frailties disappear.

On a different level but in the same vein, consider Parsons' (1951) classic analysis of the sick role and medical practice. True to the Judeo-Christian ethic, he viewed illness as a form of deviance and thus as a problem of social control, and the sick role as a tool to maintain the status quo (ibid., 428 ff). In his framework, illness is actually one of several deviant routes that individuals may take in response to the strains they encounter in their social roles. Entrance into the sick role helps individuals cope with their situations, which, Parsons assumed, diffuses the anger, frustration, and dissatisfaction that would otherwise lead to political organization and activism. The sick role, moreover, effectively isolates the deviant and prevents the organization of dissident individuals, while at the same time reintegrates them (Parsons 1951: 312-313).

The physician and the medical profession as a whole is seen by Parsons as integral to the system of social regulation, in that they each have a part to play in controlling access to the sick role (via the clinical definition of illness), and so help to reproduce systemic stratification by virtue of their technical knowledge and expertise (i.e. the competence gap between doctor and patient). The medical profession as an instrument of the system serves to rationalize the segregation and control of "deviant" individuals. Merton (1968: 117) suggests that the sick role serves more of a latent function by contributing to the system's adaptation in a way that is neither intended nor consciously recognized by those in the sick role (see also Waitzkin and Waterman 1974: 16-24, 36-41).

Deviance, like the stigma that informs it, is of course not a property inherent in kinds of behavior or in people, but is instead created, constructed, and conferred (e.g. Becker 1963, Goffman 1963, Schur 1979). Put simply, a deviant is one who is assumed to transgress or depart, either voluntarily or involuntarily, from behavioral and/or physical norms, which might include, for example, physiological and intellectual ideals, religious or secular ideologies, legal codes, cultural definitions of mental health, and cultural ends and/or means. Deviantizing is a process much like stigmatization, and "deviance outcomes" are very much the consequences and products of social interaction, economic, political, and judicial interests, structures, and institutional arrangements (Lauderdale 1980, Schur 1980). Thus, defining deviance concerns the issue of constructing stigmatizing classifications, but once an individual is stigmatized by being labelled deviant, a self-fulfilling prophecy is initiated -- one that is almost irreversible.

There are of course a host of explanatory models and theories of deviance and deviant behavior, none of which however are wholly satisfactory in "explaining" deviance. They include, among others, the psychiatric, medical, and the psychoanalytic models, personality trait, social learning, labelling, and conflict theories of deviance (see Kallen 1989: 26-33). In deviance theory generally, attention is often given to how the more powerful and norm-defining groups in society try to prevent, control and treat (sometimes "therapeutically") non-normative behavior. Much of the focus is on how so-called institutional control agents such as physicians, social service agency personnel, legislators, police, educators, and the media define non-normative behavior as unacceptable, immoral, illegal, ugly, sick, etc., and use sanctions and therapies to "contain" its occurrence (see, for example, Conrad and Schneider 1980). Thus, many of the theoretical approaches to deviance emphasize that the power to define deviance, through the propagation of stigmatizing classifications and rationalizing stereotypes, is differentially located in society.

Disabled individuals might therefore be conceptualized as a disadvantaged or minority group in that they are treated and reacted to as a category of people very much like the aged, blacks, women, the poor, and other pariah groups (Sagarin 1971). Blackness, the female gender, advanced age, and disability are presumed characteristics of biological inferiority; the disabled are thus considered (as are the others) less intelligent, incompetent, irresponsible, maladjusted, and so are deemed immature, lazy, manipulative, unreliable, corrupt, immoral and so on. Because of the way in which they have been classified, they tend to be avoided, or worse, "put away."

In addition, the disabled occupy the sick role as Parsons described it, which reinforces the presumed pervasive incompetence of the disabled, and relegates them to a state of powerlessness. But to equate sickness with disability is to also generate and perpetuate a number of oppressive traditional stereotypes about the personal and social abilities of disabled people. For example, legitimate exemption from "normal" role obligations (in the sick role) changes into an almost permanent exclusion from normal opportunities and responsibilities (because disabilities may be long-term or permanent), which leads to the belief that disabled persons will never become capable of leading "normal" social lives.

In the sick role, an individual is generally not held responsible for his or her illness, but in the case of the disabled, this is translated as an inability to seriously attempt self-assertion. By the same token, refusal to behave as a good patient *or as a disabled person* (e.g. to play the role) is seen as a lapse of conduct, and hence as evidence of incorrigible deviance. Finally, playing the role requires active and willing cooperation with "experts"; it is expected and not considered strange that disabled persons should subordinate their personal interests and desires to the therapeutic goals and programs of "professionals" who "know what is best." These are of course some of the descriptive elements of the medical model, about which more will be said in later chapters.

Thus, the inter-personal as well as inter-group treatment of the disabled continues to be influenced by such attitudes as their assumed helplessness, childlike nature, and inability to assume adult responsibilities because of their "sickness." The sick role assumes there is no place in the individual's life for meaningful work, sexuality and intimacy, leadership, and community involvement (Vash 1981). One characteristic of modern society, I would also argue, is its immense talent for deflecting conflict and shifting issues into different realms. The medicalization of illness, and in particular of disability, has therefore had the effect of transforming issues of politics, law, economics, and ethics into questions of sickness and health, deviance and normal adjustment, proper and improper management of disability, and so forth (Illich 1976). This is "blaming the victim" on the macro level.

The disabled, as individuals and as a collectivity (loosely defined), however, have not been slow to contest their stigmas, to redefine their situations, and to reject the roles into which they have been cast, as events over the past several decades here in Canada and elsewhere have shown. They have recognized that stigmatization and all that the process entails has made it difficult if not impossible for them to work together politically. The process of destigmatization, or "coming out" (described by Kallen 1989: Chapter 5), thus involves attempts by disabled people to change negative images of the disabled, and to challenge the continued production, social acceptance, and distribution of these images. This, I suggest, is the first part of the process of trying to introduce new behaviors and practices with a view, ultimately, of transforming existing structures and institutions.

The Situation of the Disabled: Decontextualization and the Transformation of Subjective Reality

Enough studies have been conducted over the years which describe the process of becoming deviant inside and outside the institutional setting (e.g. criminal, mental patient, disabled, etc.). Goffman (1961) has provided perhaps the most detailed account, demonstrating quite dramatically the connection between defining a problem in a particular way -- in this case, seeing dysfunctional behavior and physical or mental impairment as a <u>medical</u> issue -- and defining, by extension, an entire social system that apparently functions to confirm that definition by ruling out all possible alternative definitions (for example, Berger and Luckmann's (1967: 114-116) idea of "nihilation" in connection with the issue of universe-maintenance and the transformation of subjective reality). The efficient operation of any total institution requires that its inmates, or patients, learn the behavioral, symbolic, and conceptual parameters of their new social reality.

In the context of the institution, patients are obliged to accept their situation or problem as illness or disease which, from that point forward, dictates the realm of possibilities for them -- as interpreted by doctors, health care professionals, and others (Safilios-Rothschild 1970: 73-78). Once the "production of patients" has taken place, which involves validating the professionals and invalidating the patients (having turned them into objects), continued social interaction simply reproduces the inequality, domination and manipulation that is built into practice predicated on the medical model. What takes place in the institution of course also takes place in the community and in society; the disabled, and other stigmatized minority group members, learn what their positions and roles are. Society, for many pariah groups, is like a total institution. I suggest that much of what Goffman writes about what goes on inside institutions holds true for what occurs outside of them (cf. Kallen 1989: 34-39).

At the center of the process of becoming disabled (after illness or traumatic injury; for those born with disabilities, the process of "becoming" is their socialization) is what is called decontextualization (Rose and Black 1985: 29). This is defined as the process whereby the individual's subjectivity becomes severed from the objective and historical context that frames everyday human social life. In other words, the individual is removed (or sequestered) from social/historical reality. This reduction to an isolated asocial existence is bounded by a particular belief and symbol system that is characterized by medical hegemony and somatic/physical interventions such as surgery, therapies, medication, and drug treatments, and so forth. The decontextualized experiences of daily life -- now being recontextualized -- become saturated with new language and meaning, a language of illness and disability that contains such concepts as symptoms, regression, decompensation, and handicap (Safilios-Rothschild 1970: 54-59, 68-73). This is the language that reduces social reality to a kind of intrapsychic distortion; instead of living life, in whatever limited sense possible, the individual now functions according to a set of rules and standards that actually have no bearing on genuine rehabilitation or re-integration into community living (Sarason 1974: 174 ff).

Interestingly, the behaviors appropriate to the sick (disabled) role and to being a good patient or client are behaviors almost opposite those that are appropriate in ordinary social life. The good "cripple," or patient, is docile, acquiescent, dependent on others, and is ignorant of his or her rights and entitlements (Stroman 1982: 52-56). Of course, the externally imposed "new social order" becomes internalized and incorporated subjectively over time, and slowly the role and definition of what it means to be disabled is tacitly accepted. But in the process, the individual experiences what is a painful emotional and psychological withdrawal from the norms and forms that gave meaning to "normal" daily life, an experience that is most profound. The person's experience of disorientation and disassociation following illness or injury, and the medical model's rigidly-imposed definition of reality, combine to produce the "disabled" person (Rose and Black 1985: 30). Any efforts at resistance, expressed behaviorally or emotionally, are of course interpreted as part of the person's problem, and so brings about yet more medical intervention or therapy.

As the now physically and emotionally traumatized individual gains the knowledge and skills to function as a disabled person in the sick role or in rehabilitation, he or she actually looses the important knowledge and skills for living in the community. The individual's potential for independent living becomes compromised due to loosing the ability to link subjective experience to objective circumstances, and by being mystified by expertise, and fulfilling the expectations of what are essentially the power-holders (the professionals). Personhood is thus overshadowed by patienthood, and the individual's active participation in and consciousness of social/historical reality is replaced by his or her passive acquiescence or functional adaptation to and acknowledgement of their own invalid state. Disabled individuals have described this experience as a sense of being disconnected from ongoing social existence, as if their capacity to engage in the process of living meaningfully has been surgically severed (Goldiamond 1976: 103-118). It is precisely this aspect of utter physical and psychological oppression that serves to sustain the stigma of disability (Schur 1980: 72-95). The empowering process cannot be understood without fully comprehending these experiences and constraints to which disabled people are subjected and into which they are socialized.

It is critical to keep in mind, but rather easy to forget, that in the majority of cases disabled individuals, prior to injury or onset of disease or illness, were no different from anyone else. As human and therefore social/historical beings, their needs and interests are those of everyone else, which include income, adequate housing, nutritious foods, comfortable and stylish clothing, friends, intimate relationships, legal protection, and the choice to participate in socially meaningful mutual interaction with others. If anything, meeting these needs and interests is probably more important <u>after</u> becoming disabled; individuals need these resources as social beings living in the community, and not as patients or clients confined to a hospital or an institution, or otherwise segregated from mainstream life.

There has been a tendency for professional care-givers to define and interpret "universal" needs such as these in light of the assumptions of the medical model, that is, of the inherent defectiveness and deviance of disabled persons. The consequence is that some of their needs might be met, but in ways that sometimes contradict their interests. For example, sheltered housing or workshops have as their basis not some form of care for those who might have difficulty living independently, but the assurance that medical/therapy regimes will be followed. Individual case management and rehabilitation, instead of being built on advocacy or empowerment principles designed to guarantee the essential dignity and benefits needed that focuses on strengths and capabilities, instead concentrates on forging linkages for the disabled to clinics and other treatment outlets, or to services designed especially for them, that is, focusing on needs and inabilities. The socialization to the pattern of dependence is thus continued (see the essays in Marlett, et. al. 1984, for more critical approaches to treatment/service delivery).

Institutionalized, segregated, and ghettoized (that is, physically, socio-psychologically, and interpersonally "contained," Schur 1980: 90-95) disabled individuals cannot be understood apart from their context, and their forms of self-expression used in any other contexts and situations are therefore a crystallization of the distorted social relations into which they have been resocialized. Their individual and collective identities are really more of a commentary on that socialization than statements about autonomous living and a quality of life. The individual's behavior and outlook must be understood as both a learned survival and coping strategy, and as a product of regulated social relations that have developed over time. In fact, when the ideological and organizational bases on which theories of mental and physical health are based are considered, the larger context of social control (pace Parsons, and others), oppression, and domination in which both health care workers, themselves restricted to the medical model/paradigm, and their products, the disabled, becomes very clear.

The relations between health care professionals and patients or clients, in fact, is not unlike that of class relations. The disabled, for example, collectively endure common economic and political conditions. In addition to the common base of hospitalization, institutionalization, and perpetual rehabilitation and its impact on self-image and self-confidence, there are common social conditions as well. For example, there is placement in profit-organized care facilities that are regulated in one degree or another, dependence on third-party payments for medical care, services and equipment, and there is dependence on continued eligibility for different forms of social public assistance programs, and so forth (Figure 5 below). Since these are relatively uniformly the case for many disabled people, they combine to form collective subjugation and manipulation (Rose and Black 1985: 33).

Thus, the patterns of self-expression supposedly characteristic of disabled persons are understood as reflecting the social, cultural, and political forces that dominate their existence, and which further reproduce those forces, the environment itself, and their designated places and roles within it. Of course, if certain forms of self-expression, behavior, conduct and so on (e.g. that which is labelled deviant) come into conflict with the accepted roles, norms, and values of the larger social and political environment in which the disabled are encapsulated, these are interpreted as threats or challenges, not as self-determining efforts. This subsequently solicits a response from those who have an investment in the structures of control and domination, since there is an unwritten and implicit rule that people must behave appropriately and according to the dictates of the social role structures of society. Berger and Luckmann (1967: 112-113) describe the over-all process this way:

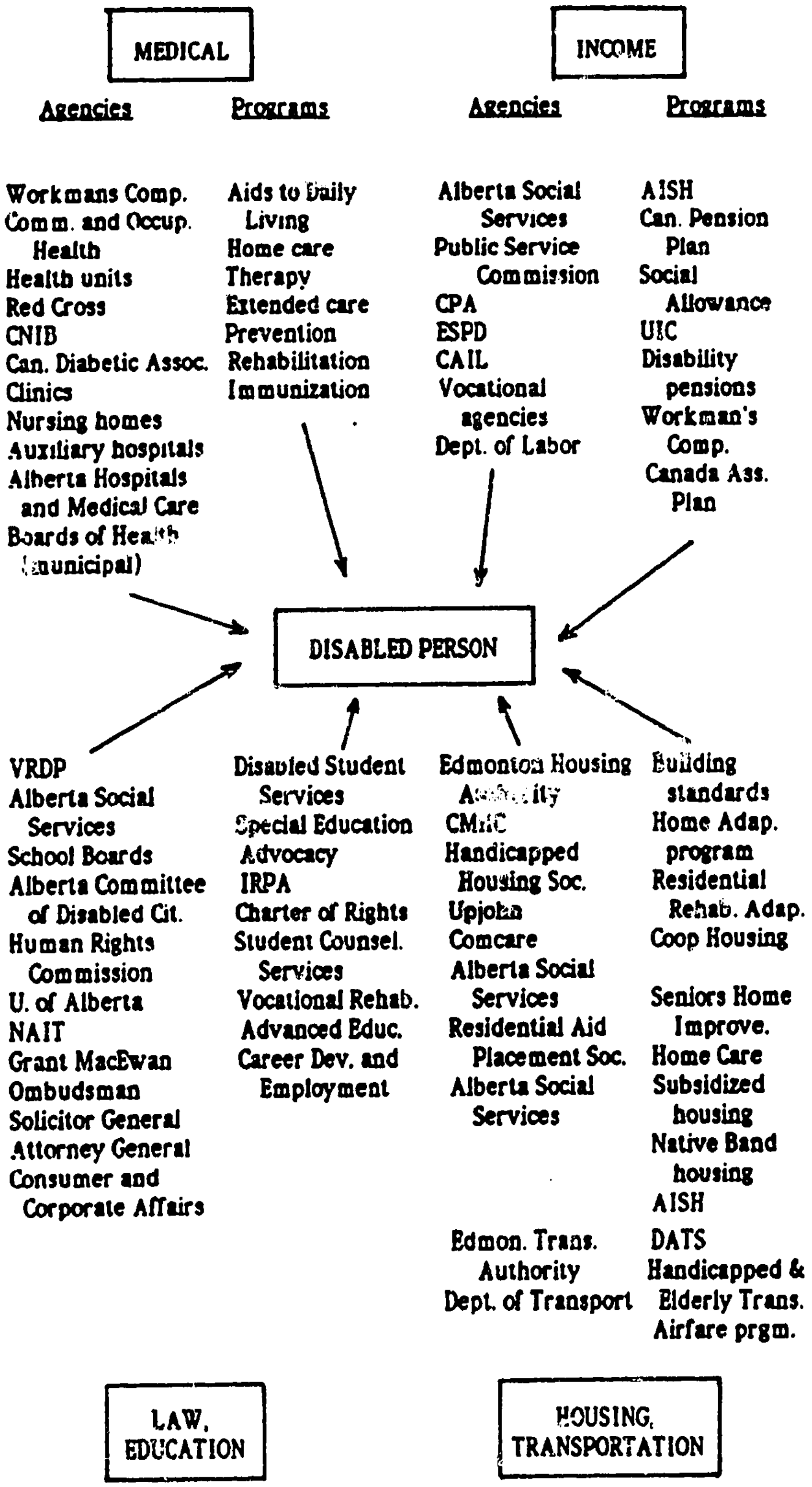


Figure 5. The Inter-Organizational Environment of the Disabled Person [compiled with assistance from the Alberta Committee, and with reference to the RITE Directory (1987/88), Government of Alberta. Three levels of government are shown.]

> Therapy [read: rehabilitation] entails the application of conceptual machinery to ensure that actual or potential deviants stay within the institutionalized definitions of reality, or, in other words, to prevent the "inhabitants" of a given universe from "emigrating." It does this by applying the legitimating apparatus to individual "cases" .... Since therapy must concern itself with deviations from the "official" definitions of reality, it must develop a conceptual machinery to account for such deviations and to maintain the realities thus challenged. This requires a body of knowledge that includes a theory of deviance, a diagnostic apparatus, and a conceptual system for the "cure of souls."

The combination of coercive physical manipulation and rearrangement of thought and subjective experience (decontextualization) to comply with a dictated reality therefore effectively extends the medical/rehabilitation model in terms of social control. In other words,

> Such a conceptual machinery [therapy/rehabilitation] permits its therapeutic application by the appropriate specialists and may also be internalized by the individual afflicted with the deviant condition. Internalization itself will have therapeutic efficacy..... Successful therapy establishes <u>a symmetry between the conceptual machinery and its subjective appropriation in the individual's consciousness</u>; it resocializes the deviant into the objective reality (Berger and Luckmann 1967: 114). [emphasis added]

In sum, the pervasive influence of this "objective" reality reinforces the demoralized self, which is communicated as disabled identity and self-expression, and so becomes the further focus and rationale of treatment by care and service providers. Furthermore, in identifying the disability with the individual (e.g. Goffman's (1963) notion of master status), the health care professionals, indeed, even the doctors, are themselves dissociated from taking responsibility for the consequences of their own activities. Sometimes we forget that the professionals themselves have been socialized into roles, identities, and into the conceptual machinery; they become just as disconnected from their real activities as do their "products," the disabled patients or clients. Their efforts are largely directed to reshaping the subjectivity of their patients or clients in order to improve their functioning <u>within</u> the disabled/sick role, thus reaffirming or reproducing (ironically) exactly those aspects of the individual that society finds most repulsive and unattractive.

Summary and Discussion

As I discussed at the beginning of this chapter, impairments are objective conditions resulting from pathologies and/or accidents. According to Albrecht and Levy (1981: 18), all societies "produce" impairments that are related to their particular levels of social organization and technology. The diseases currently prevalent in modern industrial societies, for example, are chronic in nature and produce considerable impairment and socially-defined disability before they finally kill. One may speculate and suggest that degenerative and man-made diseases like stroke, heart disease, carcinomas, and so on, are closely associated with the industrialization and modernization process. While sophisticated medical intervention and life-sustaining technologies keep impaired people alive who might otherwise die, changes in the causes of death combined with rising life expectancies probably also account for an increased incidence of disability (Haug and Lavin 1983: 32-33, 36-37).

Regardless of their incidence or prevalence in society, certain impairments are considered disabling only when they interfere with the individual's ability to perform expected social roles, and are formally classified as problematic (Albrecht and Levy 1981: 19).

Thus, the definition of some physiological conditions as disabilities really refers to the attribution of meanings and the importance of impairment to specific people in society. I would agree with Albrecht and Levy's suggestion that the attribution of meaning to impairments is learned, culturally specific, and is moderated by the individual's place in society. Attribution of responsibility for the impairment, they suggest, also tends to influence the social definition of disability. The social assignment of responsibility is open to argument, however, because there is a physiological basis for alcoholism and for cancer. Yet, those suffering from problem drinking are frequently judged responsible for their condition, while those incapacitated by cancer are not (even though smoking may increase the chances for developing cancer) (Albrecht and Levy 1981: 20).

Disabilities, moreover, are subject to moral evaluations and selective social perceptions. The effects of venereal diseases such as syphilis, gonorrhea, and even herpes simplex virus I are potentially more harmful than other communicable diseases, yet because of moral and sexual overtones little attention is directed to these problems. By contrast, the severe moral judgements and (in some cases) extreme social repercussions against those individuals with Acquired Immune Deficiency Syndrome and those who are carriers of the HIV virus show the relationship between selective social perceptions and social/cultural role expectations. In fact, the AIDS/HIV phenomenon is a clear example, though by no means the only one, of how impairment, disablement, and handicapping (as I defined these earlier in the chapter) can occur virtually simultaneously.

Disabilities can be seen as socially constructed entities regardless of their physiological bases for other reasons as well. It is in the interest of medical professionals, hospitals, nursing homes, and medical supply companies, for example, to identify treatable, chronic disabilities. Yet, I suspect that the disabilities that are identified and treated may reflect professional and occupational exigencies rather than actual consumer need. Under the medical model, disabilities are identified specifically as medical problems that require medical treatment. Albrecht and Levy make the important point that the difficulty is that the problem of imminent domain is not easily resolved: Many disabilities are the result of environmental, social, and other created conditions that are amenable to social service intervention, or to amelioration of other kinds. As I will show in Chapter 3, disabled people argue that medical care treatment and rehabilitation services cannot solve the problems of low income, social isolation, and architectural barriers that the medical model actually reinforces.

Granted, medical diagnosis does provide a necessary mechanism for controlling the flow of patients or clients in and out of programs, services, and so forth. The medicalization of disability is also a positive thing in that people in need can get the quality medical care that might not necessarily be available under, say, a social service model. Even disabled individuals admit this:

> Most people are ill at one point or another of their life [sic] and have need of medical help. Disabled people perhaps have a particular need for medical help in as much as disablements generally originate with disease or accident. Some forms of disablement also involve recurring bouts of illness or predictable requirements for medical help at various points during life. In this context the medical [model] and its function of healing is very necessary and valuable to disabled people (Derksen 1980: 15).

Unfortunately, the negative consequences of medicalization include the assumption that medical professionals know best, even for social conditions (Derksen 1980: 16). There is also the tendency to medicalize behavior labelled as deviant, regardless of the origin of the disorder. In fact, part of identifying or designating behavior as deviant consists of accepting the medical perspective of that behavior. According to Conrad and Schneider (1980) the medical perspective is used by the profession and ultimately by society to legitimate medical social control over diagnosis, intervention, and cure. Social control is thus achieved through such medical and rehabilitation technologies as behavior-controlling drugs and techniques, surgical techniques, collaboration among health care professionals and regulators that establishes control over a wide range of social behavior, and an ideology that is used to define behaviors as illness or disability.

I think what has to be made clear is that disability is an entity, a category, and a product of complex on-going social and political relationships and forces. Similarly, handicap is a social creation, not an objective truth. There is conflict over bureaucratic supremacy between the medical and health care professions, social services, and disabled people themselves. The conflict involves ideological differences concerning the nature of the "problem" and the response. Professions and other economic interest groups are powerful forces in constructing disability as a social problem. As is often the case, the struggle for control is contingent on the rewards to be gained by building an industry around a particular problem; thus, the group that controls the construction of the problem most often controls the policy reponse (Albrecht and Levy 1981: 20-22). It is in this struggle over the definition of the disabled category and the formulation of policy that disabled people want to directly participate.

Definitions of disabling conditions are often expanded in order to include the involvement and interventions of an ever-increasing number of professionals, specialists, agencies, interest groups, and other stake-holders (Stone 1984: Chapters 5 and 6). They compete with each other for power and resources, and it becomes in their best interest to maintain control and defend their interests by making the definition of disability non-negotiable, and by maintaining or creating dependency. Caught in the middle are of course disabled people themselves. What I am suggesting in this chapter is that how the disability category is constructed is determined by who is doing the creating and defining. Disability can be defined as a health issue, a medical issue, a technical issue, or as a social issue. The fact that it can be defined in so many ways proves the point, I think, that disability is a relative term, and that its "reality" should be negotiated among all interest groups, including the disabled themselves.

The struggle for control over the definition and creation of the category has produced no winners; control has been wrested away from precisely those in whose "interest" the labelling and expansionistic abuses have been applied. Disabled people have now emerged as the primary stake-holders in the struggle to deconstruct disability, and indeed, to reject and redefine the very context and process that has alienated and manipulated them:

> What will occur if [a] disabled individual does not accept the arrangements that have been made for him? What will be the result if he demands that the permanent nature of his disability be accepted by those around him and by society; if he says that he is not sick and should not be treated as a sick person? Who can predict the shape of things to be if he will demand to be held responsible for all the things that adult people are expected to be responsible for in this society; and what will happen when he demands his right to participate in every aspect of society? (Derksen 1980: 2)

The irony, of course, is that in order to begin "breaking" from imposed categories and to reconstruct themselves as human beings, disabled people must identify their disabilities and be identified as disabled. In doing so, moreover, they reaffirm the social roles and the essential validity of the social structure itself. What they are trying to do, however, is to redefine the social meaning of disability, reject the old disabled role and the behavior expectations that go along with it, and challenge the hegemonic control of the definition process. Disability itself, of course, can never be denied. To get the definition process firmly within their grasp -- in order to redefine their social, economic, and political position in the larger community -- the focus shifts from disability to ability, and from inaction to action. In Chapter 3, I begin with a discussion of consumerism and independent living, and later link that discussion with one on self-determination and empowerment -- the means as well as the outcome of the community-building process.

Chapter 3

Consumerism and Independent Living: Focusing the Concerns of Disabled People

Disabled individuals and indeed those who are vocal and most active in the disabled community are asserting as their central vision or goal their "reconnection" to so-called objective circumstances, that is, to social life. This is a pervasive theme I found expressed time and again in their actions, speeches, position papers, and so on, particularly those of the Alberta Committee and COPOH. Integration into social life involves

> .... the ability to live independently and productively in the community and to live with the same freedom of choice as a non-handicapped person. So it's not that you are living on your own but that you control where you live and have the same range of choices as a non-handicapped person (Jill Weiss, COPOH 1987d: 15).

> .... an integrated approach showing us as part and parcel of society instead of different and, therefore, special and deserving of the human interest approach (Standing Committee on the Status of Disabled Persons 1988: 17).

> My request for other Canadians is that they make the effort to relate to people with disabilities as they would to anyone else. We may look different on the outside, but we're exactly the same on the inside (Gary MacPherson, Canada, Secretary of State 1989).

A demand of disabled people is that they be understood simply as social and historical beings. The central value of this position is that of validation, meaning that not cripples, not patients, nor clients, but people who happen to be disabled, exist in history and society as actual or potential producers or participants in their own lives (Rose and Black 1985: 36-37). The idea of validation is communicated through the processes whereby people are "reconnected" to their sociality, and in turn "disconnected" from their objectified status as patients or clients. As I noted in the last chapter, existential differences are not denied but are relegated to secondary importance, and commonalities based on class or category position become the significant and essential aspects of daily life that generate such collective action as networking and the formation of self-help groups.

In this chapter I focus and elaborate on the meaning of consumerism,* and I discuss the ways in which consumerism is linked to the goal of independent living. The disabled community's idea of engaging themselves as producers/participants in comprehending and acting on their own contextual environments differs quite radically from the medical/rehabilitation model's goal of working to merely improve a disabled individual's functioning -- even though the latter claims to improve the quality of life and self-image of the individual (Crewe and Zola 1983). The difference between these two world-views can be understood, I think, as the

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* Consumerism, in general and in its present form, emerged during the 1960s, although its origins go back to the turn of the century when "purchasing power" was used to fight sweatshop and other unacceptable labor conditions and practices (and was as much a protest, even then, over the production and sale of shoddy goods). The significance of the contemporary movement appears to be its broad range of concerns with the functioning of the marketplace and its focus on many different aspects of the marketplace, including organizational and environmental issues, issues related to the introduction and impact of new technologies, as well as the more traditional concern with the production and movement of goods and services (Jones and Gardner 1976, Schon 1976: 1-19, Aaker and Day 1978: 2-18, Herrmann 1978: 27-36). For a specific discussion of consumerism in medicine, Haug and Lavin (1983) is a valuable reference.

difference between what it means to be a "producer" and a "consumer" of goods and services.

The consumer as producer, on the other hand, must undertake to learn how his or her social world is constituted in order to determine in what ways it impinges on his or her life (Derksen 1980). This learning process of course implies a conscious strategy for action, not an acquiesence to the dictates of others. As such, it also implies a process that is open-ended, constrained only by a temporary lack of motivation, understanding, and skills that are necessary to act.

I argue that merely consuming health and/or social services communicates an entirely different outcome than that which is the result of participating in that consumption as a producer. There is an interesting parallel between consuming services and consuming mere commodities: Both types of consumers are not directly in control of what they consume, both stand outside the framework or the determinants of the production process, both merely respond to what amounts to a received definition of what their needs are, and, finally, both are passive recipients of interactions which reproduce existing power relations in which they play only a supporting, never a major, role (Gartner and Riessman 1974: 171 ff). This kind of consumption often creates feelings of helplessness and pessimism (Navarro 1983: 112-114).

Put simply, consuming services such as disabled people do is a process in which the disabled consumer is obliged to take on the problem definition of the provider. In other words, the process of consuming the service consumes the person. In so doing the possibility of transcending or transforming the given universe of meaning established by the provider (who is, in turn, linked to professionals and experts) is reduced. Even the capacity to develop a critical perspective of society is diminished.

In treatment and rehabilitation programs where real people are reduced to disabled patients, where presentation of self or the "disabled identity" and the essence of the person are the same, both the person and the professionals with whom he or she is involved become one-dimensional (in Marcuse's (1964) sense). The world of the possible is reduced or collapsed to stasis and inactivity (Albrecht 1976: 20-26). As I noted in the previous chapter, social and personal life is often experienced by disabled people as domination and abuse -- it is medicalized. When the person's needs are defined in terms of medical interests, those needs which can be satisfied are often merged with those which cannot, creating either a false universe of satisfaction or, alternatively, producing a "defective" (recalitrant) patient or client.

I would suggest that consuming health care services free from a conceptual critique of the objective reality of the medical/rehabilitative model can lead to the consumption of a false reality made up of false facts. Consuming this reality (thereby reproducing it) consists of accepting the situation as it is -- without grasping the deeper implications of the causes of that reality. Living that false reality reaffirms the disabled role, the role of the professional, as well as the set of institutions and the ideology that creates and sanctions both of them (cf. Kallen 1989: 102-104). Figure 6 below contrasts the medical model with that one constructed and advocated by disabled consumers themselves.

To summarize, the independent living/disabled consumer movement and, in particular, the development of the independent living model (discussed later) has as its goal the transformation of people that have been turned into particular types of objects (e.g. patients, clients), who are acted upon in certain ways, and the transformation of the conditions which reproduce their objectification. What the disabled community is individually and collectively involved in is the struggle to transform their social reality, as they perceive and experience it, from often oppressive and exploitative conditions to circumstances where dignity, justice, and meaningful interaction can take place. This very much requires their direct involvement in, this, their own social and cultural reproduction.

MEDICAL MODEL	INDEPENDENT LIVING MODEL
Patient/client role	Consumer role
Acute condition	Chronic condition
Restorative care	Maintenance care
"Health" care	Social service care
Provider direction	Consumer direction
Physician plans treatment	Treatment planned in consultation
Aide recruited by agency	Attendant hired by consumer
Payment to provider	Payment to consumer, then to provider

Figure 6. Comparison Between the Medical Rehabilitation and Independent Living Models [adapted from Enns 1983: 4, DeJong 1983: 23, Dejong and Wenker 1983: 161-162. See also Haug and Lavin 1983]

The Emergence of an Alternative Perspective

Individuals who have become physically disabled, either by traumatic injury at work (Reasons et. al. 1981), illness from disease or from birth (e.g. the polio epidemic and the thalidimide babies of the 1950s; see also Appendix 2, Item 5), and whether for the short-term or the long-term, find themselves in a bewildering, new, and different world. It is one in which they are no longer deemed responsible for family, behavior, needs, and indeed, for most of the things they might have been responsible for as "normal" adult persons in society. Gone with these is their freedom of choice as well as their right to expect equal social acceptance as responsible adults, with respect, for example, to the rights of political and economic involvement in the community and society, access to public buildings and programs, access to private services and facilities, to travel freely, to choose employment and associates, to sexual expression and so on. All are gone, or at least are greatly diminished (Derksen 1980: 1).

The disabled individual discovers that he or she is now expected to play a specialized recipient role in relation to charitable givers; in place of the dignity of self-sufficiency, passive gratitude for what others choose to give is expected (and, admittedly, often received). Likewise, the permanent nature of the disablity (if such is the case) is supposed to be accepted, despite the fact that society as well as the helping professions reinforce the somewhat contradictory idea that he or she is "sick" and is expected to get better. The "problem" is remedied by "rehabilitation" (a term applied equally to deviants), and acceptance of the advice and counsel of a wide variety of professionals is expected to be accepted (Safilios-Rothschild 1970: 68-78, Albrecht 1976: 3-38).

Despite the fact that, in numerous instances, these clients or patients have had many active years of meaningful and gainful employment in the competitive market, they are now assumed to require employment preparation or retraining, and may be placed in a facility specifically for this purpose. If the humilation of being supervised sorting screws and returnable bottles or similarly dull work is enough to cause them not to perform well enough, they may be judged unready for the job market or unemployable, and might well be assigned to sheltered workshop employment (Derksen 1980: 1, Krause 1976: 217-218). If they and their families have become sufficiently demoralized by the new situation, residence in a nursing home or special rehabilitation housing project is usually considered as a first alternative and ready solution.

Similarly, if the disabled individuals are not wealthy, and if their self-concept has been sufficiently distorted by negative stereotypes of the disabled so that it is forgotten that their tax dollars have contributed to public transportation and that they have a right to it, they will probably accept, as a substitute, a special trip now and then in a bus operated by some charity-minded service club (Derksen

1980: 2-3). In the case of a disabled young person, he or she may find themselves attending a special school, and will learn that their only peers are also disabled, that being disabled means being different, and of the real gap between disabled and able-bodied society.

Altogether, disabled persons will find that very often all arrangements are made by assigned social workers in conjunction with other professionals (e.g. psychologists, rehabilitation practitioners, therapeutic recreologists, life skills specialists, et. al.) from a rehabilitative service agency which offers or controls comprehensive diagnostic/evaluative, educational, training, employment, housing, recreational, transporation, and social services for the disabled. In short, disabled individuals have no further need of making decisions; they are rehabilitated from the time they are disabled to when they go to their graves (Derksen 1980: 1-3, Sussman 1976: 223-233, Brown 1977: 159-194).

A significant number of disabled individuals become so in their twenties and thirties, often as a result of industrial (see Appendix 7, Item 1) and recreational accidents. They are well aware of what they had lost, and unlike an older generation of disabled persons they are not content to accept the inevitability of a life of dependence. The independent living/disabled consumer movement represents or constitutes a multitude of such individuals who refuse to accept the situation in which they find themselves, and who question it. They have come to recognize the extent to which the situation has really been defined by others.

The movement's most basic and central objectives from the viewpoint of the physically disabled consumer are <u>independence</u> and <u>integration</u> with the community (COPOH 1987d: 29-30). Put simply, independence means as nearly as possible the same degree of control and self-determination in the day-to-day living processes as are generally available to non-disabled people. Integration means as nearly as possible the co-mingling in the daily living processes with the rest of the community and society, including the fullest possible use of the comprehensive range of services and facilities that are available and used by non-disabled persons (Derksen 1980: 2, Dejong 1983). These goals comprise what is commonly referred to as independent living (also called the independent living paradigm, the IL movement, research model, etc.; I describe it more fully below).

From the perspective of disabled consumers, rehabilitation is also now redefined to mean "the careful and cogent application of medical and other interventions and/or treatments to remedy <u>only</u> the near-immediate traumatic effects of disablement upon a person" and his or her family (Derksen 1980: 2, emphasis added). While the consumer movement's independent living objectives dictate a mandate for the movement that includes a new view of rehabilitation; it cannot ignore the "environment." The environment in the sense it is referred to here includes legislation, public policy, program design, communications media, physical architecture, community structures and so on -- in short, all the opportunity structures that prevent (or allow) disabled persons from participating in the life of society as full members. The distinction between rehabilitation as defined here and the other larger environmental dimensions of community life is a critical one for the movement. Only by working to restrict the concept of rehabilitation to a treatment mode can disabled people assert themselves in society as healthy and "normal" (Derksen 1980: 2, 20-21).

It is recognized that a cornerstone of treatment and rehabilitation efforts as traditionally defined is the medical model of deviance (noted in Chapter 2; Gove 1976: 57-69, cf. Kallen 1989: 27). To get away from that model, rehabilitation has to be redefined as treatment or medical intervention to achieve a minimum level of basic health (defined as well-being and the capacity to function to potential in any given environment). Beyond that limit, however, the disabled individual assumes independence and insists on partnership in decision-making. The design, funding, and delivery of services and programs for disabled people has of course been carried out largely under the medical model, with a traditional view of rehabilitation that has been rejected by disabled consumers (Krause 1976: 209-216, Brown 1977: 291 ff). Consider the following Coalition of Provincial Organizations of the Handicapped (COPOH) resolution regarding control of a person's own rehabilitation program and examination of the process itself:

> WHEREAS the disabled consumer is seldom involved in the development of his/her rehabilitation plan; and WHEREAS the disabled consumer should be directly involved in the development and review of his or her rehabilitation plan;
> BE IT RESOLVED that COPOH strongly advocate.... that any service agency supplying rehabilitation services.... be required to develop an individually written rehabilitation plan in consultation with the consumer.... (COPOH 1985c: 51, Resolution R 5.80.4).

In addition, traditional approaches to rehabilitation policies, programs, and services have been significantly influenced by a number of ethics, or world views, which have been obstacles to the achievement of independent living. It is out of the volunteer/charity, medical, and professional ethics, for example, that the disabled consumer ethic and the goal of independent living has emerged (Derksen 1980: 4-10).

The volunteer/charity ethic is of course the one that has had the greatest impact on the funding and creation of various programs and services, and thus on the perpetuation of negative stereotypes of disabled people. A number of charity drives have used disabled children (usually with highly visible neural or muscular-skeletal and motor impairments) to solicit funds from the public. The Jerry Lewis telethons, March of Dimes, Easter and Christmas Seals campaigns, and the so-called Timmy events (originating from the Tiny Tim character of Dickens' A Christmas Carol) are notable examples of this. Until recently and in some cases still, such funds were used to support programs and services for disabled children, at the exclusion of adults.

Even though some of the funding does find its way into programs designed for all ages of disabled people, the public exposure of a fairly narrow range of individuals is nevertheless considered exploitive, and does little to ameliorate the untrue stereotype of the disabled person as pitied, child-like, asexual, passive, dependent, and incapable of responsible participation in society. The Canadian media (television, mass-circulation newspapers, radio, etc.) in general has recently been criticized for communicating negative and distorted images of disabled people (Standing Committee on the Status of Disabled Persons, 1st Report, August 1988).

The volunteer/charity ethic also magnifies and emphasizes the differences between the able-bodied givers and disabled recipients. There seems to be an almost direct relationship between the perceived degree of need and poverty of opportunities and resources in the recipient, and the felt sense of magnanimity, self-sacrifice, wealth, health and power of the able-bodied donor and provider. This relationship enhances the "abnormality" of the disabled as perceived by the public mind, and so isolates and distances the disabled population even more. The relationship is probably of greater benefit to the able-bodied; guilty feelings are soothed, social status is achieved by giving, and pleasures are derived from community group membership and participation. The publicity generated by charity drives or charity work also serves to emphasize, very subtly, the "unthinkable tragedy" of disability and thus actually encourages collective avoidance and fear reactions. From this perspective of what motivates charity work, charity, apart from the activity of raising money, does not contribute to the goal of independent living and community integration for disabled people (Derksen 1980: 4-5).

The medical ethic likewise maintains and even reinforces attitudinal barriers that disabled people encounter in the community. Despite some of the higher ideals claimed in the Hypocratic Oath, the medical ethic (or model) has resulted in the perception and subsequent treatment of persons as inert and passive bodies to be worked upon, to be repaired and "fixed." This notion of individuals as passive fields for chemical, surgical, and other interventions is of necessity some distance from the idea of individuals as whole persons with the right of active participation in decision-making. Writes Alvin Law, a victim of the drug thalidomide --

> I did, and do everything with my feet, and there is no question that my positive attitude has been the key to my success.... There are more than enough technological and medical treatments to allow for rehabilitation of the body. Using our mind is the key (Parliamentary Forum on the Status of Disabled Persons 1988: 40).

As occupants of the sick role, the disabled are expected to regain health (and little else) and become able-bodied again; the medical ethic persists in focusing solely on the physical body, measuring "ability" against admittedly arbitrary cultural standards of physical integrity, strength, virility, beauty and so on (Safilios-Rothschild 1970: 126-130, Albrecht 1976: 11-13). When the disabled patient does not respond, or cannot, medical science does not give up: Medical rehabilitation in the traditional sense becomes a permanent feature and burden in his or her life (DeJong 1983: 15-17). In the words of Pat Israel (COPOH 1987d: 21),

> I've been trying for almost a year to find an alternative health doctor who is wheelchair accessible and also has an accessible attitude towards disabled persons. I just went to one and the first words out of his mouth were, I can cure you of your disability! I said, doctor, I'm not looking to be cured, I'm looking to be a healthy disabled person!

In addition, it is important to consider the large growth industries, such as those providing health care, pharmaceuticals, prosthetic devices and equipment, therapies and so forth, that have been built up around the problems of the disabled and geared towards maintaining dependence. As I noted in Chapter 2, what is good for an industry may not be good for the individual (Albrecht 1976: 26). As with rehabilitation, medical, chemical, and surgical interventions may be indispensable means to achieve certain ends, from the disabled consumer point of view, but they should not be ends in themselves. Writes Bill Cameron,

> Our great medical system, which is saving lives and therefore, actually increasing the number of disabled people in our population through great medical techniques, is a sickness and injury treatment phenomenon (Parliamentary Forum on the Status of Disabled Persons 1988: 19).

The professional ethic is of course closely related to the medical ethic. It is based on the assumption that technical expertise be accepted without question, and that this knowledge is the property and under the exclusive control of a closed self-governing group of specialists and practitioners. This exclusivity accentuates the distance and difference between the active decision-makers and the passive accepting client, and reinforces the monopoly of knowledge in the field (Coe 1976: 250-251); this in turn cannot help but deepen and reinforce some of the negative stereotypes and the dependency of disabled people. The area of rehabilitation medicine and services has experienced the proliferation of secondary medical professions such as occupational therapy, physiotherapy, rehabilitation psychology, therapeutic recreology and so on (Albrecht and Levy 1981: 24).

Other professionals involved in service provision include the rehabilitation service administrator, the rehabilitation social worker, the professional social service program director -- even the professional fund raiser. These professionals and their programs have come to control the widest variety of programs, services, and opportunities required by disabled people (Derksen 1980: 6-9, Illich 1976, 1977). These include diagnostic, pre-school, housing, employment preparation, special recreation, and special transportation programs, as well as family counselling, technical aids supply, and other services. This specialization has led to the segregation of services to the disabled, and in turn has contributed to the segregation of disabled people themselves. Thus,

> WHEREAS COPOH supports the maximum independent living model and community integration;
> BE IT RESOLVED that COPOH take steps to discourage the professions from the tendency to segregate their services via rehabilitation-related specializations (i.e. rehabilitation engineering, rehabilitation recreology, etc.) and should.... deal with and serve the basic needs of citizens with disabilities as with those of any other consumer in need of professional services (COPOH 1985c: 51, Resolution R 5.80.3).

From the perspective of the disabled consumer, some of these professions together with their programs and services simply would not function or possibly even exist under a consumer version of rehabilitation (Derksen 1980: 7, Haug and Lavin 1983: 16-26). While useful in certain circumstances, this over-specialization has become too restrictive. A result of this proliferation of professions has also been the proliferation of separate special programming, some of which work at cross-purposes and which, in any case, continually demand clients in order to justify their existence (Stone 1984: 140 ff). Since of course the disabled population is fairly "finite," the result is often that the over-all rehabilitation process, including treatment, is lengthened far beyond what is necessary (Albrecht and Levy 1981: 24-26). In addition, "in order to receive private and governmental support, [service and/or rehabilitation] agencies may resort to recycling the same clients over and over again as a way to keep their success statistics high" (Albrecht and Levy 1981: 25).

It is significant that, despite their value, specialized programs and services as well as the people that design and administer them seem to completely ignore the possibility of expanding or improving existing public programs and community services in order to accommodate disabled people in their own communities. Whether this is a result of the mindset of the medical model, or because of the idea that program and service expansion does not pay, or both, there is little here that contributes to the independence and integration of impaired individuals. Professional help is supposed to enable the individual to lead a "normal" social life, but this is unrealizable without including the individual him- or herself in further developing existing community structures. It seems an irony that the success of the medical/rehabilitation model has in effect led to its "failure"; it is precisely this failure has provided the impetus for the independent living movement.

All this is not to suggest that these three ethics or even the medical/rehabilitation model should be totally abandoned. As I noted in the last chapter, the medical model has its distinct redeeming features. Rather, from the disabled consumer point of view, they have over time become somewhat constraining, dehumanizing, and have generated unintended consequences. There is a fundamental and basic flaw in treating any person as an object of charity, for example. Good will and generosity of self are clearly virtues, and in its appropriate role the charity ethic serves to heighten awareness on the part of the general public (and able-bodied persons in particular) of the unique needs and potential contributions of the disabled. A heightened awareness should therefore foster an equal partnership that enhances and not diminishes the image of disabled people, while at the same time produces the needed resources to solve what are undoubtedly common societal problems. Increasing awareness, as well as raising money, was largely the motivation behind the hugely successful Terry Fox, Steve Fonyo and Rick Hansen marathons, for example.

Spokespersons of the disabled consumer movement correctly point out that able-bodiedness, like youth, is at best a temporary condition and that the removal of attitudinal and structural barriers to independent living and integration is, in the long term, in everyone's interests:

> In defiance of [the] subtle denial of disabled people's subjective, persistently real, experience of human limitations and mortality, the disabled consumer movement has generated the term "T. A. B." to refer to able-bodied people. This is pronounced "TAB" and is an acronym for "temporarily able-bodied" (Derksen 1980: 6).

Most individuals are ill at one point or another in their lives and have need of medical help. Disabled people perhaps have a particular need for medical help insofar as impairments generally originate with disease or trauma, and, indeed, some impairments also involve recurring bouts of illness at various times. The medical ethic/model and its focus on healing is unquestionably indispensable and legitimate. Where the model seems to have broken down, however, is in its nurturing of the sick role and in taking the idea of physical healing too far (Derksen 1980: 16). In some cases complete physical healing is simply impossible, and disabled people insist that the medical profession should see this not as defeat or as a failure of the effectiveness of its methods, but as an indication that there is a time when the focus should be shifted elsewhere (Haug and Lavin 1983: 32-33).

Similarly, professionals are urged by disabled people to understand the limitations of the expert knowledge they claim to possess and control. Professional practitioners must recognize their need to be accountable to the community which provides them with the resources and the opportunities to practice in the first place. The sharing of expertise in order that disabled individuals may make informed and intelligent decisions does not imply interference by them, or a diminished role for scientific knowledge (Derksen 1980: 16, Haug and Lavin 1983: 20-24). This has led the Coalition of Provincial Organizations of the Handicapped to make the following statement:

> WHEREAS preliminary research indicates many disabled individuals report they encounter a great variety of inconsistent rehabilitation counselling advice and services; and,
> WHEREAS these represent very disruptive and intermittent rehabilitation counselling advice and services,
> BE IT RESOLVED that... COPOH... examine the need for a comprehensive, consistent rehabilitation process with a minimum of counselling staff on any one individual "case" (COPOH 1985c: 52-53, Resolution R 11.79.8).

Disabled consumers thus envision a somewhat different distribution of specialized knowledge, and a much closer involvement in the "production" and "consumption" of that knowledge. They are correct in asserting that all of society consumes information, services and products, not just a segment of it. The disabled are also part of a much larger social movement that insists that consumption is not the final stage of the production process or what defines the product, but that it is really its first stage. The goal of independent living, born of a consumer consciousness, is therefore understood as a necessary development from the charity, medical, and professional ethics.

The Rise of the Disabled Consumer Ethic

I would like to suggest that the independent living/disabled consumer movement is perhaps better understood in the context of the production characteristic of advanced capitalist (or post-industrial) society. In contrast to the industrial phase of industrial-capitalist production, a production characteristic of modern society is that control reaches beyond the productive structure into the areas of consumption, services, exchange, and social relations. The mechanisms of accumulation are no longer fed mainly by the use of labor power, but are served instead by the manipulation of organizational systems, information, and by intervention in interpersonal relations.

As I understand it, production itself no longer consists solely of the transformation of the natural environment into a technical environment, but has become the production of social systems, social relations, cultural orientations and lifestyles and, indeed, of the biological and personal identities of individuals. Since the personal and social identities of individuals are themselves products of social action, it is the control and orientation of that action that then becomes the "object" of contention in post-industrial society. I further elaborate this issue in Chapter 4.

My interpretation of what disabled consumers have recognized is the freeing of the concept of production from what it meant in an "older" industrial society, and its reconceptualization in terms of meaning, symbol formation, and social relations. Production might be viewed as the formation or transformation of objects, within the framework of certain social relations, by the application of certain means to a primary material. Production is not apart from nature, but is a natural process, technical as well as social. The inter-linking analytical components of production, as traditionally defined, are actions, raw materials, means of production, and social relations. However, the formation or transformation of objects already takes place within social relations; production is best conceived as the reproduction of social relations in the satisfaction of needs. Likewise, the relation of the producer to the product is simultaneously the affirmation of an identity, that is, there must be a recognition of the product as the result of the work of a producer.

This recognition thus constitutes a social relationship because it implies a reciprocity of the recognition. Social identity, then, is the attribution of the condition of "belonging to"; social identity emerges out of a situation in which one recognizes and is recognized in turn. Production is therefore the social capacity to recognize one's own work and that of others, and to have one's own recognized in turn. The social capacity also includes the will to appropriate and orient one's own work or production, since to produce also means to determine the orientation of production and of the product. Thus, one might say that production, recognition, appropriation, and orientation are the inter-linked analytical components of production conceived in terms of social relationships (Sahlins 1976: 153-161, Touraine 1977a: 92-97, 159-166). What better way, then, to reappropriate and reorient social relationships and identities than by making the disabled consumer a major or central factor in the production process itself?

The consumer movement has become increasingly concerned with the consequences that flow from the way the organization of production changes as the type of production changes. The transition from an economy based on industrial production to one based on high-tech production, information processing, and services over the past three or four decades has served to further marginalize those traditionally excluded from the work/production process. Historically, women, the young, the aged, the disabled and others were much less frequently employed in the industrial sector and were less integrated into the work system. Advanced capitalist/post-industrial society is based on a highly advanced productivity in the industrial sector that allows for even larger numbers and kinds of people to remain outside the work force. Many people are threatened to become marginal as far as purely technical production is concerned, but they are not marginal as consumers (Fuchs 1968, Gartner and Riessman 1974). Alternatively, of course, changing forms of work in an information-based economy make it possible for those previously marginalized to now participate more fully. Work is no longer necessarily labor-intensive, that is, involving brute strength or other physical requirements.

I do not think it coincidental, therefore, that disabled individuals allied themselves with women, youth, the aged and other alienated minorities during the so-called relational (or equal rights) movements of the 1960s and 1970s, which included consumer radicalism and organization (e.g. Nader's Raiders, and other action groups) (Gartner and Riessman 1974: 73-90). What provided part of the context for the movements of the 1960s and 1970s was the reaction to some of the contradictions generated by increased productivity (e.g. made possible by automation, computer technology, technical-rational administration, etc.), and the lack of opportunities to participate in that production or the means to consume the products. The independent living/consumer movement of disabled people in particular can be understood as a kind of reaction to yet another contradiction of modern society: The marginalized and dependent condition that disabled people found themselves in and the expectations of the medical model and sick role seemed wholly at odds with the focus on consumer choice in the marketplace, the willingness to take risks and to experiment, and the emphasis on individual initiative in society.

As I will discuss in the next chapter, such movements as the equal rights, youth, gay, black power, feminist, and other movements were (and still are) concerned with issues as identity, personal liberation, individual and collective rights, identity, self-actualization, and participation (Gartner and Riessman 1974: 95-107). The concerns with rights, entitlements, and identity, I would like to argue here, provided the meaningful context for what has since become a major concern: A better quality of life, growth, and participation in a consumer/service-oriented society. It is the consumer, not only the worker, who has become the weak link as it were, in the post-industrial/advanced capitalist economic structure. Exploitation, for lack of a better term, is also being experienced at the point of consumption, rather than just production.

As taxpayers, clients, patients, customers, welfare (or other benefit) recipients, community board members, workers, consumers in general have likewise turned a rather critical eye on public services, community and government programs (e.g. housing, education, health care, welfare), and public institutions (e.g. agencies, schools, hospitals, clinics, city councils). Often criticized as ineffective, dehumanizing, insensitive to human needs, unaccountable, and irrelevant or redundant, disabled (and other) consumers have been framing their demands to participate in a "new" kind of production. This means making decisions that involve services or programs, and that enables their equal access to all required services and programs in a manner such that there would be no second-class recipients.

The focus of criticisms and political action has therefore been on providing services and administering programs in new ways, for example, less professional, less hierarchical and centralized, less expensive, and now involving advocacy and self-help, and emphasizing responsiveness and accessibility. Consumption is now the same as production, that is, the production of services and programs, and so of human and social relations, as consumers exchange their patient or client roles for the consumer role. This increasing consumer/service consciousness, not surprisingly, stemmed from groups largely in consumer roles, e.g. patients, social service clients and service recipients. Out of this emerged a contemporary 1980s-style consumer politics with new tactics, forms, issues and styles -- a politics that has insisted on engaging the consumer as a direct factor in service, program, and technical production.

Thus, key to a disabled consumer politics has been the identification of the consumer as central in his or her own production, and his or her membership in the larger community. Indeed, as Glen Cave notes in connection with independent living,

> I would also like to add that independent living is a consumer issue. Disabled people living in the community

> have to be good consumers, have to demand good quality products, particularly in the area of technical aids and architectural access. Without those two we lose our mobility and without our mobility we lose our ability to function in the community (COPOH 1987d: 84).

Not surprisingly, a disabled consumer politics is also the result of the emergence of the professional/consumer dialectic (Gartner and Riessman 1974: 154-162). It was in fact Daniel Bell (1973) who suggested that the traditional conflict between worker and capitalist would be replaced by one between the professional and the consumer in post-industrial society. This dialectic has emerged from a set of contradictions that is a consequence of a changing organization and type of production in advanced capitalism. One contradiction is between the purpose of services in providing benefits for people and improving their welfare, health, education and so on, and the context of a highly individualistic and competitive political/economic framework in which service provision creates and justifies a class of experts, socializes people to the status quo, and maintains class, race, gender, and physical/mental differences between people.

A second contradiction, closely related to the first, is that increasing demands for private, local, community, and consumer-based services and programs brings them into conflict with the bureaucratization of these activities at institutional, governmental, and other levels. In addition, various bureaucratic dimensions, especially rational-formalism, Taylorism and impersonality, are anathema to activities that have humanistic ends and require relational interpersonal processes. The problems of how to plan and organize programs and deliver services for the disabled while at the same time maintaining their effectiveness (e.g. their humaneness) and increasing their efficiency persist, and are magnified by the fact that bureaucratization and professionalization often involves the manipulation of services and programs for purposes that may not seem as if they have anything to do with serving people.

The consequences? Large numbers of people in need of services, including the disabled, simply do not get them (because of ambiguously-defined eligibility criteria, too much "red tape"). Those who do receive services do not necessarily benefit by them (e.g. the revolving-door syndrome); many existing services are poorly organized and designed (e.g. misused, wasteful, or worse, inapplicable if in the case of multiple impairments); and, medical and para-medical practice itself is often inadequate (e.g. sexist, racist, class-based, elitist, and unshared). According to Albrecht and Levy (1981: 25-26),

> Social service agencies have an interest in both expanding their services to include more clients and "creaming" the pool of available clients to select those who are easy to process and will be most likely to demonstrate evidence of program success..... Other rehabilitation agencies, like state vocational rehabilitation programs and alcohol rehabilitation programs, also do not want to serve the multiple and seriously disabled because they are difficult cases unlikely to show rapid progress..... For these reasons, many rehabilitation agencies reject clients most in need and foster dependency in those clients they accept.

Impetus for a disabled consumer solution and key to understanding the independent living movement thus comes from disillusionment with the system (this is probably an under-statement). The impetus is also derived from the performance gap (between expectations, needs, what is actually delivered, and the recognition that planning and delivery modes are not socially or politically neutral) and, interestingly enough, an information gap.

Despite the information explosion, and the fact that society and the economy is increasingly information-driven, disabled (and other) consumers find themselves, paradoxically, information and thus knowledge-poor. For example, professionals and professional service providers and care-givers often selectively (and perhaps unwittingly) withhold information, assuming disabled consumers to be uneducated and to have no need for expert knowledge (a stereotype). In addition, the disabled may not know precisely what they need to know and where to find or access it, and they are sometimes unable to gather information themselves. Thus, a very real need is created to develop a means of obtaining information e.g. family and friends, networks, research/resource people in the case of a self-help organization, and so on.

Typical of a dialectic relationship, then, the professional/consumer one is characterized by both unity and the struggle of opposites. There is unity in the sense that both the professional and the consumer are factors in the production of services and programs, and that they both want the quality and coverage to be more effective and efficient, and more comprehensive. This unity breaks down, however, when questions of control and direction of planning and delivery of programs and services arise (Albrecht 1976: 26-28, Gartner and Riessman 1974: 154). Within the limits and constraints set by some of the societal/systemic contradictions I noted above, as well as by the professional/consumer dialectic, the disabled consumer solution has been to create mediating, alternate, or interfacing organizations in the quest for an independent living lifestyle. These include, for example, consumer-based community boards, consumer-run self-help groups, the use of consultants, advocates and service brokers, and networking (discussed in part below, and in Chapters 5 and 6).

These empowering solutions (part of what might called the revolt of the client) are therefore direct challenges to the social and cultural elitism of the professions and of professional practice and knowledge. I suggest that the disabled consumer resolution of the dialectic is twofold: Firstly, to place the disabled individual at the center of his or her own production, thereby (re)appropriating and (re)orienting production, and secondly, to bring about the reprofessionalization of the experts, by which means a reciprocal recognition of social and individual identities can be established.

The Means and Outcome of Empowerment: Towards Independent Living

Social movements, such as the independent living/disabled consumer movement, will hopefully eventually become institutionalized in the limited sense that a particular mode of discourse originating in the movement will find its expression reflected in public policy, professional practice and research, or both. While neither policy nor practice would ever totally embrace all the tenets of a movement's philosophy, an impact of one kind or another on the social order would probably be discernable (Giddens 1984).

The independent living/disabled consumer movement is more than simply a social movement or a grassroots effort seeking new rights and entitlements for disabled people; it is also having an impact on disability professionals and on the community in general (cf. Kallen 1989: 146-149). Not only is it reshaping the manner in which the nature and problem of disability has been defined in the past, and so is greatly influencing the thinking of experts and researchers, but it is also shifting the focus of the problem from the individual to the environment. In doing so it is providing new solutions to the disability problem, and is redefining the social roles of disabled people. On a practical level, the movement has spawned, among other things, new program/service planning and delivery models that have come to be protected by legislation and disability policies. In short, the movement -- and its discourse of independent living -- has come to constitute a new paradigm (Derksen 1980: 16, 1983, Simpson 1980, Enns 1983, COPOH 1985a, 1987d, Crewe and Zola 1983).

The paradigm that has dominated disability policy over the past several decades, in Canada and elsewhere, has been the rehabilitation paradigm (which includes medical and vocational rehabilitation). Within this paradigm, the problems of disabled individuals are generally defined in terms of measured performance in what is called activities of daily living (noted in Chapter 2), or in terms of preparation for gainful employment (DeJong 1983: 22-24, Safilios-Rothschild 1970: 142-166). The focus is almost exclusively on such factors as age, gender, psychological makeup of the individual, his or her impairment, and what bearing these intervening variables have on recovery. From this perspective, the problems of disability are those of the individual; it is the individual that needs to be changed. To overcome the problem of disability, the individual is expected to follow the advice of a physician and a variety of therapists and counsellors, all the while assuming the role of patient or client (following the medical model and the sick role, cf. Safilios-Rothschild 1970: 166-176).

Thus, the goal of the rehabilitation process, which is under the control of professionals, is maximum physical and mental functioning. Also, the success of the programs and services that are part of the process are determined by whether the patient or client complied with the prescribed therapeutic regime. In fact, the issue in the rehabilitation process is not whether rehabilitation itself works, but which kind of therapy or intervention technique works best for an individual or group of clients (DeJong 1983: 23). Science seemingly comes first, the individual last.

Over the last several decades, however, so-called anomalies have appeared that could not be adequately explained or accounted for by the rehabilitation paradigm. Through the examples of a small number of determined physically disabled persons, it was demonstrated that participation in the medically-defined rehabilitation process is not necessary in order to live independently. As early as 1962 in the United States, for example, the University of Illinois at Champaign-Urbana initiated a community living project for disabled students. In 1972 the Berkeley Centre for Independent Living was incorporated, while the Boston Centre for Independent

Living was established two years later (Zukas 1979, Coxon 1981: 3, 8-15, DeJong 1983: 8-10, Frieden 1983: 62-71, Coalition of Provincial Organizations of the Handicapped (COPOH) 1985a: 5). These centres were managed primarily by the disabled themselves, and provided such services as peer counselling, skills training, transporation, health maintenance, wheelchair repair, and so on (I discuss Canadian independent living centres in Chapter 6). Each centre offered its own unique blend of consumer services and advocacy, which eventually included monitoring (US) federal legislation.*

The independent living (IL) paradigm, as it is sometimes called by disabled consumers, has emerged as a very definite alternative response by disaffected disabled people world-wide (not merely in the United States) to meet the rapidly growing desire to achieve independence from medical intervention, institutionalization, and external social control mechanisms (Tate and Lee 1983). While some rehabilitation professionals may have introduced IL concepts into their own practice (e.g. Symington 1983), the rehabilitation paradigm has not been totally abandoned. Considering the organization of medical rehabilitation and the growth and profitability of health-related industries (chemical, prosthetic, etc.) that have, over decades, grown around this model, some opposing interests will likely remain (Albrecht and Levy 1981: 24, 26).

Nevertheless, the transition is encouraged by redefinitions of rehabilitation initiated by the disabled themselves. Canadian disabled consumer organizations have actively pushed,

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* It is interesting to note, as well, that in 1973 the US Congress passed a new Rehabilitation Act which has been referred to as the "Civil Rights Act of the Handicapped" (Pub. Law No. 93-112, 87 Stat. 355); an amendment passed into law in 1978 was significant in defining and extending services and funding specifically for independent living (Coxon 1981: 4-8, DeJong 1983: 4, 26-27, COPOH 1985a: 6).

internationally as well as in Canada, for a much more limited definition -- as opposed to the "crade-to-grave" concept. Thus,

> [R]ehabilitation is a process aimed at enabling a person to reach an optimum physical, mental and/or social functioning level in order to provide that person with the tools to direct his/her own life. Independent living and community services are not, and should not, be part of that process (Disabled Peoples' International, 1980 Charter).
>
> Rehabilitation means a goal-oriented and time limited process aimed at enabling an impaired person to reach an optimum... functional level, thus providing her or him with the tools to change her or his own life. It can involve measures intended to compensate for a loss of function or a functional limitation (for example by technical aids), and other measures intended to facilitate social adjustment or readjustment (United Nations 1983: 3).

This rethinking of the concept and its subsequent redefinition led the Coalition of Provincial Organizations of the Handicapped to formulate the following statement:

> WHEREAS the involvement by the consumer is a vital part in any system which is responsive to the real needs of the people it serves,
> THEREFORE BE IT RESOLVED that COPOH endorses the independent living model and direct its efforts to the implementation of the Independent Living Philosophy in all appropriate programs and services related to the disabled in Canada,
> AND FURTHER BE IT RESOLVED that COPOH introduce and advocate the independent living model at the 1980 World Congress as an alternative to traditional open-ended rehabilitation where it has been extended beyond the

> treatment mode (COPOH, Resolution 5.80.11, in Enns 1983: 9).

From the point of view of some disabled consumers, the transition to independence and independent living is also a frightening one that requires considerable courage not to resist change. Like "coming out" (Kallen 1989: 40, Chapter 5), independent living is easier said than done. It is easy to accept the dependency prescribed under the sick role as normative, frustrating though it may be, because it removes the obligation to take charge of one's own life and relieves individuals of many of their familial, occupational, and civic responsibilities. Moreover, dependency and passivity do not carry with them the possibility and risk of failure; so great in fact is the fear of failure that the phrase "dignity of risk" has become part of independent living vocabulary (Zola 1983b: 352-353). DeJong (1983: 20) likewise noted that,

> The dignity of risk is the heart of the IL movement. Without the possibility of failure, the disabled person lacks true independence and the ultimate mark of humanity, the right to choose for good or evil.

Or in the words of Elizabeth Semkiw,

> Two things are going to have to happen. Firstly, they're going to have to listen, to really listen to what disabled people have to say. Secondly, they have to recognize that when you control your life and make your decisions, you also incorporate a risk and that is part of life. No matter how disabled a person is, they choose to take a certain risk because it gives them certain freedoms. It is their choice and it is not anybody else's right to interfere with that choice. Very often a risk is taken again, for freedom, trading one thing off for the other. That has to be recognized by the community. That is a disabled person's right (COPOH 1987d: 58).

The so-called paradigm shift that each disabled person must undergo or experience for him or herself involves, again, a learning process undergone in the company of others. In order to learn, however, individuals have to both disconfirm some proposition in their "practice theory" of everyday life and to experiment; in order to experiment they have to be able to tolerate failure, and in fact one of the features of learning is the ability to recognize explicitly that a commitment to experiment does require failing. There are "zones" of failing and "zones" of inability to know, and there are times when failure is not attributable to incompetence but simply to the nature of the environment confronting that individual. For individuals to deal with or tolerate failure, and hence to learn effectively without destroying their innovativeness, they need to attribute failure to something other than themselves.

According to the independent living perspective, then, the problem of disability does not lie with the person but in the solution offered by the dependency-inducing consequences of rehabilitation in general and the medical model in particular. The locus of the problem is not the individual but rather the environment that includes not only the rehabilitation process itself, but also the physical environment and the social control mechanisms in society at large. From this alternative perspective, a number of environmental barriers and constraints are as critical, if not more critical, than the personal characteristics of individuals as "intervening variables" in determining disability outcomes. Key intervening environmental variables would include the social stigma of disability, the hospital/institutional milieu, availability of medical and equipment services (or lack of them), access to educational and vocational facilities, architectural barriers and access to transportation systems, unavailability or loss of financial and social benefits, lack of legislation and policy, and so on (DeJong 1983: 24-25, Varela 1983).

The independent living paradigm also differs significantly from its rehabilitation counterpart in defining outcomes. While self-care, mobility, and employment are stressed in the rehabilitation model, independent living stresses, in addition to these, a much larger constellation of outcomes, including the importance of living arrangements, intimate relationships, consumer knowledge and assertiveness, out-door and out-of-home activities, and so forth. The IL paradigm thus represents the emergence of a new value system and an entirely new lifestyle. Consideration of environmental barriers and constraints is key to understanding the thrust, and impact, of the independent living paradigm in the context of the disabled consumer movement.

Environmental variables, unlike the age, gender, race, and other physical characteristics of individuals can be created, modified, transformed, or even abolished -- given changed attitudes and political will. The strategies of advocacy, peer interaction, self-help, consumer control, and barrier removal are therefore both the means as well as the outcome of an independent living lifestyle. From this perspective, full control over one's life is deemed more important, in one sense, than control over one's body. Doing and enjoying some things, to be realistic, may have to be given up by a disabled person, but what is important is whether he or she can determine when and how these things are to be done if helped by others (Zola 1983a: 58).

The traditional rehabilitation methods that belabor the unalterable characteristics of individuals actually also have little policy relevance (and perhaps little clinical relevance as well). Independent living, on the other hand, focuses upon the larger institutional and environmental context. Here, policy issues loom large: There is, for instance, the growing public debate about the extent to which society should shoulder the responsibility of removing environmental constraints, such as inaccessible public transportation, inaccessible or unavailable housing, architectural barriers, unmet personal care needs, skills training, to note but a few. Central to this debate is the difficult issue of income and funding -- is it to be public money that pays for these improvements or for personal care services? Ready answers are not available, but the independent living perspective has identified issues that must now be resolved within a political/public policy framework involving the greater community.

By having broadened the problem of disability to include a wider variety of environmental variables and contexts, the idea of independent living has opened up the field of disability policy to other disciplines, as well as the participation of a much wider circle of sympathetic professionals (able-bodied as well as disabled). For example, an emphasis on legal and political rights has encouraged the involvement of legal professionals, the issue of architectural barriers has been taken up by architects, engineers, and city planners, and the funding issue (individual, group, as well as public) has been of concern to economists and public sector finance people (DeJong 1983: 26). Likewise, disabled individuals have sought and achieved professional training (itself testimony to the influence of the paradigm) to help with what could be loosely termed the "rehabilitation" of society. The problems associated with disability are no longer perceived as strictly those of the disabled. They never really were. They have now become the concerns of the greater community.

In short, what better way is there to describe community-building than that which characterizes the shift from the rehabilitation to the independent living paradigm, the reciprocal recognition of identity between those who are disabled and those who are not, that accompanies that shift, and the achievement of a barrier-free environment (architectural, technical, as well as attitudinal)?

Independent Living: The Goal of Empowerment

Independent living is, of course, as abstract a concept as the idea of human rights: According to Elizabeth Semkiw, "independent living really is an idea, a concept, a thought process. You apply this thought process to your lifestyle" (COPOH 1987d: 57). This concept is an outgrowth of consumer philosophy, and provides a framework for viewing the world, and is a model for the way people want to live. As a framework and model it is not static, however, but should be properly seen as part of the dynamic empowerment process whereby disabled people learn to take control and to assume responsibility for the management of resources that are required to lead the kind of lifestyle they desire within the constraints faced by everyone else in the community.

Some of the underlying concepts of the model are dignity of risk, taking responsibility, freedom of choice, consumer control, and self-determination -- to be individually and collectively realized through concerted political action:

> The handicapped consumer movement is the grassroots democratic struggle of self-expression. The goal is to enable every handicapped person to achieve his/her maximum personal independence and full community integration. Modern society has demonstrated time and time again that full social/economic equality and acceptance for any disadvantaged target population <u>can ultimately only be achieved by the target population itself</u>. This requires philosophical unity of purpose, public visibility, direct representation, and dynamic political action, preferably of the constructive democratic brand (Simpson 1980: 3). [emphasis added]

The independent living concept does not advocate a particular lifestyle. There is no pre-set lifestyle that is considered more or less independent than others: "[T]he struggle for independent living and personal determination is something each disabled person must approach in their own way" (Michael Huck, COPOH 1987d: 20). Moreover, the concept of independent living frames the idea of independence in the socio-political sense of the term, rather than in physical/biological terms (COPOH 1987d: 30). Thus, independence is not measured by the number or quality of tasks individuals can perform without assistance (this would only return us to the "activities of daily living" concerns of the medical/rehabilitation model), but rather the quality of life they can achieve even with assistance. Furthermore, according to Derksen (1983: 7),

> Many people have confused the IL concept to be a new idea for housing disabled people or delivering residential facilities for them. Many others have confused the IL concept with the provision of personal attendant care services. I believe that though such ideas about housing and care services may be important in working toward full participation for disabled people, they are really not the centre of the IL concept. Rather, the IL concept at its heart has to do with self-determination and liberation for the individual within his society through collective self-determination and self-help.... [emphasis added]

The dynamics of the independent living concept have apparently not been widely understood and as a result have been misinterpreted. Among disabled people the term actually refers to specific conceptual developments:

> When disabled consumers employ the term independent living they imply much more than what either of these words mean separately in every day usage. The independent living concept provides consumers with an analytical framework for identifying and solving problems. From this paradigm, consumers frame questions of life-style and devise new solutions to lifestyle problems (COPOH 1987d: 26-27).

The notion of self-determination (perhaps the central concept of the independent living model) is a phrase deeply embedded in the lexicon of the independent living/disabled consumer movement. Having noted earlier that independent living is a consumer issue, I would like to posit a link between the idea of self-determination and the doctrine of consumer sovereignty in economic theory (Penz

1986), as well as the notion of self-actualization in humanistic psychology (Rogers 1951, 1977). With regards to consumer sovereignty, first of all, this doctrine is a central normative principle underlying discussions of optimization and evaluation regarding the design and performance of market economies and their constituent institutions. It is also apparently the core value assumption of welfarian economics (Penz 1986: 1-2, 7-10).

Put simply, the doctrine asserts "that what is to be produced, how it is to be produced, and how it is to be distributed are to be determined by consumer preferences as revealed through consumer choices in free markets" (ibid., 10, 12-15). The free market, from this idealistic point of view, is supposedly one where there is no single, collective, control over what is produced or over how the output is distributed. Under this ideal model, consumer preference and choice is in turn determined by socially-derived individual wants and interests (Penz, appropriately, has examined in detail the socialization processes involved in the formation of wants and interests). [Penz does not discuss monopoly capitalism and quasi-free markets, and the ways in which they give the illusion of freedom and choice!].

Further to this, welfarist interest theory, from which the idea of consumer sovereignty flows, refers to what people desire for themselves, which includes enjoyable mental and physical states, and conditions promoting these. That is, "welfarist interests consist of self-regarding want satisfaction, happiness (or pleasure, enjoyment, or contentment), or whatever is instrumental to one or both of these ends" (Penz 1986: 143). Penz, as do other philosophers of economics, regards the term "interest" as it is used in political theory to be synonymous with "welfare" as it is used in economics (and so the term welfare does not refer solely to the redistribution of resources).

Thus, from the consumer point of view, interests for one's own happiness are the determinant, for lack of a better term, of production and distribution, just as in liberal-democratic political philosophy the objective of the political order is the fulfilment of the interests of individuals (e.g. Flathman 1966, Benditt 1975). Penz (1986: 9, Table 2.1) offers a useful overview of alternative conceptions of "interests" that have appeared in the literature, some of the more potentially useful of which are: rational wants, generalized opportunities for want satisfaction, justified claims, central concerns of the community, and impacts on life chances.

In not as many words, disabled persons say that, as consumers, they are the best judges of their own interests (welfare), both individually and collectively, and so should have the larger voice in determining what products/services should be provided in the disability services market, and how they should be distributed (DeJong 1983: 13, Alberta Committee of Disabled Citizens 1981: 21-23 and various documents 1982-1988, COPOH, various documents 1980-1989). The notion of self-determination is indeed a powerful one, not merely by itself but especially when it is linked to independence and the independent living model. The notion, moreover, is an example of what Penz (1986: 144) calls "essentialist conceptions of human interests." This simply means that the goal or ideal of self-determination (self-realization, self-development, self-expression, etc.) is not only generally appropriate as an instrumental means by which certain interests can be realized, but is specifically appropriate as an end in itself.

The link, therefore, between self-determination and "justified claims" and "life chances" (as interests) is an obvious one. From a political/human rights perspective, moreover,

> Freedom to decide and to determine one's own destiny is [a] fundamental human-rights principle. Indeed, the right to self-determination of all individuals -- regardless of their race or class -- was one of the earliest of the fundamental human rights to gain universal recognition.... The exercise of this right requires access to political power..... [B]eyond the political process, this right extends

> into decision-making in all spheres of life: home and family, work, school, church, club, and choice of life-style. The denial of the right of individual decision-making and self-determination constitutes oppression (Kallen 1989: 7).

The associated idea of sovereignty clearly has political overtones. Indeed, the disabled community very much sees itself existing under a condition of "internal colonialism" in which it has little or no voice in its own affairs, and must exist under (and so be defined by) the social, political, and economic policies of some "imperial power" -- not unlike the experience of other peoples and indigenous populations (though one would not want to take the analogy too far). As under colonialism, disabled individuals "suffer a spectrum of alienation from blatant neglect to overprotection," and they experience physical isolation, institutional segregation, paternalism, and tokenism (Alberta Committee of Disabled Citizens 1981: 24, Krause 1976: 218). When discussing the independent living model the disabled community often invokes the concept of citizenship, for example, when making the point that there cannot be grades of citizenship within Canada, that equality of opportunity in all aspects of life must exist for every citizen, disabled or not (COPOH, n.d.: 2-5, COPOH 1985b: 60-61) -- "[A]s part of its full citizenship philosophy, COPOH asserts that government should not do things TO and FOR disabled persons, but rather WITH us."

The way disabled consumers use the phrase (e.g. Derksen 1980, 1983 supra., Crewe and Zola 1983) clearly illustrates that they have a vision of self-determination in the specific sense, rather than in the general sense as differentiated by Penz. Put simply, the means of achieving certain goals and solving particular problems in independent living are as important, if not more so, than the solutions to the problems themselves (Simpson 1980: 8). Yet, even as an end in itself, is self-determination really feasible? Clearly, as individuals our earliest and probably most fundamental development (i.e. primary socialization) cannot be self-determined; it is only later choices and interests that may be self-determined.

An important issue is the extent to which later interests are determined by a self that has already been formed by the social environment, and to what extent the social environment still operates on forming people's interests. The vision of self-determination for disabled people therefore involves a kind of conscious un-socializing or un-learning process, the same process that is involved in abandoning the medical/rehabilitation model for the new independent living paradigm. Self-determination as an intrinsic essentialist conception of human interests and empowerment as a conscious action process are clearly tied together. Self-determination is the means by which new social and personal identities are formed, and new individual and collective self-images developed through the restructuring of motivations.

The idea of self-determination can also be linked to the idea of self-actualization, a concept that is central to the humanistic tradition in psychology. The process of self-actualization might be defined as "becoming whatever one can through activities determined by oneself." The fundamental assumption is that the human being, as an organism, has one basic tendency and striving -- to actualize, maintain, and enhance itself (Rogers 1951: 488). The human being is, in fact, "a process of becoming." According to Rogers (and Abraham Maslow, to some extent), self-actualization is also a directional process. The organism naturally moves towards the goals of maturation, increasing competence, survival, reproduction, self-regulation, autonomy, and even community (Plant 1974: 62). From this perspective, not only is individual behavior motivated by a need to realize these goals, but society itself should be concerned with helping individuals develop their highest potential. This is viewed as their right; the individual has a right to determine his or her personal action in the context of a supportive community (Plant 1974: 61-62).

The assumptions that underlie this perspective are worth noting in the context of much of what I have discussed so far concerning self-determination. Rogers' idea of self-actualization is fully compatible with Penz's essentialist conception of human interests, of course. People are viewed as essentially good, and continually strive toward a better state. Rogers suggests that any less-than healthy functioning of the individual is a consequence of the environment, or more correctly, social structures and institutions. People are themselves the best judges of what they want, need, and what their interests are. The best vantage point for understanding behavior is from the internal frame of reference of the individual. Most of the ways of behaving that are adopted by individuals must be consistent with notions of the self, which in turn is a result of interaction with the environment and, most important, interaction with others. Thus, maladaptive, self-destructive, incompetent, and dependent behavior is the result of conflicting notions of the self, derived from less-than ideal interactions and interactional settings. The cause of humanism, therefore, is to promote the awareness and the conditions that make it possible for people to become self-responsible, more flexible, make progress in self-actualization, and to become more creatively adaptive.

From the perspectives provided by Penz and Rogers, the independent living model might be described as an operational and prescriptive one (e.g. Caws 1974: 3-4, Holy and Stuchlik 1981: 19-24). It is certainly not incompatible with the doctrine of individual (consumer) sovereignty in economic philosophy, or the vision of competent and independent action in humanistic psychology. An independent living lifestyle is thus the outcome of empowerment, that specific developmental and transforming process that is constructed through learning and action by embodying certain assumptions, beliefs, and values about the relationship between people in general, and the relation between the disabled community and the rest of society in particular. In turn, the goal of independent living provides disabled people with the rationale for developing the necessary social and political skills useful for playing more conscious and assertive roles in the construction of their own social environments. In fact, the goal of independent living requires a more active role in shaping the social environment and building community:

> WHEREAS the right of disabled people to self-determination and control of their own lives must be guaranteed; and
> WHEREAS these rights are violated by the "medical model";
> BE IT RESOLVED that COPOH undertake the following plan of action:
> 1. that the consumer movement (COPOH and its affiliates) recognize the need to monitor;
> 2. educate the medical profession concerning the concept and means of self-determination;
>
> ****
>
> 5. that COPOH acknowledge the need for and encourage the formation of self-help groups on the local levels to facilitate information-sharing and mutual support, thereby lessening reliance on the medical profession (COPOH 1985c: 52, Resolution R 6.81.5).

The independent living/disabled consumer movement (at both the provincial as well as national levels) has developed and articulated a set of principles that guide both the realization of specific goals and the implementation tactics of consumer policies (Alberta Committee 1981b: 25-29). Embodying the IL philosophy, the principles are basic to the movement's task of improving the quality of lifestyle of disabled people through legislative policy change at all levels of government, information gathering and sharing, research into more viable programs, services, and delivery systems, and through monitoring existing legislation and its implementation. Embodied in the principles, derived from Alberta Committee and COPOH sources and outlined below, is also the idea that disabled people have a right to be recognized, to contribute to society; the right to exist likewise implies a right to autonomy.

Principle of Equality: During the past decade disabled Canadians, largely through the efforts of the independent living/disabled consumer movement, have made major strides forward in attaining equality by seeking to secure legal recognition of their community rights in human rights legislation, at both federal and provincial levels. The inclusion of persons with disabilities (physical as well as mental) in legislation and statutes means that discrimination on the basis of disability is prohibited in areas such as employment, housing accommodation, and access to goods, services and facilities. Of particular value to the disabled community is of course the Charter of Rights and Freedoms, specifically section 15(1) which relates to the equality rights of individuals, and sub-section (2) which endorses the development of affirmative action programs that have as their object the amelioration of conditions of disadvantaged individuals and groups.

The movement recognizes that to ensure provision of, and access to, goods, services, facilities and so forth, there must be an independently recognized authority to settle disputes. It also recognizes the need for disabled individuals to actively participate in fashioning, advocating, and defending a practical interpretation of equality that is in keeping not only with the goals of the movement and the independent living model, but with the needs of the larger community and of all citizens. Equality rights are the cornerstone for empowerment and self-determination for disabled people at both the individual and community level. The notion of "reasonable accommodation" (which I discuss in Chapter 7) is the operationalization, if you will, of the disabled citizen's interpretation of equality.

Principle of Full Participation: The disabled community has recognized there has been a tendency for non-disabled persons to speak on behalf of disabled persons in many areas of social and political life. Full participation, or consumer control, therefore includes collective self-representation. The movement is committed to ensuring that all individuals have the opportunity to participate in the planning, monitoring, and delivery of all aspects of programs that directly affect them, by such means as meaningful-proportioned representation on advisory councils, research task forces, community service boards, ownership of service-providing organizations, and consumer control (e.g. 51%) of all services and managerial structures. The principle most definitely extends to include the process of consultation and joint policy decision-making with different levels of government.

Principle of Integration: The intent of the independent living philosophy and the service delivery models that have developed from it is to enable disabled persons to assume greater control over their lives and to facilitate their integration into Canadian society. To this end, integration is conceived as the desegregation of specialized services for disabled citizens and the eventual establishment of these services as components of mainstream or generic community service delivery systems, in such areas as health care, education, and employment. There is also recognition and insistence that mainstream community service providers assume a reasonable degree of responsibility for removing architectural barriers that prevent access to public and private buildings, recreational facilities, and public transportation systems. In other words, "specialized services if necessary, but not necessarily specialized services."

Principle of Individuality: This principle is derived from an understanding that there are indeed differences between people, that not everyone has the same interests, aspirations and needs, and that not all disabilities can be treated as if there were no differences between them. Thus, it is recognized that a theory of formal equality which advocates that all individuals should be treated the same regardless of their differences would wreck havoc on those who possess characteristics which do not conform to dominant or majoritarian standards. The principle therefore endorses a combined theory of substantive and formal equality whose goal is the equality of results for individuals, but whose benefit is felt at the community level. To this end, the idea of special measures, affirmative action, and the notion of reasonable accommodation is supported. A balance is sought between tailor-made and mainstream community-based services and programs.

Principle of Accountability: One of the roles of the disabled consumer movement, in the context of the independent living paradigm, is to claim and exercise the right to monitor and evaluate existing public as well as private service and program structures, delivery systems, and policies -- at local, municipal, provincial, and federal levels. In this capacity, the movement seeks to provide the disabled and non-disabled community with evaluations of rehabilitation and other service providers, health professionals, legislators, etc., with respect to adequate benefits, quality services, reasonable costs, qualified personnel, and so on. The principle also recognizes that medicine stands between biology and social policy, between private bodies and public interpretations. Thus, disabled consumers hold both practitioners and interpreters (legislators) accountable to them, both for their actions and their non-actions.

Summary and Discussion

I find it interesting and not entirely a coincidence that disabled people have opted for an association with the generic consumer movement. From their point of view, of course, they are consumers of services and products, but what they consume and demand are not always ordinary services and products. The issues are not necessarily those related to shoddy workmanship, the promises of false advertising, voided warranties, or even the unjustified product safety claims of a manufacturer. They are however directly related to physical and mental well-being, the realization of life-chances, physical reproduction, sexuality and intimacy, intellectual and personal development, and so forth. These are things, I would guess, that all people, disabled or not, most deeply want and value.

Disabled people are potential or actual users of organizations and institutions -- the courts, governments, schools and universities, churches, businesses -- those that produce services and products of perhaps a qualitatively different sort. As with what they teach or what they produce, these institutions have also been subjected to increasing public scrutiny and skepticism, and so have experienced considerable loss of esteem. Truthfulness of information, relevance, and the responsiveness of organizations matter as much to people as product performance and safety.

In this chapter I noted that consumerism identifies both the generic and the disabled brand of consumer movement that was launched during the 1960s, partly as a result of former US President John F. Kennedy's initiative in establishing the four rights of consumers: To Safety, To be Informed, To Choose, and To be Heard (Aaker and Day 1978: 2-6). Consumerism has since come to encompass the activities of government, business, independent organizations, professional associations, and so on. Significantly, two other consumer rights have developed since the 1960s: The right to recourse and redress, and the right to a physical environment that will enhance people's quality of life. As well, the scope of consumerism has grown to include an active concern with protecting customers and clients whenever there is an exchange relationship with an organization, be it a business firm, government agency, school, or hospital (Aaker and Day 1978: 2).

The disabled community's association with consumerism (as represented by the Alberta Committee and COPOH), its adherance to consumer principles (consider the resemblance between the set of principles espoused by disabled consumers and the consumer rights listed above), and the development of a consumer ethic has significance beyond consumption. While the independent living principles are by no means new or unique, they are unique to the disabled consumer movement. They hinge on the concept and practice of an individual's sovereignty and self-reliance. To consume goods and services is not only to "reproduce" oneself but the very social relations within which these goods and services are produced. The disabled insist, as certainly do others who are not physically or mentally impaired, that they be directly engaged and implicated in the production of their own health, learning, and growth. People are therefore implicated in their own production, while at the same time their fundamental right to self-determination is exercised in the context of community.

To address the central thesis of my study, one of the key questions thus becomes: Why, then, neglect or take for granted the circumstances and context of this reproduction, by leaving or entrusting it to just anyone? From the perspective of disabled people, the struggle to regain the control over the circumstances of one's own reproduction, a control which had been relinquished only gradually and innocently (in good faith), is also the struggle to re-establish and revitalize what is essentially reciprocal in the nature of individual and social (collective) learning in the community-building process. Any kind of control that is reasserted by the disabled community over the context of reproduction, and any successful attempts to reconfirm its participation in the community-building process are at the same time steps toward self-determination and independent living.

I posit that self-determination, as I also discussed it in this chapter, is part of the larger empowerment process of moving oneself out from under what Foucault calls the clinical gaze, away from the main sources of stigmas and stereotypes. This is so that control over and independence in the circumstances of one's own reproduction can be achieved. Self-determination provides the impetus for individual and collective action. For the disabled consumer movement, breaking from imposed categories thus means coming up with and initiating new ways in which disabled and non-disabled people can interact with one another. This entails changing the form as well as the content of interaction.

The independent living philosophy and its principles, reflecting the essentialist conception of human interests and articulated within the context of the consumer ethic, must also be put into practice, or operationalized. In Chapter 4 I discuss empowerment as a conscious, progressive, mental and physical process that enables disabled people to acquire participatory skills, develop organizational structures, and gain political understandings in order to pursue the goals of independent living, equality, and social reform. Empowerment, then, is simultaneously the means and the outcome of participation in the community-building process. I suggest that the empowerment process is at the heart of social movement which itself is the basis of social and cultural change.

Chapter 4

Beyond Minority Protest: Social Movement and the Meaning of Empowerment

An argument that is part of the central thesis of my study is that the marginalization and de-contextualization of physically disabled and mentally handicapped people is not unlike what is experienced by other stigmatized minorities in the western liberal pluralistic social setting. Because "handicapping" is essentially the socio-cultural consequence of the translation of perceived physiological, cultural, behavioral, etc., differences between people into what become widely shared social designations, it is the "translation process" that must become the focus of change-directed efforts. Similarly, the relevance structures (society's normative institutions and existing community structures) within which the translation process operates and which reinforce or legitimate the outcome are also not exempt from critical examination. Ameliorating the socio-cultural consequences of the stigmatization process (or addressing the resulting handicap) is only one side of the coin. Indeed, the values and beliefs which underlie any kind of social practice and institution that has negative effects on people must themselves be examined, and if necessary, changed or eliminated.

I noted that social designations, categories, and even social structures are largely the outcome of patterned interactions as well as learned behavior. Thus, "deviant designations," the disability category, and even the medical/rehabilitation model are real only insofar as people consciously as well as unconsciously continue to participate in their creation and maintenance. Accordingly, efforts to get rid of or transform these imposed social categories and the structures that spring from them require two kinds of activities. Change and transformation involves mental as well as physical/structural activities. The specific learning process that consciously and strategically combines these mental and physical efforts is what I refer to as the empowerment process. In order to change those interactions and learned behavior patterns in society that reinforce or perpetuate the negative labels, stereotypes and stigmas, action-oriented disabled people are learning to change attitudes by constructing counter-images of themselves. They are also trying to change current structures by initiating and learning to engage in new kinds of social and cultural practices themselves.

Some of the more persistant, accepted, and (sometimes) unquestioned behaviors which most in the disabled community want to eliminate or change are those that have come to be identified with the medical/rehabilitation model and the disability category, and that are generalized to all disabled people: The sick role, patient or client role expectations, the passive recipient of care, physical segregation, presumed uninvolvement or disinterest, disability as a social problem, presumed social incompetence, unproductivity in work, and so forth. Many of the features of everyday life are deeply implicated in the long term and large scale reproduction of social institutions and practices; at the same time, macro structural properties of social institutions are implicated in even the most casual of interpersonal interactions. With the proper motivation the goal of disabled people is to consciously and strategically structure their own activities and interactions with those whose care and services they seek. More active intervention even at the interpersonal level will presumably have an impact on larger systems of action in which disabled people are engaged. And, presumably, vice-versa.

I have been making the argument throughout that at the core of the disabled consumer movement and the movement's independent living philosophy is the idea of empowerment. In her recent discussion of the protest and rights movements of stigmatized minorities, Kallen (1989) puts forward the idea that,

> Minority protest in pursuit of human rights may be organized around expressive/cultural and/or instrumental/<u>empowerment</u> types of goals. When <u>empower</u>-

> ment demands take precedence, minority protest may take the form of contention, seeking social reforms that will recognize and protect the individual human rights of minority members and will enhance their political, economic, and social opportunities. (p. 45, original and added emphasis)
>
> Organized minority protest may take the form of contention through reform movements predicated on goals of empowerment.......... In contention, the minority protests against its subordinate political, economic, and social status and demands policy and legal changes geared to the collective goal of positional equality (proportionate representation throughout the ranks) within the social order. (p. 157, original and added emphasis)

Similar statements can be found in an earlier volume that dealt specifically with ethnic minorities (Kallen 1982: 185). Though Kallen's (1982, 1989) discussions are in the context of human rights issues (to which I will return in Chapter 7), I found it noteworthy that empowerment is an integral part of her formulation, and that she has linked it (appropriately enough) to social movement activity. While social reform, positional equality, and human rights constitute empowerment goals and demands, what the actual empowerment process entails, or from where it is derived, is not made explicit.

As I argued in Chapter 1, and indeed as I argue throughout this study, empowerment, as a developmental and transforming process, is at the heart of social movement. Implied in my argument is that empowerment is not limited to discussions of minority protest activities; it is basic to discussions of social and cultural change in general and to what I have been calling community-building. From this perspective, reform and equality can only be pursued by empowered individuals who have learned and acquired action skills that enable them to now play an ever-more conscious and assertive role in constructing their own social and political environments. The subsequent achievement of reform and positional equality, whether token or really significant, in turn serves to even further empower those who continue to pursue these goals. And so on in dialectic fashion.

How can one explain the disabled consumer movement and its independent living philosophy (described in Chapter 3) in the context of social movement and the empowerment process? In this chapter, I review older as well as more recent approaches to the study of social movements in an attempt to elaborate on the significance of empowerment, and to show how and why it is an important element of social movement and community-building. I also hope to show how recent perspectives on contemporary social movement activity are particularly useful in shedding light on what the empowerment process means in terms of resistance against forms of social and cultural domination in modern society, particularly from the point of view of the independent living/disabled consumer movement.

Social Movement as a Product of Society: Old Approaches

Older approaches to social movements failed to fully recognize that social movement is reflexive activity and strategic conduct (learning) inherent in all levels of social interaction. On the one hand, they tended to reduce social movement or collective action to either expressions of radical, deviant, and disruptive behavior (e.g. the breakdown or crisis thesis). On the other hand, even in some cases with respect to more recent approaches, collective action has been characterized as resource mobilizing, identity-seeking, or liberating (e.g. the strategic symbolic action thesis).

Such has been the dualistic approach to social movements: The former is portrayed as pathological, irrational, reactionary, non-institutional, dis-integrating, and the latter as rational, proactive, institutional, and (somehow) integrating. In both instances the focus of explanation and analysis seems to be on social stability, the sharing and internalization of values, the determinants of behavior, and to some extent even on the functional needs of social systems. In both cases, too, social movements are portrayed as somehow external or extrinsic to society, acting _on_ it rather than _in_ it. Without a clearer conceptualization of what constitutes action, of what structures and institutions are (and how they relate to each other, _pace_ Giddens), for example, how can collective action be properly understood as the production of social practices by knowledgeable, reflective, and motivated actors?

Clearly, social movements need to be considered _in_ and _of_ society, not simply in relation to it, and so the focus should be primarily on the conditions and circumstances that govern both the continuity and transformation of structures, and thus the over-all reproduction of social systems. What is social movement (as empowerment and contention, to use Kallen's phrase) if it is not reflexive monitoring of action and self-regulation at the level of social structure, and what is social and cultural reproduction if it is not the organization and institutionalization of the results of this learning process?

In _The Constitution of Society_ (1984: 203) Giddens wrote that "the study of social movements has been distinctly underrepresented within the social sciences as compared with the vast literature given over to the numerous vying elaborations of 'organization theory.'" The point Giddens is making is in the context of distinguishing between social movements and social movement organizations. Giddens is arguing for a shift of focus just slightly away from the organizational aspects of collective action (not denying their importance, of course), towards the "fields" in which they operate. A focus on the former, as has traditionally been the case, tends to result in descriptions of _how_ collective action is manifested, but not always _why_. Preoccupation with social movement organizations has also tended to portray them as reacting to conflict, crisis, or social disruption generated elsewhere in society, or as being the source of conflicts themselves (as social pathologies).

In turn, by placing an emphasis on factors of strain, this approach stresses the notion of social system equilibrium, and conceptualizes the social system as a natural entity (and so fails to recognize its essential artifactual and contingent character). From this perspective it is hard to think of movements as being comprised of individuals embodying the meaning of their own actions or being able to define strategies by themselves. Movements thus tend to be viewed, on the one hand, as consequences of strain, as dysfunctions in the system's integrative mechanisms, or as structural contradiction that disturbs the equilibrium of the system. On the other hand, movements are also viewed as organized actions whose goal is the restoration of equilibrium (and therefore are considered a means of achieving social integration). In both cases, analysis turns on the adaptive reactions in the mechanisms that ensure the smooth functioning of the system (significant early works taking this tack include Coser 1956, Kornhauser 1959, Smelser 1962).

More sophisticated studies of this structural-functional approach offer explanations which consider social movements as actors (but notice, here, the individualization of collectivities and thus the assumed homogeneity or unity of movements and of conflicts) who pursue strategies and struggle against other "actors" for the appropriation and control of resources which are assumed to be mutually at stake. One advance, though, is that the social system in which the struggle takes place is indeed understood as socially constructed. Movements are also considered social constructions, and an understanding of their strategies is attempted in light of on-going social and cultural relations, that is, relations of domination, subordination, autonomy, dependence, and so on, e.g. Wilkinson 1970, Piven and Cloward 1977, Tilly 1978, and especially Touraine 1977a, 1981).

Social movements, rather than being just the consequence of the dysfunctions of the social system, are also seen as based on organizational imperatives (McCarthy and Zald 1973). Getting and keeping together individuals and reconciling differences, etc., for action requires investing considerable energy and resources in building up and maintaining formal movement organizations (the more bureaucratic the better, from this perspective, but there is disagreement as to what kinds of resources are most significant). This is known, among other names, as the resource-mobilization paradigm (Gamson 1968, 1975, McCarthy and Zald 1973, Oberschall 1973; Jenkins 1983 provides a useful review essay on the approach).

Yet, this rational-system model of social movement activity (so-called because action is said to involve the rational pursuit of interests by groups) has the unfortunate effect of turning the study of social movement into the study of strategies. It is as if movements are defined by their goals alone, and as if actors were motivated primarily by the logic of a sort of economic rationality or neo-utilitarianism, e.g. cost-benefit calculations, and little else (Touraine 1985: 769). Yet resource mobilization, the main focus of this approach (see also J. Cohen 1985: 674-677) does not and cannot occur independently from the social relations of those involved. It therefore provides at best only partial insights into the meaning of social movement for the reason that the very concept of organization/movement is equated with concepts like strategic action, decision-making, and instrumental reasoning (see especially Olson 1965).

All told, little light is shed on the nature of contemporary collective action, and the approach just described is all the more unable to account for the "new" emerging social movements of the 1980s and 1990s because both the forms of organization that are presupposed and the particular form of rationality that is imputed to individuals do not really fit the so-called new reality. To put it another way, the rational-system model and the resource-mobilization approaches are too closely tied to the conditions of a somewhat "older" industrial society. The new social movements are said to occur in post-industrial (or, post-materialist) society, a significantly different context representing a different set of possibilities and constraints for movement actors (I discuss this below).

In any event, the breakdown/crisis, rational-system, and resource-mobilization approaches to social movements (as they are called) are merely close variations on the old structural-functionalist theme (for a useful critique of the resource mobilization approach to social movements, see Foss and Larkin 1986: 10-27). From this perspective, social movements, including social movement organizations, are seen as results or products of systemic dysfunctions (the prime stimulus), and therefore function to lead the transition to the next social formation. Like a functionalist explanation, however, the consequence comes to operate as the cause -- which is too simplistic an explanation of social movement and social change.

The Duality of Social Movement

There is confusion in these older approaches to social movements about whether movement is exogenous, or whether it comes from within the social system. In the former instance, the interdependence of sub-systems and possible structural contradictions arising from their mutual interaction cannot be taken into account; this of course flies in the face of reality. In the latter instance, an account of movement arising within the system is obliged to account for perceived strain by means of the same categories used to account for collective action (with the consequence, again, operating as the cause). To do otherwise is, of course, to construct a contradictory explanatory system that is incapable of taking both structure as well as action into consideration.

The chief difficulty with these apparent dualisms (external/internal change; action/structure) is the failure to properly identify social movements as action systems operating in a field of possibilities as well as constraints. Though social movements may be conceived as both a solution and a problem in the creation of a social order, until now there has been no satisfactory model that could explain the process of the definition of the action system itself, and therefore the process by which individuals and groups recreate their social order. Thus, according to Melucci (1985: 792),

> Structural [e.g. breakdown/crisis] theories, based on system analysis, explain why but not how a movement is set up and maintains its structure, that is, they only hypothesize about potential conflict without accounting for concrete collective action and actors. On the other hand, the resource mobilization approach regards such action as mere data and fails to examine its meaning and orientation. In this case, how but not why..... Action has to be viewed as an interplay of aims, resources, and obstacles, as a purposive orientation which is set up within a system of opportunities and constraints. [original emphasis]

Just as any kind of social activity is simultaneously replicative and transformative, so is social movement simultaneously a cause and effect of change, a source of internal as well as external change, and an action and meaning system. Following Giddens' contribution to action theory, social movement is more appropriately regarded as a duality. Social movements are a cause of change because the presence of a conflict which is manifested by "deviant" or otherwise symbolic forms of activity within asymmetrical social relations must be constantly monitored by those who are in positions of power and domination and, furthermore, obliges them to react, for example, by accommodation, reform, or even repression. At the same time social movements are an effect because the adaptations made by the system of domination in reponse to them, in turn reflexively monitored by the social movement organizations and individuals involved in them, again generates strategic collective action. And so on in reciprocal fashion following the logic of Giddens' theory of action.

From the perspective of breakdown/crisis theory, then, collective action always appears peripheral, reactive, or defensive to the reproductive logic of the social system. From the perspective of action theory, on the other hand, social movements are the processes through which collective identities are constituted, the means by which a particular version of social reality is contested and reinterpreted, and the means by which the norms and values of a particular system of domination are challenged. Traditional approaches to social movements, in other words, looked at how social systems produce collective action; recent approaches, more appropriately, look at how collective action reproduces society.

Society as a Product of Social Movement: New Perspectives

Collective actors and their forms of struggle should therefore be the starting point for an analysis of social change (and so are not a residual category), where society is seen as a field of social action. Asymmetrical social relations, or power structures, are none other than normatively oriented interactions between actual or potential adversaries within a shared cultural field that is always open to opposed and multiple interpretations. Social movement, then, is synonymous with the contest between competing interests over the control of the work that society performs on itself in constantly forming norms, orientations, practices, and institutions (Touraine 1977a: 298 ff, 1981: 77 ff, 1985: 772-777).

Giddens (1984: 200) observed that social movements and social movement organizations "are collectivities in which the reflexive regulation of the conditions of system reproduction looms large in the continuity of day-to-day practices" for the purpose of attempting to alter or in some way control the circumstances of reproduction. Significantly, Giddens adds that "reflexive self-regulation, as a property of collectivities, depends upon the collation of information which can be controlled so as to influence the circumstances of social reproduction." I noted the importance of monitoring and information-gathering to disabled consumer organizations in Chapter 1. Reflexive self-regulation and the information-gathering that is part of this process, is essentially a learning process.

In order to transcend the limiting framework of interest theory, resource-mobilization theory, and the rational-actor model, and so to reintroduce the actions of individuals in the (re)creation of society, it is necessary to focus on the constitution of contention, or collective action. This, of course, would involve a reconstruction of the cultural and normative orientations of contemporary social movements, as well as an inquiry into how social movement organizations order these elements structurally to thereby constitute actions that are in fact collective. In addition, it is important to see what image a social movement has of itself, "who" or "what" it perceives its adversary to be against which reinterpreted and reformulated identities are aimed, and what the common field of action is within which struggles over "the control of the development of a socio-cultural life world" take place (J. Cohen 1985: 690, Eder 1982: 11).

Earlier views and analyses of social movements, for example those applying neo-utilitarian and rational-actor models to collective actors, were of course tied to the logic of industrial capitalist development and to a particular kind of production (specifically, economic). These analyses stressed the primacy of economic contradictions, class relations, and systemic crisis (essentially the Marxist view, cf. J. Cohen 1982: 21, 1983: 97). By contrast, current approaches to contemporary social movements recognize that the logic or identity of these movements does not derive solely from economic "steering mechanisms," for the reason that the economic subsystem is no longer isolated from political and administrative mediation (not that it ever was). The penetration of the economic subsystem, among other subsystems, by the state has complicated the traditional lines of asymmetry, division, and hierarchy by making them multidimensional (J. Cohen 1982: 23, 1985: 691).

In comparison with the industrial phase of capitalism -- and this, I suggest, is important to understand the thrust of the disabled consumer movement -- the production characteristic of advanced capitalist societies (post-industrialist, or programmed, in the words of Touraine 1977a) requires that control reach beyond the productive structure and into the areas of consumption, services, and social relations (Melucci 1985: 795-96). In this view, the mechanisms of accumulation are no longer supplied only by the exploitation of a labor force and control over labor-power (Melucci 1981: 179), but rather by the manipulation of organizational systems, by control over information, over the processes and institutions of symbol-formation, and, significantly, by intervention in interpersonal and private relations. I take the medical/rehabilitation model against which many disabled people protest as a prime example of an organizational/symbolic system that exercises almost complete control over many aspects of people's lives, including their identities.

Thus, production now consists of the transformation of not only social relations and social systems, but the individual's biological and interpersonal identity at the same time. Still controlled by dominant groups, of course, it is only the expropriation of social resources that has changed forms. The struggle for the reappropriation of the control over the resources (including social relations) of society is thus carried into areas, or fields, of social and cultural life previously untouched or uncontested. In fact, many of the movements that have occurred since the 1960s originated from outside the labor market (Offe 1985: 834, n.19). Indeed, modern society has developed the tremendous capacity to intervene in and transform not only social and cultural systems and interpersonal relations, but the very "structures" of individuals themselves, for example, their personality, their unconscious -- even their biology (Melucci 1981: 179).

Because the personal and social identity of individuals are a product or outcome of social action, it is not surprising that "identity" is what is at stake in the conflict between the requirements of the power structure and the demands of individuals for the reappropriation of society's resources. Melucci (1985: 793, 1988: 248-250) defined identity as a shared definition of a field of opportunities and constraints. What individuals are now claiming collectively is the right to have and maintain their individual identities, i.e. in terms of personal creativity and expression (sometimes in relation to labor, lifestyle, etc.), affective relations, and biological and interpersonal existence (van Steenbergen 1983: 117-121, Foss and Larkin 1986: 137-143).

Techno-bureaucratic domination, as is well known, is characterized by certain kinds of control and manipulation whose effects include an almost complete penetration of many aspects of everyday life, extending to the individual's capacity to use time and space, or even to procreational/sexual conduct, that is, people's capacity to use their own bodies (J. Cohen 1983: 98). In this assault on the individual, there is a simultaneous broadening and deepening of forms of domination and deprivation (Offe 1985: 845). The new social movements, such as the disabled consumer movement, are therefore struggling not just for the reappropriation of the material aspects of physical and mental reproduction (over which struggle I think is perennial), but also for the collective control over individual socio-cultural development, that is, for the reappropriation of social, affective, and biological relationships.

Thus, the central theme in an analysis of the new social movements is that they are "new" precisely because the sources for inequality and forms of domination are far different in modern society from those faced by the "old" movements. Because material goods are produced and consumed with the mediation of largely informational and symbolic systems (Melucci 1985: 795), conflict has now moved from the traditional industrial system to cultural grounds (Touraine 1977b: 22-27, 39-42). This deeply affects personal identity, the time and space of everyday life, and the motivation and cultural patterns of individual action. Eder (1982: 10) argues, as do others, that a prime feature of modernity is therefore the possibility of challenging cultural orientations.

In what may be referred to as post-industrial or post-material society, the capacity for cultural production becomes increasingly based on information and knowledge. Control over the production, accumulation, and circulation of information depends on codes, or rules that organize and make information usable and operational (Melucci 1988: 247-248). This "operational rationality" becomes a source of power for the reason that information/knowledge is not a shared resource accessible to everyone, but is produced and controlled by a small number of experts (Melucci 1985: 805). Information, of course, cannot be separated from the human (and cultural) capability of perceiving it. According to Melucci (1985: 804), research in biology, neuropsychology, and in the behavioral and neurosciences provides evidence for the very real possibility of turning the behavioral and motivational structures of people into an arena through which intervention and struggles for control can take place.

The implications of this are profound not only for the physically disabled and the mentally handicapped (viz the medical/rehabilitation model), but for everyone: Dominant cultural orientations and values are not only concentrated or group-specific, but are instead dispersed in time and space affecting virtually every member of society in some way. The flow of information through different media (law, education, and medicine) also make the effects of dominant values and norms more comprehensive, permeating even those areas of private life that used to be outside the realm of explicit social control (Offe 1985: 844).

This is why disabled citizens, for example, insist that "the process of informing is the function of organizations of disabled persons," and that "informing is an ongoing function" (Alberta Committee 1981b: 22). The identification of specific groups that have control over social and cultural production becomes difficult; structural power is dispersed and diffused, and is not always easily attributed to any central or clearly identifiable adversary. Foucault (1980) refers to the source of such power as the "apparatus of power-knowledge" which is exercised through the micro-practices of institutions such as schools, hospitals, clinics, prisons, and bureaucracies. Gathering information and informing oneself is therefore a means of reasserting control over one's own social and cultural production.

In sum, political and economic regulation, control, and power is no longer limited to the manipulation of the external constraints of individual behavior. There is an "invasion," in the name of technocratic standards of rationality and coordination, of the symbolic infrastructure of informal and private social systems through the use of legal, educational, medical, chemical, psychiatric, and media technologies. In modern post-industrial society, by contrast, there is a shift in social action to the internal, where intervention and manipulation occurs at the motivational, indeed, at the unconscious level, and where conflict itself is at "the seam between the system and life-world" (as Habermas puts it).

It is this shift that seems to have generated the main conflicts of the 1970s, 1980s and (almost certainly) beyond, and that has demanded a redefinition of both the "location" of social movement and its forms of action. As Melucci (1985: 796) noted, conflicts are increasingly likely to occur in those areas of the social system "which are connected to the most intensive informational and symbolic investments and exposed to the greatest pressures for conformity." From the perspective of disabled people, medicine and medical intervention/rehabilitation is precisely one of those areas.

The "Role" of Empowerment in Social Movement

The new movements, including the independent living/disabled consumer movement, should be seen in the context of perceived and pervasive threats to precisely those areas of social life that generate meaning and provide a sense of solidarity for individuals. Perhaps this is why individuals are acting collectively and publicly on very private and personal issues, and why they are taking personally broad social problems. Reaction and protest by disabled people against domination and deprivation may indeed take the form of contention through social movement organized around the goal of empowerment.

The process of becoming empowered, however, first involves learning to overcome internalized expectations and attitudes of bitterness, helplessness, self-denial, and alienation. Comments one disabled person who has cerebral palsy,

> I am angry -- no, damned mad -- most of the time every day. This should not have happened to me -- there is no reason, no fairness to the way I am. I have to accept my condition, but nobody's going to make me like it. I hate it, and much of the time I hate everyone: those more fortunate than me, because they are, and those as badly or worse off, because they remind me of my own state. I am no cheerful Tiny Tim, with a sweet nature developed by affliction, I am bathed in anger almost always (Bill Kiser, in Weinberg 1988: 149-150).

In another context, one individual notes that,

> It would never have occurred to me to have expressed an opinion on anything.... It was <u>inconceivable</u> that my opinion had any value.... That's lower than powerlessness.... You don't even know the word "power" exists. It applies to <u>them</u>.... I didn't question that that's the way the world was.... It was <u>their</u> world (Rappaport 1984: 16, original emphasis).

Empowerment is simultaneously the medium and outcome of learned resistance against control and domination at a very personal level, the motivational level. Empowerment is thus a process of becoming, an enabling process that is also achieved and further reinforced through action. To operationalize the empowerment process, I suggest that the process can be looked at in two ways. Essentially, empowerment has both motivational and relational, or interactional, dimensions.

Empowerment, or power in the motivational sense, might refer to a person's intrinsic need for self-determination (or self-actualization), and so has its base, or origin, within a person's motivational disposition. Attitude is clearly an important element of the process: "One has to want to be independent. When that's established, everything else will come" (Doreen Demas, COPOH 1987d: 61, emphasis added). Anything that strengthens the need of self-efficacy will make a person feel more powerful and "in control." Conversely, anything that weakens this need will probably increase feelings of powerlessness. Power needs are met, for example, when an individual perceives that he or she "has" power or control, and when he or she believes they can adequately cope with events, situations, and other people they have to deal with. By the same token, an individual's power/control needs are frustrated when that person feels powerless or thinks that they are unable to cope with the physical and social demands they face. According to Elizabeth Semkiw,

> Control is a key factor. Any aspect of living in which one chooses the management and organization such as medical supports, banking, or buying groceries, is an avenue of exercising control (COPOH 1987d: 57).

Comments another individual:

> I was thirty-five years old and never knew that I had rights.... It's hard for people to see what's really going on. You spend half your life helping to keep yourself down.... The more that you get involved in making power, the

> more your understanding of power changes.... The more I'm involved, the more I'm learning (Rappaport 1984: 22).

Empowerment is likewise an enabling process whereby the right circumstances for increasing a person's motivation through the development of a strong sense of personal efficacy are sought. The "right" circumstances, or setting, may also be created when the conditions that foster powerlessness are identified, so that the goal of eventually removing them by various strategic means can eventually be realized.

Empowerment, not unlike power, is also relational or interactional. It can be used to describe the perceived/experienced power or control that individuals can acquire together, as a collectivity; control and power arises when a number of individuals' action outcomes are contingent not only on their own behavior, but on what others do (or do not do) and how they respond. From the perspective of social exchange, i.e. mutual interaction, power and control could be considered a function of the interdependence of individuals. Empowerment, in other words, does not take place in a vacuum:

> .... I would say that if you are thinking about developing something for yourself.... build up some allies and people who are really interested in the type of thing you are doing. You really need other people for input.... You can't build something for disabled people and be the only one interested in it. You have to look around for people (Connie Oxelgren, in COPOH 1987d: 65).
>
> I think disabled people should put some energies into developing their own personal support network. It is really tough to go from a very controlled environment like an institution to full blown independent living. You are all of a sudden put in the position of having to make every decision for yourself. It's a real learning process.

> Not having a well developed personal support network can be disastrous [sic] (Rick Laird, in COPOH 1987d: 87).

At the interpersonal and intergroup levels, some of the resources that can enable individuals and groups to have control over their own circumstances might be the personal characteristics of the persons themselves, their structural position, their access to material resources, and their expertise, knowledge, and access to information. This focus on resources then leads to a consideration of strategies and tactics by which to obtain further resources to enable one to increase one's own power and control. From this perspective, the empowerment process entails the decentralization of community resources (i.e. making resources more accessible, or demanding that they be). This would include decision-making powers.

Individuals can help empower others, have others empower them, or they can try to empower themselves. Regardless of who is "doing" the empowering, it is the belief in one's self-efficacy and self-worth that has to be strengthened while at the same time one's belief in personal powerlessness is weakened. A person's motivation to increase his or her power and control also depends on expectations that their efforts are going to result in controlling more resources (which ever ones are considered relevant, for example, funds, materials, space, time, information, expertise, etc.). The expectation is also that by controlling or having access to more resources, certain other desired outcomes can be achieved.

What is most important in empowerment, however, is that the person's need for self-determination or self-efficacy is met, not necessarily that their outcome expectations are always met -- "the very means of solving a problem is as important as the solutions to the problem itself" (Simpson 1980: 8). It is therefore the motivational dimension of the empowerment process that is stressed; even under conditions of failure to achieve certain outcomes (and failure certainly occurs) individuals may feel empowered if their efficacy beliefs are somehow reinforced and if their motivation persists. Individuals convinced of their powerlessness will probably be inclined to behave in ineffectual ways, just as their perceived self-efficacy will weaken the impact of direct experiences of failure by sustaining their actions in the face of difficulty or failure.

My interpretation is that empowerment has a great deal to do with reversing the internalization of the assumptions and expectations of the so-called medical/rehabilitation model, that is, recontextualizing the disabled individual in social life and "revalidating" him or her. Clearly, this has to be accomplished first at the motivational level, and only later at the level of pursuing reform, equality, and rights. By the same token, however, the motivational and interactional dimensions of the process cannot be separated from each other -- just as agency (or action) and structure cannot be considered separately from each other. The links between motivated action and social interaction are supplied by such empowering devices (for lack of a better term) as open communication and networking between peers, the creation of opportunities for participation in collective decision-making, and autonomy from professional and bureaucratic interference. With respect to disabled consumer groups, Simpson (1980: 8, 27) writes,

> So few organizations in society realize that each problem-solving and sharing process is and should be a vital learning growth experience for every individual involved. This author firmly believes and contends that how the self-determination and involvement process of solving any societal problems is carried out can be actually as important as the solution itself..... Motivation can be achieved through group sharing, learning, and goal setting.....

The feeling of empowerment or self-efficacy for the disabled person thus comes from experiencing <u>ability</u> in the performance of tasks (however small) and in making decisions. It also comes from observing and interacting with peers going through the same process in a group setting (and observing those who have progressed), from verbal interaction, and from receiving strong emotional support that reduces feelings of anxiety, fear, and helplessness. Communicating, networking, organizing, and participating are the principal means by which action (individual as well as collective) is both motivated and sustained. What is empowerment if it is not the melding of the motivational and relational dimensions of human interaction, in order to "make a difference," in Giddens' terms? In fact, what is social movement, implicated in the empowerment process, if it does not also have motivational and relational dimensions?

The empowerment process, with its motivational and relational dimensions, provides the thrust, or underpinning, for the independent living/disabled consumer movement. An independent living lifestyle, of course, presupposes a belief and a confidence in one's own ability to act, to take risks, to make decisions and to live by them. In dialectic fashion, individual action and decision-making have an impact on larger action systems, which in turn can motivate, enable (or constrain) future action. Knowledge and skills are constructed largely through actions; experience is at the core of empowered learning, and the building up of skills progresses through a repetition of cycles of action and self-reflection. This is the essence, also, of what Giddens calls the duality of structure. In different words,

> You've got to live it. You've got to <u>do</u> it. It's like, you can take an instruction course on how to do sex best, but if you don't go do sex, if you don't go and try it, then all you know is the hypothesis.... It's the same way with going through experience with community organizing.... You have to <u>build</u> it up (Rappaport 1984: 26, original emphasis).

While empowerment is a labor-intensive individual learning experience, it is sustained and nurtured by the effects of collective effort. Grassroots organizing and organizations best serve as the locus of support and learning. Thus, the various support organizations and networks built up by disabled people (described in Chapters 5 and 6) not only enable independent and community living, but, more importantly, are recognized as the outcome of the empowerment process.

Defining Features of the New Social Movements

The so-called new social movements, then, address problems that are located on the motivational level, with the "life-world" as the arena and the "public" realm as the systemic field. It is at the motivational level that techno-bureaucratic domination operates, and so it is at the motivational level that resistance and challenge must take place. The movements are also concerned with organizational and technological over-complexity (the external) that seems to be accompanied by severe cultural and psychic impoverishment (the internal). Thus, the new contemporary social movements should be seen in the context of real and perceived threats to those "spaces" which generate meaning and a sense of community for individuals (Melucci 1988: 259). In the developmental frameworks of Habermas and Touraine, for example, in post-industrial society there is an emphasis on reflexivity, an expansion of the public realm, and the reestablishment of more familiar discourses (rather than rational-technical ones).

For Touraine, reproduction based on the activity of socio-cultural production gives rise to a "more evolved" action system, one in which struggles over the direction and orientation of social and cultural life occur. The basic assumption is that human societies have an evolutionary capacity to develop themselves through learning processes, and so obtain the capability to generate their own normative orientations by increased self-reflection (reflexivity). Eder (1982: 12-15) described Touraine's framework as implying an evolutionary logic of cognitive and moral development, but J. Cohen

(1985: 704) has criticized Touraine for not developing a theory of action to accompany this thesis of increased reflexivity.

From Touraine's perspective the new social movements articulate conflicts within a field of possible experiences that seek the institutionalization of new competing cultural and moral competencies. Unfortunately, Touraine does not offer a clear means by which it is possible to determine how individuals themselves actually translate ideas about values, meaning, and so on, into intentional or strategic action. Touraine's (1981) The Voice and the Eye instead emphasizes the usefulness of intervention by objective (yet sympathetic) outsiders, e.g. action sociologists, in helping social movement actors define their strategies and, indeed, their movement.

Habermas' (1979, 1984, 1987) framework complements Touraine's, in the sense that it seeks to elaborate the ideas of cognitive and moral development, and focuses especially on the role of knowledge and communicative interaction with respect to social action. For Habermas, given that language is the medium of social interaction, human society has the capacity to invent more effective ways of discursively dealing with conflicts and contradictions. In his communications-theoretic foundation for a critical theory of society, Habermas sees different types of societies, or systems of historical action, as characterized by different kinds of collective discourse. Societies, according to Habermas, have their own logic of justifying and rationalizing the interpretation of values and norms, which is achieved through socialization processes and specific forms of communication (e.g. language use).

Socialization processes are themselves motive-forming: As individuals are socialized and as their identities are formed via the "kinds" of languages they speak, certain kinds of social relations (asymmetrical, autonomous, dependent, dominant, subordinate, and so on) are going to be reproduced at the motivational level (McCarthy 1978: 337-353). Individuals, in short, learn their "places" in society.

The reproduction of society is thus achieved (or determined) by the normative self-understanding of communicatively-socialized actors (Honneth 1987: 372-376). Habermas argues that an increasing reflexivity _via_ the creation and institutionalization of norms and values can in fact be reconstructed in terms of an evolutionary logic of rationalization of communicative interaction that involves _learning_ in the dimension of moral-practical insight (J. Cohen 1983: 105, Thompson 1984: 297-299). Habermas (following Piaget, correctly or not) suggests that societies, much like the cognitive development pattern of individuals, progressively move from a preoccupation with their immediate needs towards an expanding awareness of the world and the needs of others. In other words, there is a growing awareness and sense of community that is emerging in modern society.

An expanding awareness therefore carries with it the possibility of separate social action-realms, a growing capacity for purposive and strategic action, and the potential for increased reflexivity. Habermas argues for a conception of society in which there emerge differently organized spheres of action, each distinguished by separate forms of rationalization and discourse. In modern society, for example, two spheres or systems of action -- economic production (the market economy) and political administration (the state) -- have become separated from the life-world. System and life-world undergo a progressive un-coupling, where the life-world -- that collectively shared private symbolic space of interests, values, and beliefs within which cultural traditions and personal identities are reproduced and sustained (Melucci 1988: 258-259) -- attains the status of just another sub-system among others.*

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* I would suggest that Habermas' conceptualization of the life-world is not unlike that of the relational and psychological sense of community as I discussed it in Chapter 1. In addition, Habermas' system/life-world distinction parallels those of the typological tradition in general (e.g. Tonnies, Durkheim, Weber, etc.).

The different action spheres, however, still have to be somehow anchored to the life-world in order to maintain moral and authoritative domination, and to ensure the participation, commitment, and loyalty of all individuals. Anchoring, or integration, is achieved by the intrusion into the life-world (its colonization) of a purposive-rational mode of discourse that is not *of* it. The result is that the life-world itself, or community, becomes increasingly rationalized and instrumentalized (Honneth 1987: 375-376, Thompson 1984: 289-293). Domination in the modern world is said to depend, for instance, on a homogeneous culture, mass literacy, and on a monolithic and uniform education system. The life-world, in which cultural transmission and socialization takes place, and in which an individual's personal identity is structured, thus takes on the instrumental and functional values of the greater system. The denial of meaning, feeling, identity, individual autonomy, and the appropriation and commodification of the behavioral and motivational structures of individuals that accompanies this uncoupling and colonization process has been aptly described as the "determining pathology of our times" (Honneth 1987: 376).

Put simply, the penetration of such "steering mechanisms" as the economy and political administration into people's private and personal lives triggers conflict between the normative/motivational structures that constitute people's social identities. There thus arises serious controversy over "what" and "whose" norms, interests, and goals take priority. As the life-world (as community and as symbolic space) becomes more and more saturated with the rationalizing values of the larger system, society itself is increasingly seen as a system capable of producing and generating its own normative and motivational guidelines -- for everyone: Hence the truly *social* and *cultural* struggle between power/knowledge apparatuses and their users or clients (the public) over the control of the production of society itself.

Habermas is correct to have linked the administrative penetration of the socialization and cultural reproduction processes both to the emergence of social movements as well as to the identity and autonomy crises of individuals. Both Touraine and Habermas have probably gone furthest in providing a framework by which it is possible to understand contemporary social movement as a crucial element in the social/collective learning process, and as a vital means by which to reassert the viability of the life-world and thus the re-creation of community. It is not simply an issue of life-world/community versus system, but of a range of possible discourses and action types that can bridge or link the two.

The process of de-colonizing the life-world (and rebuilding community) and resisting against an ever-expanding instrumental rationalism (irrationalism?) therefore involves the creation of new solidarities and new "public spaces" whose purpose might be to try to reintroduce the normative dimension of social interaction back into political life (what Melucci has termed the democratization of everyday life). Both Touraine and Habermas see contemporary social movements as structured by cultural tradition and as the "learning mechanisms" that link what they perceive are two important dimensions, namely the creative reinterpretation of existing norms and values, and the institutionalization of new discourses. Institutionalization here means the development of new structures that involve organized social interaction of some sort, the formal articulation of new associational forms, and the establishment of "legitimate" channels of communication (J. Cohen 1983: 110, Simpson 1980: 36). What is at issue is not necessarily the replacement of existing institutions or structures (as in revolution), but rather changing the meaning of existing relations and interaction.

Does not the defense of society against an alienating rationality, an attempt to revitalize basic institutions and sub-systems, and a bid to participate more fully imply an affirmation and a general acceptance of the system as a whole? J. Cohen (1982, 1983) has interpreted the new social movements to be essentially institutional reform movements that seek the continuity, albeit with some modification, of present structures. Indeed, as I have noted in earlier chapters, disabled people accept the essential validity of the social system; their contentionist orientation (cf. Kallen 1989) as well as their construction of parallel or alternate structures is essentially integrationist in outlook. Changes are sought within the existing social order and majority social formation.

Habermas, however, takes this as evidence of how deeply the life-world [community] has already been colonized. His position is that people have become so integrated that they can no longer even conceive of truly alternative ideas and values. Giddens (1985: 201-202), however, argues convincingly that an expansion of the administrative reach of the system (i.e. the state) actually increases the possibility of reciprocal relations between dominant and subordinate groups, because "the more reciprocity is involved, the greater the possibilities the dialectic of control offers subordinate groups to influence the rulers." Even within constraints there are choices, from Giddens' perspective:

> Independent living really is an idea, a concept, a thought process. You apply this thought process to your lifestyle. I would think that even if a person were in prison and the only choice that they could make would be whether they would eat their food when they first got it, or eat it an hour later, they would still be practicing independent living (Elizabeth Semkiw, COPOH 1987d: 57).

Or, as another individual remarks: "I'm a firm believer that anything in this life that affects you, you have control over..." (Rappaport 1984: 24). The success of the independent living/disabled consumer movement, as I will show in Chapters 5 and 6, tends to support Giddens' argument rather than Habermas'.

I will now outline several characteristics shared by such social movements as the civil rights, feminist, gay, disabled, peace, anti-nuclear, ecology, ethnic, student, and so on (see Freeman 1983). One interesting feature of contemporary social movement is the fact that conflict is not necessarily confined to the actions of any single social group that can be identified by a particular culture, lifestyle, or class. In what is often described as mass society, in which cultural models and ways of life tend to become homogeneous, conflicts mobilize those categories, groups, and individuals that find themselves directly and immediately manipulated and affected by the forces of socio-cultural production.

There is therefore no central leading collective actor (compared to, say, the worker's movement of an earlier time), and really no clearly defined opponent. A challenge facing the new movements is therefore to determine against whom, in what direction, and to what degree "unitary" strategic action should be aimed (given the diffused nature of power and domination, and the absence of a clearly defined opponent). Coalition-building and working relationships with "natural allies" (Simpson 1980: 13 ff, 25) are two strategies.

A second feature is the blurring of public and private spheres and the appearance of conflict at the "seam" between system and life-world/community (J. Cohen 1982: 29, 1983: 102-104). Those areas which were previously fields of private exchanges (e.g. sexual relations, biological identity) have become stakes in conflict situations and are the scene of public collective action. At the same time, the public field and the political arena is subjected to the pressure of individual needs and demands. Birth and sex, health and illness, aging and death have become critical points around which collective action is expressed. These are now in the realm of public conflict, and are the "objects" being reclaimed by various groups. Similarly, sexuality and the body, leisure and consumer goods, relationships with nature (van Steenbergen 1983: 121-22) and so on, are likewise no longer simply the loci for private pleasure, use or consumption, but have become areas of collective resistance and demands raised in opposition against those who have appropriated them for entirely their own use (and abuse).

A third important feature (perhaps one that is also recognized by the more traditional approaches to social movement) is the tendency for some kinds of collective action to be identified with non-conformity and deviance, and for some individuals to be treated as deviants, or worse, as victims (Melucci 1981: 176). But the fact remains that when a particular form of socio-cultural domination permeates daily life and impinges on rules of existence, or on "ways of life," opposition -- in whatever form -- will be interpreted as a form of marginality and deviance. Derksen (1980: 13), for example, remarks on the reaction of rehabilitation service providers to disabled consumer activity:

> [One] reaction, which was most unsuccessful, has been to use covert influence these providers have on governmental and private funding sources to deny resources to emerging consumer groups. This was often accompanied by offers of assistance and resources to disabled consumer activists and/or their organizations.... When these offers were refused, there were often charges that disabled consumer leaders were maladjusted, unaccepting of their disability, or even mentally and psychologically unbalanced or ill because of their disability. Consumer movement activists were accused of being radical or militant.

A consequence is that there has been a proliferation of public agencies whose primary task is to process and monitor social demands and needs that are potentially conflict generating. This so-called "public intervention" is designed to reduce conflict and deny the legitimacy of demands and needs by relegating them to the status of pathology (by removing them from the political arena and depoliticizing the issues), and by subjecting those who voice them (the clients of bureaucracies and clinics, cf. Eder 1982: 18) to counselling, therapy, or rehabilitation. Because of the power structure's increased capacity for surveillance (via control over the production and dissemination of information through its agencies), it becomes relatively easy to stigmatize and label all unacceptable or conflict-based behavior as deviant.

Since what is at stake is the reappropriation of individual identity and autonomy, collective action very often centres around the issue of individual as well as group identity. Thus, a fourth feature that may be considered characteristic of contemporary social movements is the fact that solidarity (the attempt or ability of individuals to formulate, communicate, and share a collective identity) is a primary objective. It is also a means by which a "diffused" or anonymous adversary can be confronted (Melucci 1981: 176). In some cases, ascriptive membership based on gender, race, age, physical and mental ability, sexual orientation and so forth (i.e. focus on the body) becomes intrinsic to the formation of both the individual's and the group's identity and sense of solidarity (Habermas 1981: 36). Thus, particularism of both identity and issue becomes the specific forms of resistance against power and domination that is itself generalized.

The formation of a collective identity or group image also involves, on a slightly different level, the "exposure" of the contents of the motivational level of consciousness. Since the actions of individuals are motivated, rationalized, and reflexively monitored, any penetration of the individuals' motivational structures by the system of domination will of course influence how action will eventually be carried out. Since people's motivations are themselves structurally integrated through a common learning process and are an integral part of their identity, individuals seek to "restructure" their motivations with the aim of reformulating, redefining, and confirming their new identities.

Interestingly, in some cases this also entails an emphasis on direct participation in the political process (again, accepting its validity), and a concomitant rejection of third-party representation (the independent living/disabled consumer movement, for example, insists on this rejection).* The refusal to accept political mediation is based on the notion that the mechanisms of control and manipulation against which the struggle is directed in the first place will simply be reproduced, albeit on a smaller scale (Offe 1985: 829). It has been argued that the core institutions and mechanisms of the political system, e.g. the parties, parlaiments, elections, unions, have simply lost some of their capacity to provide collective identities and solidarities (J. Cohen 1983: 99). Hence the importance of direct action and of direct participation, and perhaps the need for spontaneous, anti-authoritarian, and anti-hierarchical forms of organization. At the same time, some form of political representation and some level of participation is essential for a movement's credibility and viability (Melucci 1985: 815).

Finally, another feature of some of the new movements is that they are not necessarily always focused on the political system. Characteristically, the movements are not oriented towards taking political power or taking over the state (Melucci 1981: 180), but rather towards expanding an individual's or group's autonomy and independence vis a vis different systems of domination. However, in those instances where a movement might be politically oriented, the goal is to increase the possibilities for direct political participation by trying to open new channels for the expression of demands and needs, and by trying to create new forms of participation in such areas as policy-making.

The goal of new social movement actors is therefore to try to "revitalize" the life-world, or community, by deflecting the often hard-felt impact of the economic and political/administrative sub-systems. Participation in the larger social system is based on

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* Melucci (1988: 258-259) noted that participation means taking part in terms of promoting one's self-interest. Participation entails belonging to a system, and that this belonging is the enjoyment of the benefits of an identity. Representation, by contrast, means remaining different and never being heard entirely; the enjoyment of the benefits of one's identity is deferred.

interaction that might presuppose a particular type of discourse and way of communicating, but whose rationality is consciously rejected. Deflecting the impact of this rationality therefore entails monitoring and to some extent changing the process or means of communication. All these are elements and important aspects of the community-building process.

Summary and Discussion

My intention in this chapter was to offer an interpretive-theoretical analysis that would provide for a deeper understanding of the disabled consumer movement and its discourse of empowerment (the idea of independent living) that I presented in Chapter 3. Accordingly, my interpretation of the independent living/disabled consumer movement is that it should not be regarded just as a social reform movement or just as a minority rights movement. Rather, the movement is first and foremost a process by which "rehabilitated" bodies and minds, "spoiled" identities, and the deeply "colonized" behavioral and motivational structures of disabled individuals are being reclaimed and reappropriated.

Insofar as the independent living/disabled consumer movement is contentionist in approach and its goals essentially integrationist, the meaning of the movement is perhaps best understood in terms that make explicit reference to the structuring of personal and collective identity, autonomy, and interests. The argument I want to make is that handicapping based on widely shared social designations, the category of disability, and even acquiesence to the medical/rehabilitation model all constitute learned behavior patterns. Another way of putting this is that domination and subordination (what categorization and labelling entails) is learned behavior, and that this kind of behavior is embedded in the consciousness of disabled as well as non-disabled individuals, and becomes an integral part of their motivational patterns.

Empowerment in its motivational and relational dimensions thus constitutes an unlearning and then a relearning process.

In modern society systems of domination have come to operate by manipulating and embedding specific needs, desires, values and a particular world-view into the motivational patterns of individuals; successful domination is sustained by carefully perpetuating and reinforcing these internalized dominant values, beliefs, and interests. The persistence of deviant designations and of social categories is testimony to the power of meaning and the role it plays in the reproduction and maintenance of interactions, relations, and structures. The effect of this "internal colonization" is that the participatory competence of individuals is severely curtailed. The marginalization, isolation, dependency, and powerlessness that is directly experienced by disabled people (and others) can, from this perspective, be understood as the structural outcome of both externally and self-imposed physical and psychological constraints.

The whole point of the independent living/disabled consumer movement and the struggle to regain control over the setting, context, and circumstances of disabled people's self-production is to increase the awareness of the conditions imposed on their actions in order to act upon them, "to make a difference." The empowerment of disabled individuals thus involves not only the restructuring of motivation and a relearning of interaction skills, but their resocialization into beliefs, needs, and interests that are different from those held by others (e.g. doctors, specialists, service providers, politicians). I speculate that empowered individuals become capable of "sensing" how their wants, interests, and options in life are limited and reinforced by their very articulation. What is important in the empowerment process and in social movement is that they eventually act, individually and collectively, on the knowledge they have acquired (Gadacz 1987: 162).

As I noted earlier, empowerment is really a process of becoming, an enabling and transforming process that is constructed and achieved through action and practice. It is movement from a feeling or actual position of powerlessness to one where control and power can indeed be exercised. As such the process is not directly observable, but its effects or results are. This "emergence" is a learning process, a process of becoming, involving a necessarily progressive development of participatory skills and political understandings. Individuals are not just acquiring new skills in becoming empowered, rather, they are reorienting deeply engrained systems of relations with those "who know better." All the more remarkable is that disabled people are often involved in this process in precisely the same environments and contexts which enforce their oppression and which continue active and implicit attempts to maintain that oppression.

The learning and becoming process subsequently extends to the more conscious and active development of peer support relationships within a caring community of peers and friends. Over time, and through on-going efforts, individuals will be able to construct more viable strategies for action, come up with more effective mechanisms for collective expression and support, and develop more sophisticated capacities for resource development. The eventual development of a grassroots organizational setting with peers is considered vital in cultivating social and political skills (e.g. Berger and Neuhaus 1977: 1-8). A grassroots organization -- such as the disabled consumer organization that I discuss in Chapter 5 -- provides individuals with a sense of strength in numbers and an organizational setting in which individuals can collaborate in mutually supportive problem-solving.

Many more effective coping skills are eventually developed, as are more technical organizing and leadership skills. Participatory competence is only realized in the context of direct action, which means the creation of new situations and contexts for further action by combining acquired knowledge with other kinds of resources.* New situations for direct action that might be called empowering solutions include consumer groups, self-help service groups, networks, the development of service brokerage models and independent living centres, and so on. I discuss these particular organizational innovations in Chapter 6.

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* Of course, not all disabled individuals become empowered, attain participatory competence, are "recontextualized," or become involved in issues and debates concerning themselves and the disabled community. Few will achieve any degree of the critical awareness that is essential to an over-all capability of successfully challenging established structures and social-political interests. As with non-disabled people, not every disabled person will join a self-help group or will subscribe to the philosophy of a social movement (Simpson 1980: 7). Many prefer to have minimum contact with other disabled people (indeed, by denying their impairments some will not even consider themselves disabled).

Chapter 5

Organizing for Empowerment: The Disabled Consumer Organization

In the last several chapters I emphasized that the independent living/disabled consumer movement as a social movement is nothing less than a particular means of (re)appropriating and (re)structuring a people's social reality. Movement, as I tried to suggest, must also be seen in terms of what it is, not only what it does. As such it constitutes the very essence of community-building. In a sense, the activities of movements such as the independent living/disabled consumer movement are part of what might be called autopoieses, that is, self-creation. In the specific case of the disabled consumer movement, I would suggest that self-creation refers to the practice of independent living in self-made contexts. This in turn is a crucial aspect of the on-going community-building process for the reason that community structures and institutions are themselves self-made. Anything less than participation in the process would mean, once again, imposed structures, segregated community living, and second-class citizenship.

According to Melucci (1985: 792), a social movement such as the independent living/disabled consumer movement is an action system operating within a systemic field of opportunities as well as constraints. The ways individuals build or constitute their actions (that is, their organizations) serves to establish links between meaning, orientation, and the systemic field. Thus, the way the movement is structured and organized is an important factor in understanding its meaning within the larger community and the social order. Without being structured in some way, collective action would probably not be possible; action would have neither unity nor would it be continuous. At the same time, of course, any attempts to define or create structures by disabled people requires that they consciously shape and define action itself.

In the context of Chapter 4 I would have to argue that the organization of social movement should not to be identified with any particular identifiable empirical feature or formal structure. While the empirical forms of collective action might indeed be legitimate objects of inquiry, they have no real meaning apart from the movement and so constitute only one level of inquiry (Touraine 1981: 150-151, Tilly 1984: 305-315, 1985: 731-737). Of course, the empirical forms would also not make sense without accounting for the mobilization of resources (e.g. the allocation of material, funds, capabilities, values, decisions, etc.), leadership and membership issues, and so forth. Again, however, these are not the "causes" of collective action, movement or community-building, and so cannot be solely considered points of departure for analysis.

Social movement, as I have noted, is the struggle for change and innovation in community life and the struggle to participate actively in that change. On a practical level, disabled consumers must face society in ways in which they can sustain their demands and actions. Struggling against particular systems of domination and presenting conflictual demands means that action must also, to some extent, be strategic, consistent, and continuous. The development of a (contentionist, social reform, etc.) movement such as the independent living/disabled consumer movement is not the consequence of any sort of internal logic of a particular organization or group's development. Rather, it corresponds to a continuous two-way process by which the system of domination the movement is trying to transform (e.g. the medical/ rehabilitation model), checks, absorbs, and deals with the challenges and innovations the movement members have come up with. In this process, of course, both the movement and the community influence and change each other.

For action-oriented disabled individuals, this means that they have to choose a certain logic of action, that is, they have to select one sense or kind of action among a number of possibilities -- all the while leaving plenty of room for improvisation and innovation (Tilly 1984: 307-308). Likewise, they also have to fulfill the instrumental, mundane, requirements of organized action. Community-building must "oscillate" between the level of pure demands or pure expressive action, and the level of group or institutionalized action. The spirit and vision of integrated community living for the movement would be sacrificed were action to be located at either of these extremes. Instead, it is only when a position somewhere midway between the two extremes is taken that fruitful interaction is possible with other interests within the community.

I would suggest that, for the independent living/disabled consumer movement, the logic of the community-building process that is adopted is determined by what it means to be a consumer and by what it means to be living independently. As I noted in earlier chapters, consumerism from the point of view of disabled people involves making the disabled consumer the central factor in the "production" process itself. Production, from this perspective, is the transformation of people as objects into subjects within a framework of social relations; it involves the recreation of social and thus community relations, as well as the biological and personal identities of individuals. In reorienting social relationships, both in form and in content, the production/consumption process is probably best conceived as the reorganization and reorientation of community relations for the satisfaction of individual and collective needs.

Thus, the specific empowering solutions adopted by some disabled people that I describe in this chapter and in Chapter 6 are the instrumental means by which their independent living needs and those of other members of the community can be satisfied. At the same time, the mediating or alternative structures created by disabled people represent the challenge of "pure expressive action," albeit in articulated form. In this chapter I view the empirical forms of the disabled consumer movement as the context (medium <u>and</u> outcome) in which the process of organizing and strategic community-building can be looked at systematically. First, however, I want to return to the discussion to empowerment, to discuss a little more of the kinds of changes people go through in the organizing process.

From Objects to Subjects: Empowerment and Agency

Guided by the independent living philosophy, the disabled community and its members may begin to recognize the dialectic between objective conditions and subjectivity, wherein the subjective aspect exists only in relation to the objective aspect (the concrete reality which is the object of analysis). "Subjectivity and objectivity thus join in a dialectical unity producing knowledge in solidarity with action and vice-versa," according to Freire (1984: 22). A raised consciousness is based on a growing solidarity between people as subjects; as Freire puts it, subjects know and act, while objects are known and acted upon. Subjects know their social world and continually act to transform it, while objects merely consume aspects of their social world and exist to reproduce it. Objects, that is, disabled persons within the medical model, would not be unlike commodities, "things" manufactured to maintain and reproduce a certain social reality. By contrast, subjects are dynamic, and are participants as well as consumers and producers. The transformation of objects into subjects, of clients or patients into producers/consumers is what Freire calls praxis.

Like what Rogers had in mind with the concept of self-actualization, Freire suggests that oppressed people, perhaps more than others, have a direct interest in transforming their world, that their interest is inherently part of their humanity, and that this interest is premised on ideas of justice and freedom. The oppressed have what Freire calls an ontological vocation, that is, they are immersed in a natural struggle "to recover their lost humanity" (1984: 28). They may not be completely unaware of the fact that they are downtrodden, of course, but only that their perception of themselves is impaired by the reality in which they are submerged. They also have the feeling that they are somehow being held accountable for "the way they are" (e.g. ambivalence, scapegoating, deviance, blaming the victim, and so on): "Arthritis occurs with people who are filled up with pent-up hostility" (Vash 1981: 30), or

> I also had to deal with the way other people felt. What happens to people with hidden disabilities is that others are very angry at them. The anger is not shown directly because this is not socially acceptable. Each disability has a different social situation. For a person with a hidden disability it can be very hard because people don't see you as trying, they see you as giving up (Jill Weiss, COPOH 1987d: 16).

Championing the work of Paulo Freire, disabled individuals recognize that changes in themselves or in society will never take place without their own direct involvement in changing the conditions and circumstances of their oppression (Henry Enns, speech at the 1986 Alberta Committee's annual general meeting; see also Simpson 1980: 3). Some of them (e.g. action-oriented disabled people) have come to learn and understand that they have internalized the content and process of their oppression that is now part of their identities, and so catch glimpses of themselves submerged in a reality not of their own making.

Thus, in order to prepare themselves for the struggle to reconnect themselves to social/historical reality, "they must perceive the reality of oppression, not as a closed-world from which there is no exit, but as a limiting situation which they can transform" (Freire 1984: 34; cf. Ortner 1984: 152-153). It would seem that many disabled people have come to realize that injustice, domination, oppression and so forth are mutable historical facts, and are not aspects of an underlying and immutable natural order. With respect to social and physical barriers to independence and integration, "a corollary of the barrier-free environment is that social and cultural settings can be effectively changed" (Alberta Committee 1981b: 20, emphasis added).

My own interpretation is that disabled persons also recognize their domination as having two dimensions. First, objectively, there is the power relations and structure between doctors, rehabilitation health care professionals, service providers, agency personnel (in short, the health care industry), and the disabled community itself. Second, subjectively and reflexively, they see that the way they express and present themselves as disabled people, as a category of people, is a reflection of this asymmetrical relation (e.g. Zola 1983a). The latter dimension refers back to the first one, that is, the objective manifestation, for example, in the continuous communication of pathology or illness, inability, incompetence, deviance, and fault. Writes Irving Zola (1983a: 57),

> [W]e who have chronic diseases and disabilities must see to our own interests. We must free ourselves from the physicality of our conditions and the domination of medical professionals.... In particular, I refer to the number of times we think of ourselves, and are thought of by others, in terms of our specific conditions.... Whatever else this does, this distracts our attention from our common social disenfranchisement. Our forms of loss may be different, but the resulting invalidity is the same.

As I noted earlier, the primary theoretical model or paradigm that is imposed on disabled people is the medical/rehabilitation one. This model is seen (by those disabled individuals who have become empowered, as well as others) as essentially closed-ended and static; the world of the disabled person seems to revolve around an axis having diagnosis and medication/therapy as its endpoints. In this circle of certainty, as Freire describes it, there is nowhere for the disabled person to go. The disabled person merely becomes a "better" disabled person or patient, and so less of a whole human being. It is exactly this world, this circle, that the disabled individual must see critically and from which his or her "escape" must be planned.

Following Freire, I suggest that part of recognizing the experiential dimension of submergence requires that its omnipotence be fully grasped. Enmeshed in the medical/rehabilitation approach, disabled people must learn that their behaviors and their very consciousness is shaped by role expectations; they recognize that the so-called circle of behavior-consciousness-behavior is fixed and closed -- it goes nowhere, except back to reinforce both itself and the social context that created it. Transformation therefore requires reconnection to an objective world where oppression might be of a different order, but one that can probably be dealt with more directly and is even preferred. In a sense, the oppression of the closed world of the medical model has to be exchanged for the discrimination and oppression of the larger community. Again to quote Zola (1983b: 352-353),

> "The world in which we live is not always safe, secure, and predictable. It does not always say "please" or "excuse me." Every day there is a possibility of being thrown up against a situation where we may have to risk everything, even our lives. This is the REAL world. We must work to develop every human resource within us in order to prepare for these days. To deny any retarded [physically disabled] person his fair share of risk experience is to further cripple him for healthy living" (op. cited)..... An environment or device that prevents any kind of risk produces not a real life but a mirage of one. There is human dignity is risk. There can be dehumanizing indignity in safety.

Subjective revalidation, therefore, is possible only through a process of rehumanization, of becoming an actual participant in producing the complete social world, and not just the world of the sick or disabled. This is a learning process that can only be begun by disabled (or non-disabled) persons who are not so submerged, who have had the opportunity to reflect critically about their domination and oppression or that of their fellows. Their leadership and work in the wider disabled community thus revolves around the efforts of identifying aspects of the no-exit reality, in order to show how it is a product of the manipulation of resources, rules, and so of interactions between people. The focus of this limit-setting activity by individuals (as Freire calls it) is to learn to see reality as permeable.

> "I suddenly hated all the manhandling -- being lowered into the water by someone else with everyone on the beach looking on. All of my plumbing (catheter and leg bag) were [sic] exposed. I became acutely aware that I did not have the beautiful body that you see on T.V."
>
> "Yeah, there are big bodies, little bodies, straight bodies, and not so straight bodies. With us the old locker room concerns about penis size and breast size become very insignificant."
>
> We both laughed and proceeded to compare notes on experiences we have had as persons with disabilities. Many sessions followed where we talked about and experimented with various coping mechanisms we used, to deal with everyday problems..... I realized how important it was for a person with a disability to have the experience of meeting and talking with another person with a disability (Patricia Sisco, COPOH 1987d: 105).

Reflection on reality and the disabled person's experience in it is therefore initiated through what Freire calls dialogue and what disabled consumers call peer counselling, that is, the mutual identification of specific problems, complaints, issues, and so on, by involvement with peers. How and why do things happen as they do? Who benefits the most from current arrangements? In this process, the disabled individual is legitimated and validated as a critical commentator about his or her own situation, while at the same time his or her own questions and concerns are elevated to a more general, collective, level where some kind of action might be contemplated.

Part of the process of empowerment therefore involves examining the relationship between the situations people find themselves in, and their perceptions of themselves in those situations (since the kind of action people take is a function of how they perceive themselves situated). Considering that the "situations" by and large constitute the therapy/service/consuming activities of the disabled individual, it is precisely these that become the focus of inquiry. In other words, what the professionals and experts of the health care/health service industry want "obscured" now becomes the focal point for reflexive observation and the starting point for critical debate and purposive action. Thus, what was previously immutable and inevitable now becomes historical and alterable. The next step might be to locate these consuming activities in the larger contexts of law and legislation, policy decisions, regulations, court decisions, program funding, etc. In similar fashion these are targeted for both reflexive monitoring and strategic intervention.

In sum, those within the disabled community who are committed to an empowerment action orientation would probably agree that one of the most critical needs of human beings is the need to be a creative and effective participant in one's environment (Rose and Black 1985: 57-60). To act upon the social world and to transform it, thereby creating new possibilities for expressing one's individual and collective interests invokes Giddens' idea of the dialectic of control. An empowerment action orientation sees disabled human beings, regardless of previous dehumanization, exploitation or mystification, as potentially capable of critical intervention into their own realities.

In direct contrast to the unidirectional or unilateral aspect of rehabilitation practice, empowerment and independent living involves coming up with different strategies that are designed to address the independent and community living needs of disabled people in both the objective/social and subjective/emotional dimensions. The focus of these strategies, for example, would be the development and implementation of service programs, specialized and accessible community housing, accessible transportation, attendant care, daily living skills training, and so on. Successful implementation would in turn generate a measure of validation, support, and legitimacy for disabled individuals, on both an individual and collective basis. In turn, validation and legitimacy not only alter self-concept, but also influence the ability to exercise control over the so-called objective conditions thrust upon and endured by disabled people.

"A Voice of Our Own": The Disabled Consumer Organization

Disabled organizers emphasize the fact that consumer organizations, groups or group coalitions are essentially modelled after, and are parallel to, the major political structures of the community and of society. Unlike the so-called anti-organizational stance taken by some feminists, for example, disabled consumers insist that some degree of parallelism is essential in providing an effective consumer balance to existing structures. This, of course, is in keeping with the independent living/disabled consumer movement's contentionist orientation and its integrationist stance. Comments Allan Simpson (1980: 23),

> It is essential for consumers to gain an appreciation of how group dynamics, consensus building, group sharing and internal decision-making procedures are evolved and implemented at the political/bureaucratic levels. The individual must learn how the political system works.......

Disabled consumer advocacy organizations do not directly provide hard or technical services (such as equipment and devices (and their repair), prosthetics, pharmaceuticals, transport systems, career training, housing, and so on). Instead, they provide information about these and other things such as consumer education, on-going research into developing technology, available programs and policies, and so forth. They do so in order to empower disabled individuals to participate in the community and in society, and to become partners in policy decision-making processes at all levels. Anti-organization would clearly be antithetical to this goal, and would only serve to further isolate and alienate disabled people.

Despite the historically activist profiles of some disabled organizations in both Alberta and other provinces (and a reputation of some of the earlier disabled leaders for radical activism), their goal and purpose has never been to take political power or to usurp state power. On the contrary, the disabled community seeks institutional reform and revision, not revolution: "Confrontation tactics and absolutist ideologies will be avoided by the Canadian Disabled Consumer Movement" (Derksen 1980: 18). The disabled consumer movement can probably best be described as an institutional reform movement. This of course implies the continuity of present structures (the goal of demedicalizing disability and deinstitutionalizing disabled people notwithstanding): "Consultation and cooperation, not confrontation" is thus a key action phrase that has emerged since the end of the 1970s (COPOH 1982).

To effectively link disabled people to each other as well as to the larger system, parallel/alternative and cross-disability consumer organizations ("of" the disabled) are the most successful in operationalizing the goals of the independent living model. It is worth noting here that cross-disability representation is essentially a 1980's phenomenon; until this decade organizations of the disabled were single-disability in orientation, with the disabled population as a whole largely unorganized and without a collective consciousness (Kallen 1989: 146-147). Disabled persons have found it increasingly necessary to work within the framework of parallel organizational structures in order to learn about organizational dynamics and to develop skills transferable to and useful in the general community. Similarly, the disabled and non-disabled need to work through shared and familiar structures in order to understand their mutual needs. How else could community be achieved anyway? Before going on, however, to profile the structures, goals, and activities of both a provincial and a national disabled consumer coalition organization, I want to outline some general features of these kinds of consumer organizations first.

A more formal consumer organizational model consists of the authority and organizational structure that is typically centralized around a president, an executive director, an elected board of directors, various committees (e.g. executive, finance/budget, etc.), and a hired staff. The membership component consists of paid-up active individual, associate and corporate (other organizations) members. Membership policy directions are generally established at annual meetings, conferences and at the annual general meeting. Board members and appointed executive officers are authorized to coordinate the members' policies and resources, and to implement detailed strategies for specific approaches to the political level. The general membership can become directly involved through one or more of a number of research committees or specific action sub-groups.

In turn, the executive director, administration staff and office assistants may carry out actual research, gather information and disseminate it on the request of members as well as the public (they may also produce a newsletter and manage a working library), and generally look after office business (no small task). A structure such as this usually operates under established procedures (there are published by-laws and/or a charter, and detailed policy/job descriptions); it provides an excellent context for individuals to learn basic and essential administrative skills, and to gain some democratic decision-making experience as well (Simpson 1980: 13, Alberta Committee 1982c: 9-15, 1983a: 1-9, COPOH 1985d).

Alternatively, local consumer action groups may also have a more dynamic informal structure -- possibly one that is alot more empowering -- one that is coordinated by a few experienced individuals rather than formally structured around an executive and administrative staff. Under this model, all members are encouraged to unite and concentrate on one or two fundamental (and preferably cross-disability) issues at any one point in time. At conferences, open assemblies or similar such forums (these are the highest decision-making bodies; no other level of organization can revoke their decisions), issues or organizational goals are presented for discussion and adoption by the membership. Efforts are directed at involving the entire membership in planning as well as implementing strategies. The assembled membership modifies and approves such things as position statements (of issues that happen to be under discussion) and plans of action; both the statements and the strategies can be drafted first by a research committee and elected board members (as in the formal model), or else they can be the outcome of workshops held at conferences. Tasks can be assigned by the assembly to various sub-groups, who in turn work within agreed-upon time frames (Simpson 1980: 14-15).

What is significant about this kind of flexible organization is that it provides a context for total involvement, sharing, and a means of producing "a broad group of informed leaders" within and across the entire membership. Consequently, greater internal accountability reflects the enabling process of empowerment in which the whole organizational membership is involved -- something which may not be possible in a traditional hierarchical structure with its divisions of labor, power, and responsibility. Members work closely with one another, and develop strong sensitivities to the needs and interests of others in different disability groups.

Cross-disability involvement and focus, moreover, is significant for the reason that it is a direct effort to counteract and overcome the fragmenting consequences of the medical/rehabilitation model: The focus on disability and on the patient results not only in the decontextualization of individuals, as previously discussed, but in the creation of categories of individuals and their social/historical separation from each other. The movement's cross-disability focus and its coalition structure serves to unite and integrate what has in essence been a fragmented community; it is this process of integration in the context of organizational involvement that has consequences for the empowerment of those involved, and that is the beginning of the community-building process.

In the more formal organizational model, then, there is a greater tendency to rely more on the formal leadership to "OK" a plan or strategy, and on an office staff to do some of the technical work. A feeling of being left out or of not knowing one's role in the organization can often be the result of an arrangement such as this one. Central staff, separate from the group's members, could conceivably become a competitive force within the organization. In the formal model, impatience can develop on the part of the board and other elected officers to get consensus and have issues resolved quickly as they sometimes work against timetables set by others (such as politicians, agencies, etc.) over which they have minimum control. Individual empowerment may not be possible under circumstances such as these. In certain contexts and situations, of course, a formal structure is probably useful.

In reality, consumer groups find it desirable to utilize a combination of these two kinds of organizational approaches (Simpson 1980: 15). Formalized board representative elections through annual meetings combined with administrative coordination by a board executive and hired staff allow for special meetings to plan, initiate, adopt or implement new policy resolutions (top down). The more informal structure, clearly an effective and motivating form of membership involvement, allows for greater grass roots participation (bottom up) and the articulation of issues of immediate concern. With this sort of combination, members feel much more motivated and derive greater meaning from the process of learning how to cooperate in the decision-making process. What is significant here is that individuals share in the creative process of organizing themselves; this process is simultaneously a vital part of community-building because community-building *itself* is an on-going organizing activity.

Thus, members of the consumer group depend not so much on their elected officers for leadership, but instead look to themselves as "leaders in the larger community." It is important to reiterate that integral to the empowerment process, as a social and cultural process in this instant, is dialogue, or mutual communication. Members recognize that they share concerns in common, that joint action promises more benefits than working apart, that the means to accomplish resolution and consensus-building ensures their participation that is required to move on issue positions, and, finally, that each member has a part to play in the creative process.

Combinations of these two ideal types may be found at the various levels of consumer organization, though one finds that structures tend towards the more formal at the provincial, national and international levels (i.e. the larger the jurisdiction, the greater the bureaucracy), and towards the more informal at the local or community level. The local consumer group (e.g. Edmonton/Calgary Action Group for the Disabled), for example, serves as a setting for individual self-development, growth and confidence-building, and as a vehicle for leadership development. It could also be seen as a kind of low-level communications system that links the smallest elements of the disabled community to one another (individuals and/or other small self-help groups), and that provides a means of linking or bridging the disabled and other communities to one another.

From the point of view of action theory, a consumer group, even the small local one (e.g. Edmonton Action Group for the Disabled), is more appropriately seen as a kind of coordinating action network for individuals and even smaller local uni-disability advocacy and semi-service or self-help groups (e.g. Cleft Lip and Palate Clinic, Deaf and Hard of Hearing Services, Multiple Sclerosis Society, Arthritis Society -- there are some 700 of these small local uni-disability groups in Alberta). As such the coalition is "the most important implementation structure" in the independent living/disabled consumer movement (Simpson 1980: 16). It is at this level that practical community service delivery systems and benefits for individuals can be realized through local action. It is the local consumer coalition group that often demonstrates on specific issues, lobbies elected and appointed officials, and directly negotiates with various community and political leaders that are responsible for delivering specific public (and private) services.

A provincial consumer group such as the Alberta Committee of Disabled Citizens is likewise a "coordinating action structure/coalition" comprised of individuals and numerous local-issue/uni- and cross-disability consumer groups as well as semi-service organizations (e.g. Edmonton Employment Services for the Physically Disabled, Handicapped Housing Society, Alberta Association for the Deaf, including the provincial chapters of various national associations). Provincial consumer groups tend necessarily to be more formally structured. The provincial coalition is described as "the most effective and important strategy coordinating arm" of the independent living/disabled consumer movement, since it has both the geographic and jurisdictional scope to fully involve individual members in the region, and the technical/funding means to support and mobilize local and smaller groups even in rural areas. The provincial organization also organizes marches and demonstrations, and conducts extensive consultation, political lobbying and monitoring activities at the provincial level.

At the national level (e.g. Coalition of Provincial Organizations of the Handicapped) the coalition, or umbrella alliance, is comprised not only of all the provincial consumer organizations (those who wish to be included, in any case), but it also enjoys the participating memberships of such well established national organizations and associations ("for" the disabled) as the Canadian Paraplegic Association, Canadian National Institute for the Blind, the Muscular Dystrophy Association of Canada, the Canadian Cancer Society, and so on. The purpose of the national coalition is to focus on major national human rights legislation, and legislation covering the direction and funding of such vital and major policy areas as transportation, housing, education, employment, social security, rehabilitation services, independent living support systems, and so forth (COPOH 1985c).

As a national voice (COPOH's by-line is "A Voice of Our Own," which is used as part of this section's title) of the disabled and non-disabled, the coalitions's goal includes acting as a representative (cross-disability) body at the federal level. It is COPOH, for example, that works closely and directly with such bodies as the Canadian Association of Independent Living Centres (CAILC), the federal government's Standing Committee on the Status of Disabled Persons, the Public Service Commission, numerous federal government ministries and departments (Canada Employment and Immigration, Health and Welfare, Treasury Board, etc.), and even the Canadian Labor Congress.

Beyond the national level, Disabled Peoples' International (DPI) is an international cross-disability coalition of people with both mental and physical disabilities (COPOH, of course, is part of that coalition). Conceived in Winnipeg at the 1980 World Congress of Rehabilitation International, DPI was formally established in Singapore one year later at its First World Congress where its first World Council was also elected (it now holds Congresses, that is, open international meetings, every four years). In 1982 a delegation from DPI made a presentation concerning world-wide human rights abuses of disabled people to the United Nations Subcommission on Discrimination and Protection of Minorities in Geneva. The result was that in 1983 the United Nations Economic and Social Council recommended, and agreed to, consultative status for DPI within the UN framework. Its Head Secretariat is in Stockholm, and its Development Office, out of which a development program that organizes leadership training seminars in Africa, Asia, Latin America and the Caribbean is run, is located in Winnipeg (COPOH 1985d: 126-128, 1988b, Issues 1 and 2, see also Driedger 1989).

Organizations of disabled people from almost 70 countries are represented on the World Council; DPI has divided the world into five regions and is working to develop an infrastructure of regional assemblies and councils. DPI's interest is in mobilizing disabled people in North America and Europe, in order to raise awareness of, strengthen support for, and empower their brothers and sisters in Third World and developing countries; there is also considerable interest in the kinds of treatment programs and medical systems that exist (or that might be lacking and could be developed) in these countries and how they impact on the disabled.

Now, whether at the local, provincial, national, or international level of organization disabled consumers make an important distinction: Theirs are organizations "of," rather than "for" disabled people. A group "of" disabled persons, appropriately, is made up and controlled by disabled persons, with respect to structure, policy and program decisions, and external representation. "For," on the other hand, implies control by non-disabled persons (or disabled persons who are not consumers), with externally produced policies and programs/services aimed at disabled individuals without their input. It is precisely this that is also an aspect of the medical model that disabled people reject outright (Alberta Committee 1981b: 37-38). The essence of this important organizing principle (or philosophy) is summed up well in the following statement made in 1982 by COPOH's national coordinator to the Standing Committee on Justice and Legal Affairs:

> We are an organization OF disabled persons as opposed to FOR disabled persons. We are based on the philosophy of citizen participation and self-representation. We believe in our society there has been a tendency for non-disabled persons to speak on behalf of disabled persons, and essentially what we are saying is that disabled persons have the right to represent themselves (Minutes of the Proceedings and Evidence of the Standing Committee, 1982, Issue No. 115: 9, op. cit. in COPOH n.d., page 7).

The point, of course, is that community-building takes place from within; it cannot be imposed from without.

Alberta Committee of Disabled Citizens (ACDC)

In the province of Alberta the disabled consumer movement came under the leadership of a well organized and tough-minded provincial alliance organization that had been active since the early Seventies.* The Committee was founded in 1973 under the name Alberta Committee of Action Groups of the Disabled (a merger of two smaller local organizations, the Edmonton Action Group, and Disabled on the Move from the city of Lethbridge). Percy Wickman (one-time president of the Committee in its formative years, past national chairperson of COPOH, long a respected Edmonton alderman, and an elected [March 20 1989] Liberal MLA), said this of the decision to form an action group:

> Frustrated by the failure of established agencies to bring about necesary change, this group was determined to do it for themselves. Why not -- what the hell -- it's our lives that are affected -- why shouldn't we determine our own course?

According to the Committee's historical notes (Alberta Committee 1980a),

> The Alberta Committee was the first group in Canada adopting the philosophy of groups of disabled people working towards improving the lifestyles of disabled people. For a number of years, it was the only organization in Canada intervening on behalf of disabled

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* What follows in this section in drawn primarily from the following documents: Alberta Committee n.d., 1980a, 19801, 1981b, 1982c, 1983h, 1987e, 1988d, 1989.

> people.... The Committee is one of the leaders in self-advocacy.

The movement gained significant momentum when, later in 1975, the Alberta Committee played a key role in forming a somewhat unique body, the MLA/Handicapped Joint Committee. Again according to the historical record (Alberta Committee 1980a),

> In particular the MLA/Handicapped Joint Committee has provided a forum for the exchange of ideas as well as an important communication link between the disabled and the legislators. That Committee was formed as a direct result of a luncheon held in November, sponsored by the Edmonton Action Group of the Disabled and attended by forty members of the Legislative Assembly (op. cit. statement by Alberta Premier Peter Lougheed, February 12, 1979).

This particular committee consisted of five disabled consumers, and included the Ministers of Labor, Advanced Education, and Social Services and Community Health, as well as the Leader of the Official Opposition and the Leader of the New Democratic Party. They met approximately four times a year, from 1975 until the Joint Committee disbanded in1979, to discuss and implement policies, services, and programs aimed at improving the lifestyles of persons with disabilities.

Consultation of this kind led to the successful implementation of programs, services, and amending legislation that included Assured Income for the Severely Handicapped (AISH), Alberta Aids to Daily Living (AADL), Alberta Home Adaptations Program (AHAP), and even the Alberta Human Rights Protection Act. It was cooperation and success of this sort that helped establish the credibility of both the Alberta Committee and of the greater movement it is part of (Alberta Committee 1981b: 32-33).

By 1980 the Alberta Committee had accomplished even more. It was one of three founding groups of COPOH, the Coalition of Provincial Organizations of the Handicapped, with which almost every other local and provincial organization in the ten provinces and territories eventually became affiliated. [Through the hard lobbying work of its affiliates, it was through COPOH, incidentally, that the wording of section 15 of the Canadian Charter of Rights and Freedoms was changed to include mental and physical disability; COPOH's role in the movement will be discussed later]. Five years of consultations, two major provincial conferences, literally dozens of briefs to the Alberta Legislative Assembly, the Premier, various legislative committees, the Alberta and Canadian Human Rights Commissions and other federal and provincial bodies also resulted in the acceptance of the Alberta Committee's suggestions for amending the Alberta Individual Rights Protection Act (which became law on September 1, 1980) to include the rights of physically disabled individuals. To-date (1989), however, the rights of mentally handicapped individuals are not protected under Alberta legislation.*

By early 1981 the Alberta Committee was faced with a number of issues which led it to question its future policy orientation and activities. Was the organization to tie its policies to wider human rights and consumer issues, or was it to continue as an action-oriented group concerned solely with solving the problems of individual consumers as they arose? Having already established strong community and government ties and having accomplished many of the things it had originally set out to, the Alberta Committee was forced to priorize its concerns and objectives, lest it offend a (reasonably) friendly government and a (relatively) enlightened citizenry. As a sign of the organization's maturity and prominent

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* At the time of writing the report of the Review Committee on Services to the Mentally Handicapped (Alberta Family and Social Services) released its report entitled "Claiming My Future: A Person with a Mental Disability Today and Tomorrow." This report makes strong recommendations for IRPA protection, among other things.

place among the province's policy communities, and most certainly in recognition of the importance of maintaining image, it changed its name that year to the Alberta Committee of Consumer Groups of Disabled Persons.

Under the new name and entering its twelth year of operation by the time I approached the Alberta Committee to begin research on this thesis, a great deal more was being accomplished. It was during this time, too, that submissions and oral presentations were made to the Alberta Committee on Tolerance and Understanding (under authority of the province's Minister of Education), the Special Committee on Participation of Visible Minorities in Canadian Society (which produced the report EQUALITY NOW), Judge Abella's Royal Commission of Inquiry on Equality in Employment, to the (federal) Sub-Committee on Equality Rights of the Standing Committee on Justice and Legal Affairs (EQUALITY FOR ALL), and, finally, to the Royal Commission on the Economic Union and Development Prospects for Canada (also affectionately known as the Macdonald Commission).

The Committee's slogan "from grassroots to full participation" was eventually given a second interpretation, which was to mean the participation of both disabled and non-disabled individuals in the independent living/disabled consumer movement. By 1985 participation and board as well as executive membership had indeed been extended to include both non-disabled people as well as the continued representation of a cross-section of disabilities (e.g. the deaf, hearing impaired, blind, visually impaired, amputees, mobility disabled, hidden physical, mental and emotional disabilities). The board, however, maintains a two-thirds majority in favor of disabled persons. The eventual inclusion of the non-disabled -- or the "temporarily able-bodied" (TABS) as they are referred to by the disabled -- was described by Committee members as a clear sign of greater maturity and independence on the part of the organization, and, indeed, on the part of society. Independence might better be understood to mean interdependence; hence the invited involvement, full cooperation, and separate but equal partnership of the temporarily able-bodied. The Alberta Committee made it clear that control of the organization will always rest solely with the disabled.

In late 1985 the organization once again elected to change its name, this time registering itself as the Alberta Committee of Disabled Citizens, a name, it was felt, that better reflected its politics, its empowered position, and the spirit of cooperation it helped establish in the community and province. Significant developments in Alberta since then have included the establishment in March 1986 of the Edmonton City Council Citizens Task Force For Physically Disabled Persons (see Appendix 4, Item 1), and on-going consultations to form a Premier's Council on the Status of Disabled Persons by late 1988 (see Appendix 5, Items 1 and 2).

The Committee's logo, found on its letterhead, business cards, pamphlets and on lapel buttons depicts a solitary oak tree, profiled above and below the surface of the ground. Accordingly, the strongest part of the tree are the roots: This is representative of the disabled consumer movement where its strength lies in the grassroots participation of individual members. Shown as tall and sturdy with leaves even though the limbs are missing on one side, the suggestion is that disabled people who have impairments are still able to contribute and participate in society, and that they are growing stronger -- just like the consumer movement. Finally, the single acorn that is depicted on the tree stands for the idea of new growth and the manner in which small groups have given birth to other, larger, ones: COPOH, for example, was founded by three provincial groups, which in turn was instrumental in the development of Disabled Peoples' International.

The structure of the Committee itself includes a maximum seventeen-member (minimum of 7) volunteer, but elected, board of directors that collectively represents a cross-section of disabilities including the deaf and hearing disabled, blind and visually disabled, amputees, mobility disabled, and those with hidden physical, mental and emotional disabilities. This is essentially the Committee's policy-making body. One-third of this board, however, can be made up of individuals who are termed "the temporarily able-bodied" (for example, spouses, immediate family, close friends, and others, including health care and social service professionals), provided that their personal philosophy is compatible with that of the Committee's. The board elects a president, vice-president, a secretary and a treasurer from its numbers (this is the executive committee), and is also responsible for the formation of sub-committees such as finance and budget, fund-raising, the AGM committee, public relations and membership, building standards, independent living, human rights, transportation, disabled natives, and disabled women (and others, as may be required to fulfill the objectives of the organization). Each board member serves on at least one sub-committee, with the grass roots involved on a volunteer basis (Alberta Committee n.d., 1982c, 1987b).

At the administrative end of things, core hired staff include an office administrator, a managing director that carries out the daily business of the Alberta Committee between meetings (and takes policy statements from the minutes of board meetings), and a research/communications officer whose task it is to collect and disseminate information as requested by the membership and others. All are directly accountable to the board of directors. In addition, disabled consumers and others may be hired on an ad hoc basis (e.g. paper work, envelope-stuffing, photocopying), or on a seasonal basis (e.g. STEP and PEP students). In any given week the Committee's small office in Edmonton can buzz with the activities of three or four such individuals, in addition to the regular staff.

Overall, the goals of the Alberta Committee are to improve the quality of life of the disabled community through educational, legislative, and positive policy change at all levels of government, using as the basis the philosophy of consumerism as articulated through the principles of independent living. More specifically, the Committee acts as an empowering tool both for individuals who join it, as well as those who wish to form action groups of their own. To this effect, the Alberta Committee has (since 1986) opened small offices in Grande Prairie and Calgary. It sees its role as developing informed consumers, since an informed consumer becomes the best judge as to what his or her barriers to independence might be, and what solutions and services are needed and might be developed.

In its advocacy role (defined as representing the rights and interests of oneself and/or other individuals, and speaking on one's own or others' behalf, in order to realize the rights to which they are entitled, to obtain needed services, and to help remove barriers so that their needs can be met), the Alberta Committee of course does not offer any hard services such as equipment or residential options. Rather, it fulfills its mandate through the following four-fold set of soft service objectives, or empowerment resources. These are the building blocks, one might say, of community-building:

(1) Information

According to the Alberta Committee (1981b: 22), "the process of informing is the function of organizations of disabled persons." The Alberta Committee handles a wide variety and large volume of requests for information from service agencies (private as well as public), government offices, the general public, and of course from disabled individuals. Information that is requested ranges from employment equity legislation, different sources of income, specific service providers (and their quality), availability of technical aides, social support services, access to transportation, to finding out which local restaurants and office buildings are accessible to the mobility impaired. To make intelligent and relevant decisions, disabled consumers clearly need accurate and the most current of information; office staff endeavor to provide it. In interviews with the press and other media, policy positions as they are formulated by the membership and by the board (as resolutions that have emerged from workshops, etc.) are explained in detail (usually by the managing director).

Information and the knowledge that is gained from it is recognized as crucial to the elimination or reduction of barriers that "wedge themselves" between independence and integration. The focus on information as a community resource for empowerment is stressed, for the reason that choices and decisions made with regards to services and lifestyles would otherwise not be informed ones. Recalling the discussion in Chapters 3 and 4 on consumerism and knowledge/power,

> Information is a consumer product just as food is a consumer product. Information is also a consumer conditioner in the same analogous way as food is a consumer conditioner. Information, like food, can be either nourishing or debilitating, depending on what it is composed of and how it is prepared. It seems quite natural to pay careful attention to what foods we consumer and demand that those who produce and provide our food pay careful attention to its production and that they be accountable for their actions as regards food production.
>
> It is important that the same considerations be observed in the production, distribution and exchange of information. The quality of any product can be ensured directly by the participation in the production of the products; and/or indirectly by monitoring the production of the products preferably in cooperation with a responsive and accountable producer/provider (cited from the "Spokesman" in Alberta Committee 1981b: 20-21cited from the "Spokesman").

In its role as information broker or information "clearinghouse," the Committee publishes a quarterly newsletter ("Awareness is the Key," 1985--) which it circulates around the province, emphasizing distribution in the rural and northern areas of Alberta. Used as an information/networking tool, the purpose is to keep the grass roots informed on many topic issues and up-coming events (social and political). The Edmonton office maintains an active and specialized resource library of books, background research reports and briefs (government, private and self-produced), legislation, newspaper articles and so forth which members (and the public) are free to use. It is interesting to note that full use of these facilities are made by community college and university students throughout the year; in fact, special education and health care/nursing students often spend some of their time at the Committee as part of their practicum requirements.

The Committee is also an affiliate of the DISC network (Disability Information Services of Canada), operated from the Walter Dinsdale Centre (Calgary) and the University of Calgary (it is managed by staff, a management team, and a national advisory committee). DISC is a national electronic information and communication network system that can be accessed by modem, upon subscription, either privately or from libraries, drop-in centres or other organizations/facilities. Through the use of electronic bulletin boards, ever-developing databases, electronic mailing and conferencing, individual consumers, or those involved in outreach programs, rehabilitation, independent living and employment centres, government agencies, small businesses, physicians, bioengineers, and other professionals (the list is endless) can communicate with each, and importantly, with consumers as well. Extensive use is made of this network as it presently exists by many individuals; networking is an obvious empowering tool in the community-building process.

(2) Public Awareness and Consumer Education

As part of its community-building efforts, the Alberta Committee seeks to raise relevant issues at all levels of government through the process of on-going research and written and oral presentations to elected and appointed officials, including school board representatives, municipal government representatives, local business-Chamber of Commerce people, service club officers, and many others. It initiates, conducts and organizes workshops, seminars, public speaking events and public awareness campaigns on an annual, or on-going, basis in order to both increase the profile and visibility of the disabled community and the consumer movement, and to identify physical and attitudinal barriers in such issue areas as housing, employment, transportation, recreation, education and public facilities. The Committee's AGM, for example, to which the general public is invited, is usually organized around a theme, featuring a keynote speaker from a relevant policy area, and a series of session workshops. The theme of the September 1988 AGM, for example, was "Families in Transition -- Dealing with Disabilities"; sessions were organized on family violence, sexual abuse of children, role of spouses and caregivers, and so on. The 1989 AGM continued with the same theme (Brian Laird, ACDC, personal communication).

The Committee is clearly an image-building tool for the disabled community. Public awareness campaigns, for example, might involve mall displays, posters, the preparation of audio-visual materials for loan purposes, "open house" on organization premises (which could include group homes, co-op housing), public service announcements (local radio/cable television often set aside specific times for these), and even press conferences. These are, of course, prepared, organized, and conducted by disabled individuals themselves. The goal is to at all times portray disabled individuals positively, that is, living and working in the same variety of life circumstances in which one would expect to find anyone else. Two prime examples of strategies for creating positive images of disabled people are the PATH display and National Access Awareness Week. The PATH (Positive Attitudes Towards the Handicapped) display is a set of mural-posters, audio-visual and other educational materials that is organized by a group of agencies in Edmonton (since 1982), whose coordinating committee is chaired by the Alberta Committee. This educational display makes its annual rounds one or two days a year in shopping malls, community colleges and other post-secondary educational institutions.

The Alberta Comittee is also the Edmonton/northern Alberta regional National Access Awareness Week coordinating committee. A federal government initiative in recognition of Rick Hansen's "Man in Motion Tour," a national week of recognition and awareness for people with disabilities was declared in 1987 (organized in terms of national, provincial and community-level committees). In 1989, June 4 -10 was the week in which extensive awareness campaigns were presented, together with social and cultural events and sports activities in all major Canadian cities, including Ottawa. Part of the planning and coordinating network of committees, the Alberta Committee acts to facilitate the flow of information from the national level to local communities, and helps establish steering/planning committees in smaller centres so individuals may further organize themselves with respect to activities. The Alberta Committee also helps people to develop action plans that enable them to identify barriers that isolate disabled persons from full participation in community life (Secretary of State of Canada 1988a, 1988b, 1989).

A significant NAAW (community-building!) strategy adopted in 1988 and 1989 by many communities that is part of the planning and implemention of permanent change is the creation of the Five Star Community. This refers to a kind of monitoring program conducted by the disabled and non-disabled (who are called "partners in community action"). A Five Star community is one where the five essential elements of community life -- housing, employment, transportation, recreation and education -- are rated in terms of availability/accessibility. Since these may mean something different to each person, the community as a whole attempts to identify the range of options that would encompass the needs of all its citizens (Secretary of State of Canada 1988a: 6). As well, the larger the community, the greater the effort and the more people involved in this monitoring process.

Because there is no one system that can possibly provide access to all individuals, it is necessary to look at the possibility of several options within each area of concern. For example, accessible housing does not mean only houses or apartment buildings with ramps and wide doorways, but can also mean group homes and co-op housing that includes attendant care. In the area of employment, the workplace should be barrier-free, technical aids should be available, as should be employment equity programs so that the disabled can successfully compete for non-traditional jobs on an equal basis with the non-disabled. Accessible transportation includes better access to the regular transportation system (taxis, buses, planes, trains), not just a separate or parallel one.

With respect to education, classes could be integrated or specialized to meet the needs of a particular group of students (as the case may be), teacher's aides might be made available, and adapted transportation to and from school could be organized if it is needed and does not already exist. Similarly, specialized sports activities or "buddy" programs would ensure the participation of disabled children and adults in community leisure and recreation activities. These are all clearly means to community integration.

It is the task of the Alberta Committee to sensitize and educate the public and even other disabled people to not only [illegible] the needs of the disabled who may live, sometimes isolated, right next door, but <u>who</u> the disabled are. The process of raising awareness, or image-building, on a wider community level includes efforts to change the way people talk about disability and the way they refer to disabled persons. The Committee recognizes that language is a powerful tool, that it can evoke images and ideas that strongly affect perceptions. Language use is clearly critical in changing attitudes about disability (see the Standing Committee on the Status of Disabled Persons, 1st Report, August 1988, for content analyses of certain media that bear this out). The argument that is made is that the whole range of human emotions, characteristics, and attributes that are applied to non-disabled persons should be shown to apply equally to disabled persons.

Thus, disabled people should be treated with respect and dignity, and language that arouses fear, guilt, pity, suffering, or abnormality should be avoided. An impairment or disability is also a fact of life, and so should be recognized and referred to without embarrassment. Disabled people object strongly to using euphemisms to describe disabilities. The term "partially sighted," for example, implies avoiding the acceptance of blindness. Terms like "mentally different," "handicapable," or "differently able" are considered condescending. Other examples are (Secretary of State of Canada 1988b: 33-36):

Inappropriate	Appropriate
the handicapped	disabled person(s)
cripple	physically challenged
spastic (noun)	person with cerebral palsy
deaf-and-dumb	person with impaired hearing
lame	mobility limited or impaired

Medical language should be avoided altogether, unless its use is appropriate to the topic of conversation. Reference to disease, for example, is acceptable only in the case of chronic diseases such as arthritis, multiple sclerosis, cerebral palsy, or Parkinson's and Alzheimer's. Disability that results from anatomical or physiological damage (e.g. cerebral palsy, spina bifida) should be referred to directly. As well:

Unacceptable	Acceptable
invalid; infirm	person with....
patient; case	person with....
suffering from MS	person with MS
afflicted	caused by....
deformed	born with....

Technical aids should be referred to in a matter-of-fact way, rather than in emotional terms:

Unacceptable	Acceptable
confined to a wheelchair	wheelchair user
wheelchair-bound	"wheelie" (acceptable slang!)
gibbles around	person who uses crutches
home-bound	limited mobility

Finally, language should not pick out differences or make odious comparisons with non-disabled people; the living and working activities and circumstances of disabled people should be emphasized, rather than their impairments or disabilities (which do not measure ability in any case). As well, people should be mentioned first, rather than their particular functional limitation:

blind lawyer	lawyer with a visual impairment
disabled manager	manager with.... an impairment
mentally retarded worker	worker with a mental handicap or is developmentally disabled
sick; defective	person with a disability

In the Committee's research briefs, press releases, oral and written presentations and submissions, brochures, and so on (various dates, see bibliography), the emphasis on appropriate language use is evident. In the process of redefining just who disabled people are, specific language is utilized to show that particular impairments or disabilities do not in fact measure ability, that mental and physical disabilities really occur along continua (not unlike abilities), that disabled people do not constitute a homogenous group, and that functional impairments do not necessarily limit all other life functions. Blindness, for example, is a problem for driving, but not for playing the piano or practicing law. Attitudinal and perceptual barriers have just as great a negative effect on disabled people as physical and architectural ones. The removal of both kinds of barriers clearly contributes to the integration of disabled people and to their recognition as persons.

(3) Research

Research, of course, is the principal means by which information is gathered and processed on an on-going basis. The kind of research the Alberta Committee undertakes is determined as often by the needs expressed by its grass roots membership as by requests for input and consultation with the provincial and federal government, service providers, rehabilitation professionals, and so forth. The most crucial topic areas include transportation, housing, employment, education, and recreation (see bibliography). Thus, research is conducted on the possible implications of existing legislation, services, and programs on the well-being of disabled persons; as well, solicited (and sometimes unsolicited) research input might form the basis for the future development of proposed or pending programs, services and laws.

The research process is usually conducted by the research officer in cooperation with the information officer, library technician, and the communications officer. The researcher officer's responsibilities include collecting studies relating to specific issues, drafting briefs as requested by the board, and keeping the group up-to-date on developments regarding changes in legislation, programs, and services. It is the information officer's job to initiate and maintain personal contact with government, and to liaise with other local action groups as well as agencies regarding desirable legislative and policy changes related to the interests of disabled people. The communications person, finally, coordinates material on local and provincial concerns for the membership, and deals with the media. He or she also assists local actions groups research and write their own materials, and prepares press releases.

In this integrated process, these individuals have a very close working relationship with sub-committee members, who in turn are in direct contact with the grassroots. The orientation and specific wording of briefs, for example, and other research items is reviewed and endorsed by the sub-committee, who may then submit the final product to board members for approval, adoption, and presentation. In this way, briefs and reports to agencies, commissions of inquiry, task forces, and so forth are considered to be "as close to representative of the points of view of the coalition membership as possible."

Research that the Alberta Committee has conducted since the 1970s has ranged from vocation and education integration, job adaptations, taxicab service, barriers to domestic air travel, voting in elections, income security, local architectural barriers, housing options, and so on. The results were presented to such bodies as the Alberta and Canadian Human Rights Commissions, Alberta Legislative Assemby, various legislative committees, task forces, and ministers, the Canada Transport Commission, and to such federal government appointed groups such as Judge Abella's Commission on Equality in Employment, and the Macdonald Commission on Economic Union and Development. The pay-off is the Committee's ability to provide accurate and critical information when needed, the reputation it has earned for providing balanced perspectives on emotionally-charged issues, and its acknowledged leadership role among disabled people.

Over the past several years, the research briefs and reports the Committee prepared and submitted to the provincial government also led to specific programs that had a positive impact on the quality of life of disabled Albertans. Examples of programs which have been implemented in Alberta since 1980 which reflect consumer input include Assured Income for the Severely Handicapped (AISH), Alberta Aids to Daily Living (AADL), Alberta Home Adaptations Program (AHAP), among others. Input that found its way into specific (Alberta) legislation, including amendments to existing laws, include the Individual Rights Protection Act, the

Dependent Adult Act, the Social Development Act, the Incapacitated Voting Act.

Another example is Bill 27 (formerly Bill 59 in late 1987), which became Alberta's new School Act [1988]. Uproar and controversy was raised by a specific clause in Bill 27 that would have had the effect of denying universal access to education to an individual deemed "non-educable," because of "a severe lack in intellectual functioning or severe medical fragility" (e.g. Edmonton Journal, May 7, 11, 1988). The Alberta Committee, in conjunction with other groups and individuals (e.g. Severe Handicaps Alliance for Public Education, the Liberal/ND education critics, and students and staff in the Rehabilitation Studies program at the University of Calgary) prepared and submitted extensive documentation detailing the practical, legal, moral, and political implications of the clause containing the phrase "non-educable." A persuaded minister of education subsequently rewrote the Act so that it would now guarantee handicapped children universal access to programs and services to meet their education needs (by way of a Special Needs Tribunal that will be established to facilitate the assessment process).

(4) Advocacy and Monitoring

Advocacy is considered an underlying theme of empowerment and of the independent living/disabled consumer movement, and is defined as:

> Providing individuals with assistance in presenting their situation to others who are often not supportive of their needs or position (COPOH 1987d: 32).

The primary focus of the Alberta Committee is to foster support for the establishment of local consumer-controlled initiatives, for example, action groups, independent living and support groups of different kinds, by working directly with these groups and by representing them. The purpose of the advocacy process is to ensure that the needs of disabled persons are met through consultations with them, and with their cooperation and on-going participation; the process involves a variety of actions and decision-making techniques, depending on what is being advocated. Thus, the rights and best interests of the disabled can be directly represented in actual service planning and provision processes. Professionals, paraprofessionals and other service providers can be advised, on behalf of the disabled person and his or her family (or even by them), about specific needs-meeting strategies that might be useful in helping that person achieve certain goals.

The idea of advocacy means the self-representation of individuals and speaking or acting on one's own or another's behalf. This is very much a reflexive activity. Ideally, disabled persons learn to eventually reassert control over their own particular concerns and aspects of their lives; this is the purpose behind the skills training workshops, conferences, seminars, and research activities of the Committee. Of course, self-representation is facilitated by and is the result of working relationships with government officials, service providers, the business community, and the general public. Without a positive self-image of the abilities and contributions of disabled persons communicated through the advocacy process and the responsiveness of society, the empowerment/community-building process could never unfold or evolve.

The advocacy and monitoring process cannot be considered separately from each other, or from such needs-meeting strategies as natural support networks, brokerage, individual program planning (IPPs), peer counselling, and so on (discussed in Chapter 6). With some of these strategic solutions in place (according to the needs of a particular individual, for example), and a sensitized and informed public, the Committee may gradually withdraw from the advocacy role. Monitoring the services and programs with which an individual or small group of individuals is involved continues, of course, ensuring their continued reciprocal involvement with those whose services have been contracted. Thus,

> We expect equal recognition and participation at all levels of government.... Alongside this expectation, the consumer organizations and their members must also be recognized as monitors, evaluators and creative critics of existing programs, services and policy models. Without such recognition, at least in terms of financial and manpower resources, research and innovative programs, policies and services cannot occur (Alberta Committee 1981b: 40).

Since late 1987, however, the Alberta Committee (1987a, 1987b) stepped up its monitoring and advocacy activities with respect to what it and the membership regards are three emerging critical areas of concern: The concerns of northern/rural disabled citizens, women with disabilities, and disabled Native Canadians. While all disabled people are considerably disadvantaged in areas such as education, employment and income, those in rural areas, women and Natives are significantly more disadvantaged and face some additional unique problems. Not the least of these include physical isolation, total lack of resources and facilities (e.g. adequate housing, funding, and technical aids in the case of reserves), physical and sexual abuse, lack of access to such generic facilities as women's programs, shelters, jurisdictional wrangling, and so on.

As a result, the Committee has taken steps to prepare research reports on these issues, to liaise with Native organizations on and off reserves, and with such bodies as the Alberta Advisory Council on Women's Issues, the Alberta Status of Women Action Committee, establish contacts within generic agencies, organize co-joint workshops and consumer courses, and to encourage participation in and growth, for example, of such young national networks as DAWN (Disabled Women's Network, see COPOH 1988b, Vol. 1, Issue 3: 2-6, and the excellent discussion of the formation, goals and philosophy of DAWN in Stone and Doucette 1988; see also Fine and Asch 1988 for many more of the substantive issues).* In May of 1988, for example, as part of its general awareness raising strategy, the Alberta Committee together with the National Film Board presented "The Impossible Takes a Little Longer," a film about disabled women. This premiere was followed by a forum, moderated by the vice-president of the Standing Committee on the Disabled and Handicapped, on the topics of women and employment, and work and family responsibilities.

Coalition of Provincial Organizations of the Handicapped (COPOH)

A Disabled Persons Conference, held by the Canadian Rehabilitation Council for the Disabled (CRCD) in Toronto in 1973, provided the vehicle for disabled people to meet from across the country for the first time. It was at this conference that disabled people learned that, just a few years earlier, people with disabilities in Alberta (the Alberta Committee) and Saskatchewan (Voice of the Handicapped) had actually organized themselves in order to lobby for transportation and accessibility needs. The result was that organizations were quickly formed in other provinces shortly thereafter. In 1975 the Manitoba League of the Physically Handicapped was formed; in the same year a Fall conference was organized by the Manitoba League to which representatives of the Alberta and Saskatchewan groups were invited. Discussions largely revolved around the possibility of creating a national organization. Following a series of meetings throughout 1976, a national cross-disability coalition structure was finally consolidated, with groups from the western provinces forming the core of the organization.**

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* The formation of DAWN was in fact precipitated by disabled women breaking away from COPOH. Disabled women argued that COPOH did not adequately represent their interests and concerns.

** This section draws extensively from the following sources: COPOH n.d., 1985c, 1985d, 1986, 1988.

The goal, of course, was to build the coalition from coast to coast (COPOH n.d.: 3-4, 1986: 17-18, Driedger 1986).

COPOH gained provincial affiliates with the help of six national coordinators, and by the late 1970s almost all provinces were represented on COPOH's elected National Council (or Assembly), and were participating in the annual Open National Forums that COPOH was organizing, in which national issues were discussed and resolutions passed. COPOH's major provincial affiliates, who are independent and autonomous, are themselves comprised of about 85 local groups, which in turn are accountable to an active membership of approximately 30,000 individuals; each major provincial affiliate appoints two representatives (and two alternates) to the Council. This system in conjunction with the Open National conferences ensures a fair population-balanced delegate system for things like ratifying organizational and policy resolutions. In addition to its provincial affiliates, COPOH is currently developing links and liaisons with the Yukon and Northwest Territories, and with disabled Canadians of Native ancestry throughout Canada.

The National Council of Representatives is administratively responsible for electing National Executive Committee officers, which include the Chairperson, Past Chairperson, Vice Chairs (External and Internal), Treasurer, and Secretary. The Chairperson serves as the senior spokesperson of the organization, and ensures the coordination of national policy decisions. COPOH's central office in Winnipeg is run by a staff consisting of a National Coordinator, research analyst, development education officer, comptroller, and administrative assistants; the office, under the national coordinator, provides the research and communication vehicle for information to members, as well as the coordination and processing of grant applications that are part of the funding process. COPOH's Ottawa Information Officer, part of the staff, maintains the Coalition's profile in Ottawa by meeting with public servants, private sector representatives, and other organizations (COPOH 1985d).

The tasks and responsibilities of each of these executive and staff positions are detailed in the Council's terms of reference, in COPOH's By-Laws, and in the Job Descriptions (1985d). The National Coordinator, for example, assists Executive officers and committee chairpersons to communicate the policy resolutions of the membership to the appropriate federal authorities. The Coordinator is also in direct touch with provincial consumer organizations, and assists them in strengthening their structures and consumer-oriented influences.

COPOH's mandate as a national coalition "of" disabled consumer organizations is clearly articulated: To improve the status of disabled persons through their full participation and integration in Canadian society; to encourage and promote the idea of self-help; to provide a national democratic structure whereby individuals can voice their concerns on issues that affect their lifestyle; to act as a monitoring body; to promote strategies and policies to ensure improvements in the status of disabled persons in the community and at all levels of politics; and, by acting as an educational and motivational force, to create awareness of disabled Canadians' concerns and establish an altogether different image of "ability" in the public mind.

To fulfill its mandate, COPOH's National Council creates various committees (more or less permanent), appoints chairpersons, and approves their action plans (COPOH 1985d: 70-76, 1986: 8-15). The Telecommunications committee, for example, has worked on a number of projects (in cooperation with the federal government's Department of Communications), one of which concerned the implementation of a communications system for COPOH that was designed to improve the communications network linking the national and provincial consumer groups' offices. Modern communications systems encourage information-sharing, and have important and obvious implications for subsequent social policy development (Dobell and Mansbridge 1986: 23). Perhaps more significantly, the committee is engaged in monitoring print, television, and radio media with respect to negative images and stereotypes of disabled people. Other concerns are with the financing of consumer-basd publications, closed captioned television, publicity guidelines for charity telethons, access to government information for the print and hearing impaired, and so on (COPOH 1985c: 5-9).

The Human (and Equality) Rights committee, as another example, has over the years developed a comprehensive and "battle tested" plan of action. This plan includes lobbying for the introduction and passage of human rights laws, evaluating the impact of case law on persons with disabilities, monitoring policies and programs to ensure they are in compliance with laws (such as the Canadian Human Rights Act, or the Charter of Rights and Freedoms), and pursuing legal challenges of disabled persons in the courts (COPOH 1985c: 1-4).

In fact, it is significant that it was through the efforts of COPOH and its committees, including of course the Human Rights committee, that disabled Canadians finally gained legal protection -- through several years of intense lobbying and public demonstrations -- under an amended Human Rights Act (in 1983), and under a new Charter of Rights and Freedoms (in 1982, with the important equality rights section (section 15(1)(2) becoming law in 1985). In advocating human rights, such strategies and tactics as media campaigns, public speaking, rallies, and protests are undertaken by the committee and its supporters.

The Rights committee, following COPOH policy, also liaises with other political and advocacy organizations, such as labor, women's groups, anti-poverty organizations, and a number of ethno-cultural organizations. The Coalition, in fact, established the following resolution as a matter of policy:

> WHEREAS the goals and objectives of the labour movement and the disabled consumer movement in Canada are similar;

> BE IT RESOLVED that COPOH approach the labour movement, the business community and other similar bodies in the general community in order to set up a formal network of cooperation.... (Resolution M 6.81.7, COPOH 1985c: 57).

In the words of Jim Derksen, COPOH's national chairperson in 1986,

> I believe we are at a very important stage in the evolution of our movement in as much as we need to develop new attitudes toward the boundaries of our organization and our activities. Firstly, I believe COPOH should move toward a more open coalition mode, similar to that of the National Action Committee on the Status of Women (NAC) and the Council of Aboriginal Peoples.... Secondly, we should also improve alliances with organizations representing various disadvantaged sectors which have much in common with disabled people in Canada. Such coalition building must be done in a careful and skillful manner to minimize any philosophical, policy, and/or strategic compromises which may be called for, and to maximize advances in the status of disabled persons in this country (COPOH 1986: 2).

Other active committees in COPOH include Transportation Implementation, Parking, Income Security (which includes employment), Housing, and the COPOH/DPI International Coordinating Committee. While accountable to the Council, the latter committee's (ICC) mandate, for example, is to stimulate interest in international disability issues (in Canada and abroad), and to provide leadership to coordinate Canadian efforts internationally in the disability field (in conjunction with such organizations as the National Institute for Medical Rehabilitation, and the Canadian International Development Agency). The committee also makes recommendations to the federal government to take action on international documents (e.g. COPOH 1987e).

The ICC's development education staff officer, for example, helps prepare and coordinate resource material with respect to disability issues in the developing world for ICC representatives (drawn from provincial affiliates). Moreover, COPOH Council and the International Coordinating Committee appoints some of its (that is, ICC's) representatives (taking into consideration regional representation, women, language and various disability categories) who then participate directly in Disabled Peoples' International activities.

As with other consumer organizations such as the Alberta Committee, COPOH does not provide direct hard services itself but works to make certain that information about services, programs, and facilities, as determined and demanded by the disabled community, are provided and made available. By far the most effective means by which COPOH realizes its goals and objectives is through its established committee system, its consultation unit, and its Open Forums (COPOH 1986: 18-19).

COPOH's first Forum was held in Winnipeg in 1978, on the subject of employment. Disabled people affirmed that employment was not only a right, but that working in the community with all other citizens was the best option for them. At the time, some 19 resolutions were passed: These ranged from job training programs, funding for job/business creation programs, contract compliance legislation, provision of work-site aids and equipment, to awareness training for Public Service Commission recruiters. (see COPOH 1985c: 10-18; the issues of employment and human rights protection are taken up in detail in Chapter 7). Subsequent Forums since 1978 have resulted in additional resolutions dealing with employment that, again, have been the bases for strategic action (e.g. protests, media campaigns, monitoring programs). These forums have also helped establish the beginnings of an active two-way process of consultations with federal as well as provincial governments in such matters as employment equity (e.g. Bill C-62), reasonable accommodation, and contract compliance (especially since 1985).

[Despite progress in some areas, it is not rapid enough with respect to certain issues that have been on-going: Concerning employment, for example, a newly formed coalition only peripherally associated with COPOH, called Disabled People for Employment Equity, filed a complaint with the Canadian Human Rights Commission on November 17 1988 against nine major companies, including Canada Post, the CBC, Bell Canada, and the five major banks. The coalition claims that these nine companies hired only 94 disabled individuals out of 13,000 people that were hired in total (Edmonton Journal, November 18, 1988, page A5)].

In any event, one consequence of the developing two-way communication process has been that COPOH has set up what might loosely be termed a consultation unit, that is, a research and consulting team that functions separately from the regular staff, and whose membership and activities may change with the issues (COPOH 1982):

> WHEREAS governmental departments require assistance on the formulation of plans and bills concerning disabled people; and
> WHEREAS these same people have been continually using the expertise of our national organization (COPOH);
> BE IT RESOLVED that COPOH set up a unit of persons separate and apart from the regular staff to be designated as a research and consulting team... (Resolution M 3.85.13, COPOH 1985c: 58).

This group of disabled individuals works closely, on a fee-for-service basis, with those federal government departments, equipment manufacturers, service planners, builders, etc., who require the expertise of COPOH in the formulation and development of plans, bills and devices in such areas as equipment testing, company/business staff training procedures, communication devices, building/structural design, and so forth. Though the unit exists and functions, unfortunately little by way of actual documentation has emerged that describes the consultation process or what specific kinds of consulting has been done to-date (e.g. COPOH 1986: 14-15).

However, as far as the independent living/disabled consumer movement is concerned, consultation is an ever-developing process that need not always involve teams or units as such, though they are valued as a means by which the process is facilitated. Presence on advisory boards, councils, research task forces, and participation in joint committees is recognized as entirely appropriate, indeed necessary, in bringing about a mode of discourse that best mediates between "society" and certain of its members. In fact, the greater the presence and participation of disabled persons (or others, for that matter) in the consultation process, the less need there may be for formal structures of representation.

In 1979, another Forum -- COPOH's second -- on Accessibility of Transportation (Ottawa) that coincided with the Canadian Transportation Commission's public hearings resulted in a number of positive things, for example, a National Policy on Transportation of Disabled Persons (Department of Transportation), and greater accessibility of such carriers as Air Canada, VIA Rail and others. Action on resolutions ranging from tri-level government cost-sharing, liability waivers, employee awareness training, installation and use of wheelchair lifts, power batteries and safety, research and development, and labor union support has been the priority of the Transportation committee.

Rulings in favor of the consumer* against such carriers as VIA Rail and others helped establish a number of key principles in

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* The 1985 Canadian Transport Commission decision in the Clarris Kelly case is regarded by COPOH as a major milestone in its efforts to secure access to transportation. Kelly was initially denied transport by VIA Rail because she was not travelling with an attendant. CTC ruled in her favor (1985b: 7-8, 1986: 10-11). COPOH (1986: 10) reports a Charter of Rights challenge against Air Canada on the issue of self-reliance, i.e. travelling without being

transportation policy for disabled people: Self-Determination, One Person/One Fare (i.e. "no special deals"), Equality of Access and Service, Dignity of Risk, and Dignified Travel. These principles serve as the basis upon which equitable access to transportation through the removal of environmental and attitudinal obstacles can be achieved; disabled travellers recognize neither cost as a justification for not providing access, nor do they consider routine assistance in boarding, moving about and deboarding as an "extraordinary" effort by carrier personnel (when called upon) (COPOH 1985b: 23-30, 81-85, 1985c: 24-38, 1986: 10-11, 18-19).

Other Forums were organized to address such issues as Rehabilitation (Vancouver, 1980), Consumerism (Quebec City, 1981), Income Security and Employment (Edmonton, 1983), and, the last one to-date, Independent Living and Transportation (Montreal, 1985). It was the forum on Rehabilitation in 1980, for example, that resulted in the redefinition of rehabilitation, the formulation of the philosophy of independent living, and the start of the independent living movement (discussed in Chapter 3). The next one will be held in 1989 (theme and location has not been determined at the time of this writing). COPOH has indicated, in agreement with its provincial affiliates, that future Forums are likely to continue to focus on two of the most pressing issues facing the disabled community, that of employment and integrated community living.

It is precisely the issues of employment and integration that are at the heart of independent living: To earn or receive an income in order to exercise one's choice in having one's own accommodation, getting an education, marrying and having children, going to theatres, restaurants and so forth. Put simply, COPOH does not believe that just because disabled people have had medical intervention, or rehabilitation, that it is necessary to persist in

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required to be accompanied by an attendant (see also COPOH 1985c: 26-27).

classifying them in a "health" category when issues of rights or living life to the fullest in the community is concerned.

Summary and Discussion

In moving towards a deeper understanding of the empowerment and community-building process, I would suggest that empowerment involves a transformation (as Freire calls it, rather than stages or steps) that disabled people, individually and collectively, go through. This is their transformation from objects into subjects, and as such is an unending process: The process does not, and will not, stop with independence or community integration, for these are likewise unending states of being. My interpretation is that organizational structures and the means of organizing themselves (such as the Alberta Committee, COPOH and other such structures) enable this transformation process.

My analysis is that the disabled consumer group as profiled by the Alberta Committee and by COPOH: (1) facilitates disabled persons in discovering, formulating, and defining the problem of powerlessness, (2) provides the setting in which alternative explanations regarding the causes and dynamics of powerlessness are generated, (3) facilitates the decision-making process with respect to the identification and removal of obstacles to learning, growth, and participation (including poor self-image, apathy, etc.), (4) facilitates the implementation of individual as well as group action decisions (e.g. from research to protest), and (5) enables individuals to monitor or get feedback of the results of their own actions and the reactions from other parts of the social system.

The purpose of consumer organizations is thus to enable individuals perceive themselves as causal agents in achieving their own solutions to independent living and community integration. They also help them recognize that other disabled and non-disabled persons have useful knowledge and skills as peer-collaborators in the problem-solving/community-building effort. The following are, by way of summary of the profiles of the Alberta Committee and COPOH, a few of the more important "action principles" that guide the operation and organization of disabled consumer groups as empowering settings (adapted from Simpson 1980: 24-32):

1. An open membership is maintained to ensure that all citizens, of whatever disability, and whether disabled or not, can participate in open discussion and open assembly conferences to raise issues and voice their concerns. This is regarded as a basic citizenship right and responsibility.

2. The group endeavors to communicate regularly with its membership, in a variety of ways, taking care to respond to specific needs and communication disabilities. The primary purpose of the group is to coordinate member's views and concerns.

3. The organization is founded on a democratic constitutional basis, operating with reference to clearly outlined job descriptions, in order to motivate members through maximum involvement in all fundamental internal policy decisions, and to encourage individual involvement in related community policy- and decision-making systems.

4. The consumer organization is considered autonomous and operates on the basis of maximum self-help. It is not controlled or influenced by any external force, large or small, other than its membership.

5. General funding is accepted only from philosophically supportive sources, "without strings attached." Few "true" consumer organizations will accept funds from service agencies who have raised their public funds through the traditional charity-sympathy appeals or who otherwise have unacceptable public fund-raising images. By the same token, because consumer monitoring and research efforts benefit the entire community, serving as an

important social feedback mechanism to the public sector, it is considered appropriate to accept "core" government funding where such is openly negotiated for a specific purpose. Consumer groups are non-partisan, however, and are above party politics as a matter of principle, despite government funding.

6. All consumer action projects, whatever their initial goal, attempt to fulfill two additional consumer goals, namely, that of building cross-disability cooperation, experience and trust, and establishing greater public/political credibility for the consumer group as a responsible force serving the whole society, not just the disabled community.

7. Consumer groups, at whatever level of organization (e.g. local, provincial or national), avoid becoming professional or permanent service organizations, or owning a direct service, other than providing information or consumer research data to members, agencies, and the general public. At the same time, groups avoid the image that disabled people want segregated services or special/favorable treatment. Only essential support systems with the necessary and appropriate modifications are requested, preferably provided through regular and established community delivery systems.

8. Internally, staff domination is avoided by ensuring the hired staff are committed to providing a strong information and administrative base. They are to build cooperation and facilitate communication, and do not take sides on internal political issues.

9. Externally, consumer organizations try to develop strong in-depth working relationships with what are considered three "natural" allies of the consumer movement, namely, labor unions, the business community (e.g. Chambers of Commerce), and inter-faith community religious organizations (e.g. the Council of Churches).

10. Consumer organizations try to establish a clear policy understanding, internally and externally, that only they, through their policies and elected representatives, have legitimate authority to be their own spokespersons and negotiators. Organized disabled persons avoid communicating through so-called "handicapped advisory committees" that are appointed by government (or others) to coordinate and represent the views of disabled people. Such is considered a direct contradiction and challenge to the right of people to organize in order to represent themselves. It is more appropriate for a Minister or a department, for example, to invite consumer groups to name their own representatives to a specific, time-limited, study advisory group or council [for example, the MLA/Handicapped Joint Committee in Alberta with which ACDC was involved (1975-1981), the current (Alberta) Premier's Council on the Status of Disabled Persons (Appendix 4, Items 1 and 2), and the (Alberta) Premier's Commission on Future Health Care for Albertans 1989].

Disabled consumer groups, however, are only one of other forms of "strategic" organization, as I will show in Chapter 6, that enable disabled people to empower themselves and to begin the long process of community-building. Consumer organizations such as the Alberta Committee of Disabled Citizens and the Coalition of Provincial Organizations of the Handicapped, as profiled above, have adopted a basic operating philosophy to ensure that the powerlessness experienced by disabled individuals is either reduced or eliminated altogether. Open membership, cross-disability representation, direct participation and so forth as elements of community-building would ensure that at least the opportunities for developing skills and understandings are available.

Indeed, the powerlessness that disabled people (and others who have traditionally been negatively valuated) feel and exhibit is probably due more to power absence rather than to power failure. I would suggest that integral to empowerment as an element of the community-building process is the identification of the power blocks, or power structures, that contribute to this absence. Integral to this process is also the development and implementation of specific strategies aimed at reducing or eliminating the effects of what might be called indirect and direct power blocks.

Indirect power blocks might be those that are incorporated into the developmental and learning experiences of the disabled individual as mediated by those with whom that person is in close contact and with whom he or she interacts (e.g. family members, therapists, doctors, etc.). Thus, negative valuations or stigmas attached to the meaning of disability become incorporated into the person's motivational structure, preventing full development of such personal resources and skills as positive self-concept, cognitive skills, physical and mental competence (at whatever level). I discussed this in an earlier chapter. This lack of development further limits the growth of interpersonal interaction/relational skills, which in turn can affect the performance of valued social and community roles.

On the other hand, direct power blocks might be experienced by disabled people; these are the ones that are "applied" by some agent of society's major social institutions, or they may be inherent in the way community institutions themselves are set up or structured. Thus, a power block exists when, for example, well-intentioned but no longer relevant health care services become an obstacle to the normal development of other aspects of a person's mental and physical well-being. On another level, though an individual may have the personal resources required to use his or her interpersonal and other social/technical skills, blocked educational, employment, and other kinds of opportunities limit or deny that person the right or chance to access or use those resources, to develop them further, or to learn new ones.

Finally, either valued social and community roles themselves are denied or some material resources that are important for the effective performance of social roles are withheld (e.g. adequate income for the performance of the parental role; accessible transportation or worksites to perform as an employee, and so on).

Power blocks on all of these levels have to be recognized, understood, and the capacity for dealing them learned and developed, by the process of empowerment -- at the individual and group levels. In other words, integrated community living requires the dismantling of power blocks on a number of levels. My conclusion is that consumer organizations such as ACDC and COPOH might be considered uniquely set up to initiate this dismantling and rebuilding process.

Whereas I would define powerlessness in the individual as the inability to obtain and utilize social and other valued resources to achieve such personal goals as independent/integrated community living, powerlessness on the group or the comunity level may be defined as the inability to get and use resources to pursue and achieve collective goals (which includes group identity, cohesion, as well as integration). More specifically, however, I would suggest that powerlessness refers to the inability to manage emotions, knowledge, skills, and material resources in ways that make possible the effective performance of valued social and community roles. Part of the process of becoming reconnected to and recontextualized in social life (e.g. validating oneself) involves reclaiming previously denied social and community roles.

Individuals within the disabled population are often prevented from achieving some goal due to power deficiencies that may be a direct or indirect consequence, for example, of a negative group identity, or image. The consequence is indirect when it is related to underdeveloped personal resources and interpersonal/relational skills of individual group members. It is direct, however, when these individuals, as a group, cannot obtain such necessary resources as funding, legal or political sanction, etc., to accomplish their collective goals. Consumer groups like the Alberta Committee and COPOH work to rectify the disabled population's image problem, and try to provide the means of obtaining the necessary resources needed for integrated community living.

It is far from the truth, of course, that all disabled persons are powerless. Despite negative valuations and images, individual (i.e. direct), institutional, and systemic (i.e. indirect) discrimination, many disabled persons are able to obtain and utilize a broad range of personal, interpersonal, and social-technical resources to pursue and achieve their goal of independent living (e.g. with reference to Giddens' dialectic of control). This fact alone brings into focus the whole point of empowerment, which is not to reinforce the stereotyping of a total group on the basis of characteristics of only some of its members, but to clearly expose why power absences occur in the first place and what effects power blocks that derive from discrimination can have on individuals.

The idea of empowerment is a goal for what could be called self-intervention at the individual, group, and community level; as a process, it deals with a very particular kind of power block, namely that imposed by the external society by virtue of a stigmatized collective identity. I would argue that empowerment is, in a sense, a culture/social-specific process, since it assumes the experience of membership in a socially stigmatized category, the experience of non-membership, or exclusion, from community life, and the experience of trying to transform both. Empowerment as a transforming process thus entails developing different kinds of specific support systems and action strategies by those disabled people who have been "blocked" from achieving individual or collective goals because of the complexity and degree of discrimination they have suffered.

The consumer group may help individuals perceive the power structure as multidimensional and multipolar, not as monolithic, thereby indicating that some parts of this structure are indeed "open to influence." This could encourage creative solutions to the problems of independent living and community integration. The over-all goal of this kind of organization, as I understand it, is to enable disabled individuals who have been subjected to systematic and pervasive negative valuations to perceive themselves as causal forces capable of exerting influence in a world of other people, and capable of bringing about some desired effect.

This is not to deny, of course, the power and significance of external forces in creating obstacles, but it does place a greater emphasis on the latent potential in disabled individuals. As I noted before, this emphasis on individuals as causal forces focuses away from the medical model of finding "a cure." The idea of the individual as a causal force instead emphasizes the forces effecting change or solving problems, rather than the inimical forces which contribute to the creation of the situation in which the individual may find him- or herself.

As a final comment, a consumer organization such as the Alberta Committee or COPOH as a cross-disability coalition structure is probably the most effective means of coordinating and structuring relationships for monitoring and influencing public policy. Given the social reform and contentionist goals of the independent living/disabled consumer movement, the consumer organization is a vital tool in the reform process. Reform, of course, is integral to community-building. As Dobell and Mansbridge (1986: 20-22) have noted:

> Impact upon policy development is greatest when these different levels and arms [various kinds of NGOs] form a consensus, coalition, or alliance around specific themes, policies or programs. While most networking and coalitions in the social policy field are formed in response to government agendas and funding decisions, a number of recent liaisons and networks have been forming around non-government agendas. The reason for this is that NGOs are searching for solutions that existing government institutions seem unable to offer.... The most visible linkages between groups and sectors are the established coalitions..... Since most issues and programs in the social policy field involve federal and provincial jurisdictions,

> and can include municipal implementation, coalitions often develop locally and in each province. Alliances and networks are most easily and quickly coordinated at a community level to meet emerging current needs.

Disabled consumer groups as a specific category of non-governmental organization play an important role within the social policy/community-building process. The networks they establish provide important channels for information-sharing and the building up of formal relationships, not only between a number of similar-interest and local/issue groups but also between professional organizations, service organizations, and government-related institutions and agencies. Networking is a rather important means of sharing and relaying information.

Coalitions such as COPOH, on the other hand, serve to structure relationships between different kinds of smaller regional and local organizations that then allows them to work together, yet enables them to develop and operate separately. Self-reliance and autonomy within a formal partnership arrangement is, moreover, demanded, ensuring the integration of micro and macro policy and planning initiatives. In this way, independent local or regional groups provide valuable data and program/service evaluations about unmet needs that need to be embodied in macro policy formulation. Since it is acknowledged that no service, program, or policy evaluation is value neutral, the independence with which this "social reporting" is conducted is a significant feature of this process.

Chapter 6

New Solutions and Innovations for Empowerment and Community-Building

In reference to the work of Carl Rogers, I noted in an earlier chapter that one of the assumptions of the process of self-actualization is that people know best what their needs and wants are, and what is in their best interest. As well, individual behavior is said to be motivated by a need to mature, gain competence, have some degree of autonomy, in other words, to fully realize one's growth and learning potential. Freire calls this our ontological vocation. According to Rogers, any less-than healthy functioning of individuals is a direct consequence of their social environment. Behavior that is not self-actualizing is, from this perspective, a result of constraining and inhibiting social practices, interactions, and structures. Unfortunately, Rogers' account does not seem to take into consideration the possibility that self-actualization can be achieved by, or is an integral part of, an intentional and conscious (re)structuring of one's own social environment apart from intervention by experts.

The principal shortcoming of Rogers' theory that struck me was that the social environment is separated from people, that is, people are seen as somehow separate from the structures within which they interact; they have little or no influence on them, or are always interacting in situations that are structured by others, never themselves. By contrast, what I find especially appealing about Giddens' (1984) approach to action (structuration) is that it accounts for the possibility that individuals can participate directly in the structuring of their own interactions. Not only are structures, that is, social (and community) environments, the outcome of patterned and reciprocal interactions between people, but they are the intentional and directly motivated outcomes of purposive and conscious actions.

The idea of self-actualization as originally conceived by the likes of Rogers would be incomplete, I think, if it did not include a view of social structures, and indeed of society, as constituted by and contingent on the actions of knowledgeable agents. From Giddens' theoretical perspective, the ability to transform the less-than ideal social environments and interactional settings that foster maladaptive and dependent behavior is entirely within the power of those affected by them once individuals have come to understand how and why certain interactions, structures, and institutions prevent self-actualization. Indeed, I have argued throughout this study that empowerment is best conceived as a learning and structuring process at the level of personal, organizational, and community interaction. I do not think that the alternative and innovative organizational structures developed by action-oriented disabled people in the context of their movement would make sense without a much more dynamic view of the relationship between structure and individual action. That innovative organizational structures are being developed at all is proof that the constraining nature of existing imposed structures is indeed recognized by disabled people, and that they understand the reciprocal relationship between self-actualization/self-determination and enabling structures.

The consumer coalition structure with its research/monitoring organizations that I discussed in Chapter 5 is by no means the only structural context through which disabled persons can empower themselves to achieve independent living. Consumer groups are not the only possible mediating structures situated between the segregated rehabilitation world and integrated community living, as I want to show in this chapter. As one node in the network, it is the consumer organization that is instrumental in focusing, translating, and communicating the needs of disabled consumers in a language that is comprehensible to both the wider disabled and non-disabled communities. The disabled consumer organization is first and foremost a vehicle for consumer and public education and lobbying, and a means of evaluating and monitoring existing legislation, policies, programs, and services. By providing in part an organizational setting in which the evaluation and reflexive monitoring process can take place, a consumer group such as the Alberta Committee tries to provide education, encourages the establishment of support networks, gathers information, diagnoses consumer needs, and engages in action planning. It also attempts to integrate and diffuse the results of its activities within the over-all coalition structure or network, out to disabled individuals generally, and out to the community in particular.

In this chapter I want to go beyond the consumer organization to discuss the other kinds of innovative structures that disabled consumers have built that enable them to pursue the goal of independent and integrated community living. Organized according to the principles of independent living, the purpose of these structural innovations is to provide viable and workable alternatives to existing agency arrangements and/or service approaches. In the instance of independent service brokerage, for example, an entirely new consumer empowering solution may be initiated. Because of the radical nature of the shift in philosophy and approach that service brokerage represents, there is concern that traditional agencies, services, and government policies have no way of assessing the approach's value or effectiveness (Marlett 1988: 42-43). The consequence is that public support and legitimacy as well as government funding may not be granted for initiatives that might be "too new." While it is important to innovate, innovation may nevertheless be constrained. The limiting power of existing social and community structures cannot, therefore, be under-estimated.

In the context of my discussion of empowerment and community-building, however, the significance of these initiatives rests largely with their meaning. These new structures redefine ways in which people interact with one another; in fact, the very basis of their interaction represents a significant departure from what is expected of members of a stigmatized minority. Contrary to the expectations set up by the medical model, disabled individuals are not incapable of critical reflective rationality, are not dependent, are not unable to form and articulate their own beliefs and desires. Nor are they unable to act with others in a common world. Disabled people as persons are indeed "self-legislatively, self-defining creatures" and so, within limits, are fully capable of defining and shaping their own lives (Rorty 1987).

The notion of personhood implicit in the definition of self-actualization or self-determination is a significant one: The imposition of handicap or any social designation, whether physical, mental, gender, age-based, or whatever, reflects a lack of agreement over and denial of some fundamental presuppositions of personhood. Presuppositions or conditions for what would constitute a "person" would include a capacity for reflective rationality, autonomy, decision-making, forming beliefs, entering into mutually affective relationships, and so on (Rorty 1987, passim). Thus, the creation, structuring, and organization of new ways of interacting involves both asserting the positive aspects of the presuppositions that constitute personhood, and showing that the negative ones are unfounded or illegitimate. By developing structures that form the context of their social and political reproduction, disabled people prove participatory competence, responsibility, autonomy, creativity, and world-making. In short, they demonstrate a full capacity for independence and integration.

"Taking Charge": Experiments and Innovations in Independence

I think it is worth reiterating that a number of related factors have contributed to the development of the independent living model and to the articulation of an independent living philosophy. First of all, there has been an increasing disillusionment and growing impatience with the expansion of the so-called (medical) service model over the past two decades, particularly with respect to the rising costs of services, increased professional control, and impenetrable bureaucratic structures. Second, there has occurred a steady demedicalization of disability, that is, a shift from a strictly medical approach to more of a political economy critique of disability as a social phenomenon.

Significantly, these two developments have also been accompanied by an extremely strong opposition to institutionalization. Although the movement of people from institutions back to the community is neither systematic nor wide-spread in Canada, most would agree that institutionalization represents loss of self-determination and isolation from the rest of society. The dehumanizing consequences that this brings are no longer tolerated; furthermore, institutionalization or hospitalization has seriously been likened to "arbitrary detention or imprisonment" viz section 9 of the Charter of Rights (COPOH 1985a: 9, op. cit. Just Cause 1983/84: 7; see also COPOH 1985c: 47, 49 for Resolutions IL 3.85.11 and 3.85.18 and 3.85.19 concerning the deinstitutionalization of disabled people). In particular,

> Institutionalization dehumanizes because personal liberty and self-determination are exchanged for the care that is received and the institutionalized person is isolated from mainstream society.... Despite these negative characteristics, a large number of citizens with disabilities in Canada live segregated from the community in institutions, not by choice but because of the paucity of community supports (COPOH 1987d: 41, emphasis added).

Rejection of the service model and forced institutional living (itself a service delivery mechanism) has thus encouraged the disabled community to stress the principle (or process) of what is called normalization, that is, the emphasis on the value of people with disabilities able to have ordinary life experiences, and the focus of attention on the ways that language, images, and programs can enhance autonomy or, likewise, maintain people in dependent social roles. Proponents of normalization thus strongly support both community integration and the exposure of people with disabilities to culturally and normatively valued experiences "in order to establish and/or maintain personal behaviors and characteristics which are as culturally [and socially] normative as possible" (Wolfensberger 1973, Brown 1977: 456-459, Kallen 1989: 159-166).

Rather than segregating individuals in residential institutions or placing them in specialized service care in attempts to make them "normal," efforts are instead focused on bringing these individuals into lifestyles and conditions that are as close as possible to typical, or normal, living patterns (taking into consideration, of course, their age, the nature of their impairments, and so on). Following deinstitutionalization, this means re-integrating the disabled individual into as many facets of family and/or community life as possible. What this process does not try to do is make that person "normal" in any physical or mental sense (normalization is often misinterpreted as precisely this; see Kallen 1989: 164-165). Reintegration into family and community life is key, because

> Deinstitutionalization [alone] does not address the question of individual empowerment. Peer counselling, advocacy and information and referral are not components of deinstitutionalization. Deinstitutionalization does not address direct consumer control or the involvement of disabled people in service delivery (COPOH 1987d: 41).

Together with self-help, consumerism, the push for deinstitutionalization, and the idea of normalization, the over-all concept or philosophy of independent living has therefore generated a number of strategies for community-building, that is, for revitalizing and re-establishing links between disabled individuals and various generic education, employment, transportation, housing, recreation, and other services. The most viable alternative to institutionalization (as a service delivery mechanism) that has been developed is the so-called independent living service delivery model. This model has two components, namely IL programs and IL centres (Alberta Committee 1987d, 1987e, Coxon 1981, Lord and Osborne-

Way 1987). Most broadly defined, independent living programs are those that improve the life conditions of disabled persons by providing them with the ability and means to make their own decisions and to be self-sufficient. These are the tangible programs and support services often available through IL centres. These support programs and services are developed according to the underlying ideas that the focus of the services is on environmental changes (ecological intervention), and that the disabled person know his or her own needs best.

Independent living programs include residential, transitional and service provider programs. These would involve the further development of very specific or individualized services (e.g. through individual program planning, or IPP) such as live-in personal attendant care, daily living skills training, physical environment modification and/or adaptive/technical aides, mobility training, social and other functional skills development, time management, sexuality, family support counselling, and so forth. The idea is that specific needs are not only determined by the disabled person him- or herself, but are also met either by themselves or by their peers (for example, through peer counselling, by selecting, hiring, training their own personal support attendants, or by directly negotiating with their own physicians, therapists, counsellors, or other hard service providers). Flexibility, availability, and variety are the key to successful programs. While the services provided by a community/independent living program may vary considerably from community to community depending on the needs of the disabled individuals living there, the overall goal of most IL programs is to ensure the maximum independence and participation of disabled persons in their own affairs.

To this end, IL programs are based on a number of implicit operating principles which are called community living principles (Alberta Committee 1987e: 13): First, services are designed according to specific individual needs, choices, strengths, and, to be realistic, with available and appropriate resources in mind. In other words, the right service mix for the individual is sought. Second, services are always flexible and responsive to the changing needs of the individual. Here, the focus is also on choice -- the decisions that are made and the actions taken should be directed by the individual him- or herself, with full knowledge of the possibilities and information necessary to make an informed choice. Third, the disabled person should be able to have a personal network of committed individuals (e.g. family, guardian, friends) that can assist in program and service decision-making, and who could challenge decisions made by others that might adversely affect the disabled person. This means, too, that the disabled individual's personal network must have access to that person's service system.

Fourth, and finally, there has to be what is called a "fixed point of responsibility," that is, a single group of people, or a sole individual to whom the disabled person can go to get assistance in coordinating required services. The responsible group or individual develops and helps maintain program linkages and ensures the continuity of care from all involved service providers. Coordination is of course the key, since it is the gaps in services primarily due to the lack of coordination that can translate into tragedies.

Over-all program and service coordination and delivery, reflective of these four operating principles, is achieved through a number of different mechanisms, which can be organized or actually provided through what is called an Independent Living Centre. It is to a description of independent living centres and their various service delivery mechanisms and associated mediating structures that I now turn to first.

Independent Living Centres

The following is a comprehensive definition of the term "independent living centre" that has been adopted by the independent living/disabled consumer movement:

> An independent living centre promotes and enables the progressive process of disabled citizens taking responsibilities for the development and management of personal and community resources. A centre, while reflecting each community's unique character will be: consumer controlled, community based (local ownership), cross-disability, non-profit, advocates of independent living, promoters of integration and full participation (via use of existing services). Essential program components are information and referral, advocacy, peer counselling, service development capacity (via research and planning, demonstration programs, service delivery and coordination, service networking, consumer monitoring), and including such direct services as housing assistance, attendant care, transportation, vacation relief, and technical aid loans (COPOH 1985a: 3-4, 1987d: 92-93, see also COPOH 1985c: 45-49, specifically Resolutions IL 6.81.2, and IL 3.85.7).

Independent living centres are of crucial importance to the independent living service delivery model because it is they that facilitate the effective operation of the various programs (such as those noted above). They form the bridge, or focal point, between the independent living/consumer movement and the new service delivery model that the movement has inspired and created. The IL centre is a transition between rehabilitation and integration into the community where, increasingly, the growth of generic services is stimulated and thus utilized. Without the IL centre the other cluster of independent living programs and soft services such as peer counselling, individual advocacy, information and referral, personal support services, and so forth, would be difficult if not impossible to put into practice. Significantly, although an independent living centre provides services it is also an extension of the self-help ideal of the independent living movement in that the centre is governed and controlled by disabled people themselves; ILC's represent a "bottom up" rather than a "top down" approach.

The unique aspect of independent living centres is not just the individual services it provides, but the delivery approach which is flexible and open to new ideas as the needs of individuals are identified. An ILC is open to persons with any type of disability, and its staff will deal with any area of concern, such as housing, transportation, employment, sexuality, and access to available social services. The centre seeks to fill gaps in service that are identified by disabled consumers by implementing pilot projects which can then (ideally) be continued by other, more appropriate, organizations or individuals. Thus, a centre acts largely as a distributor of information about services offered by other social agencies, while providing only a limited number of direct soft services itself. These services are provided by volunteer participants interested in the self-help approach, by the coordination of cross-disability information, by facilitating access to services that already exist in the community, and by stimulating the development of new ones. This latter point is important, since the ultimate goal of independent living is community integration, not the creation of separate services that would further isolate disabled people.

Examples of proto-types, or fore-runners, of the larger and more well-known independent living centres (three of which are described below) include the Disabled Living Resource Centre (opened in 1980 in Vancouver), Ten Ten Sinclair (Winnipeg), the Community Enrichment Project (started in 1975 in Edmonton by the Alberta Rehabilitation Council for the Disabled, and since 1980 based at Grant MacEwan Community College), and the Residential Aide Programme (likewise based at Grant MacEwan Community College). These centres range from being "a one-stop shopping centre for visual and specific information," an apartment complex for tenants exhibiting varying degrees of disability (severe to non-disabled), to college-based and taught daily living skills courses involving nutrition, money management, apartment management, personal care attendant training, and so on.

These various initiatives, however, while certainly responsive to some local needs, were largely developed by outside agencies and not at all through consumer action. Not all of them are or were managed or controlled by disabled people themselves (though disabled people are involved, for example, as instructors), nor are they organized or implemented according to the four community living principles described above (Lord and Osborne-Way 1987: passim). Despite all good intentions, these so-called proto-types remained accessible to only a small segment of the disabled community, and the different programs and services were not coordinated in any significant way. The development of centres owned and operated (though not necessarily founded) by persons with disabilities who are aware of local community needs and the extent of available community services is the logical next step.

The first "real" independent living centre (and thus the "oldest" in Canada) was started in 1982 in the twin cities of Kitchener-Waterloo, Ontario. This ILC was conceived and funded by the Mennonite Central Committee in response to the International Year for the Disabled (1981). The ILC board of directors is made up of both disabled and non-disabled persons, with broad representation from the Mennonite community (Lord and Osborne-Way 1987: 10-11, COPOH 1987d: 71-72). The MCC constitution apparently continues to guide the Kitchener IL centre structure, though over the years plans have been underway to make the centre more autonomous. At the present time the IL centre consists of a ten unit integrated apartment project, a downtown resource centre and office, and eight community-based locations where satellite or outreach support systems (since 1985) are provided to the area's 260,000 people. Current staff includes a director, three program coordinators, and several administrative assistants.

The independent living centre's major initiative during its first three years of operations was an apartment project with in-house attendants, with funding obtained from such sources as the MCC, the Ontario government, federal grants, donations, and so on.

Information and referral capabilities, a peer support program, individual advocacy, and consultations in housing design were subsequently developed. Since mid-1985, however, peer support, advocacy, and consultations (considered core functions at other centres) have not been official programs of the Centre.

In 1984 Winnipeg's Independent Living Resource Centre (ILRC) grew out of a joint initiative involving the Handicap Concerns Program of the city's Mennonite Central Committee and the Manitoba League of the Physically Handicapped. It was called a resource centre for the reason that it would not be confused with a residential independent living program. The primary goal of this ILC was the establishment of information and referral services, an advocacy support program (handling things like employment problems, disability insurance questions, home-care complaints, etc.), an attendant care support service, and something called vacation relief (the provision of attendant care services for disabled persons while on vacation, or while primary care givers such as family members or full-time attendants are away). Since 1984 Winnipeg's ILR centre established further projects and services, such as a Peer Counselling Training and Support programme (the only Canadian centre to have one), a self-managed attendant care training program, independent living skills training seminars, a registry of accessible housing and apartments, a leisure education demonstration project, and sponsorship of a technical aids and equipment display centre (COPOH 1987d: 75-78, Lord and Osborne-Way 1987: 12).

Funding by way of operating grants for these various consumer-initiated and controlled projects that are part of Winnipeg's ILR centre has come largely from both private (e.g. United Way) and public sectors (e.g. Health and Welfare Canada, Canada Works, Secretary of State). Consumer control is emphasized here, as the ILR centre is staffed by disabled individuals (a managing director, program coordinators, administrative personnel, researchers, and volunteers); as well, the majority of ILR centre's board and its several program advisory committees are made up of disabled consumers, as outlined in the centre's by-laws. Cross-disability consumer representation and involvement is also sought.

After some three years of prepatory work the Calgary Association for Independent Living (CAIL) finally opened its doors to the community in 1984. As in the case of the other independent living centre's, CAIL grew out of an active national and provincial consumer movement, but also received early support from the Mennonite Central Committee. Part of the Walter Dinsdale Centre for the Empowerment of Canadians with Disabilities (a.k.a. the Dinsdale Disability Information Service Centre), CAIL subsequently developed strong links with the University of Calgary (e.g. the University's Rehabilitation Studies and Social Work programs). During the first year of operations the Calgary centre chose to concentrate mainly on education, that is, information and referral. This is of course a function other ILC's focused on early in their developmental history, since an essential first step is the coordination of information of available community services and programs for those disabled people who need it. By 1986 CAIL had fully developed its referral capacity, a year-round vacation relief program, as well as advocacy and various support and self-help functions. Importantly, all board members of the Calgary Association are persons with disabilities; however, open board meetings and an annual general meeting may be attended by both disabled and non-disabled consumers and citizens.

CAIL has led the independent living/disabled consumer movement in developing innovations in individualized services. For example, CAIL, with the University of Calgary, developed the DIBS line (Disability Information Brokerage System), which is a computer accessed data base containing extensive listings of services for disabled people. Three kinds of registries are provided on this data base: Service, Attendant Care, and Job. The DIBS line allows people with all kinds of disabilities to choose what is appropriate to them, according to their own particular service, personal one-on-one care, and employment or work needs. Other important innovations that clearly distinguish the Calgary centre from other independent living centres is the establishment of Service Brokerage, and what is called the Joshua Committee.

Service brokerage and Joshua committees as structural/community service development innovations are unique enough to merit description later in this chapter. Both of these promote the principles of independent living, and provide empowering alternatives to traditional services. For one thing, they ensure that disabled consumers have both direct access to funding and have the ability to choose the support services they want, not necessarily the traditional services that agencies or government feel are appropriate. Moreover, it is the disabled consumer him- or herself that secures and purchases the services, allocates his or her own resources, and who is directly accountable for any funding assistance received. This represents a significant departure from the traditional "balance of power" between professionals, agencies, and the client. As MacLean et. al. (1987b: 5) have summed it up,

> Are we also intimidated by the professional monopoly -- an entrenched labour force created to operate human services under the societal assumption that the disadvantaged groups require servicing? Independent Living challenges the traditional power balance, in that it asserts that disabled persons best know their own needs. This does not mean that there is no role for professionals and social welfare officials, but that current roles would be realigned in a partnership.

The Formation, Organization, and Structure of IL Centres

The independent living centre as a service delivery model and a means of community-building are clearly a necessary development of the independent living/disabled consumer movement. An important feature that distinguishes the independent living approach with respect to the core functions of independent living centres such as those just described is the clear separation of hard service provision, and individual or collective advocacy (soft services). Such organizations as the Coalition of Provincial Organizations of the Handicapped and the Canadian Association for Independent Living (CAILC) have taken the position that service agencies cannot be free of their own service objectives. In order for any consumer organization (including an IL centre) to be an effective voice of disabled citizens, it must be free from the vested interests of service provision:

> Disabled consumers have determined that service delivery is not an appropriate role for the consumer movement. The consumer movement has been mandated to monitor service provision, not engage in it. If an organization is providing a service it cannot effectively monitor that same service. A conflict of interest arises (COPOH 1987d: 33, see also COPOH 1985c: 45, Resolution IL 6.81.2).

The emphasis, again, is on stimulating and encouraging the development of generic community services and programs, and on avoiding situations where the drive for innovation, flexibility, and change may be compromised. Independent living centres obviously serve a unique purpose in the community-building process, and so should be more than just another form of service organization or agency.

Several key common and inter-related elements can be identified in the historical development of independent living centres. They include: Leadership from and cooperation between disabled and non-disabled people, sensitivity to, awareness of, and direct response to local and community needs, and support and backing (legitimacy) from the community as a whole. From the information available about the founding and establishment of independent living centres, especially those described above, it is evident that a core group of disabled individuals provided the initial impetus. In point of fact, much of the leadership and vision for the actual development of the first centres came from Henry Enns of Winnipeg, himself disabled. Mr. Enns was both consultant to the Mennonite Central Committees of Kitchener and Winnipeg, and acting director of both the Kitchener-Waterloo centre and Winnipeg's ILRC (Lord and Osborne-Way 1987: 17; as an interesting side note, Mr. Enns is (1988-1989) Disabled Peoples' International's chairperson).

In Kitchener, Winnipeg, and in Calgary core groups came from the indep-endent living/disabled consumer movement to staff the emerging centres (e.g. Kitchener's Action League of Physically Handicapped Adults, Winnipeg's Manitoba League of the Physically Handicapped, and Calgary's Action Group). From the point of view of empowerment, leadership plays a critical role in articulating vision and commitment, demonstrating the competence of disabled people, and in ensuring that the consumer perspective does not become lost in the shuffle.

As I have stressed in earlier chapters, the process of empowerment is best facilitated by disabled people themselves. Of course, this is not to say that non-disabled people have not been intimately involved in this process. Only at CAIL, however, have non-disabled persons never served as board members, though they provide support in technical, service, research, informational, and "political" areas. Consumer direction and control is of course important, but the independent living/disabled consumer movement also recognizes the critical support and collaboration provided by the non-disabled, and the importance of establishing legitimizing links with the wider community (especially with established community organizations). Writes Jim Derksen (1980: 16-17),

> It is important, in my view, that disabled consumers recognize society at large and the able-bodied people in it have interests in common with disabled consumers; that

> in a sense all of society consumes or is impacted upon by the way services are provided for disabled people....
> This means that the membership requirements of disabled consumer organizations will in many cases need to be modified so as to allow participation by able-bodied people.....

As well, collaboration with select community groups such as regional planning councils, human service agencies of all kinds, clubs, and even neighborhoods is an effective (and necessary) way of gaining public end-orsement of the independent living philosophy and acceptance of disabled people as fellow citizens.

Data suggest, nevertheless, that despite some community support, it has not been smooth sailing for the independent living centres within their respective communities (Lord and Osborne-Way 1987: 20, cf. Kallen 1989: 163-164). They have often been criticized as "inappropriate, unnecessary and irrelevant" by municipal planning councils and traditional human service organizations, but, as disabled consumers have remarked, conflict is inevitable and legitimacy is achieved only with persistent effort and work (a function of time and communication). In fact, it is as much a question of effort and sheer presence in the community as it is of dealing with different perceptions (sometimes negative) of the centres. As with the early stages of any organizational innovation -- considering how innovative the centres are -- reactions of uncertainty and skepticism as to purpose and role are bound to occur.

To overcome these uncertainties, to establish the centres' legitimacy, and to act as mediating structures between disabled people's (former) segregated lifestyles and a participating community lifestyle, systematic ways of supporting individuals to being part of the community have to be developed. This is why links with community groups and associations that serve all citizens must be forged, and why image is important. IL centres cannot be islands unto themselves; just as with disabled consumer organizations such as the Alberta Committee, a correct balance between independence and cooperation, and thus interdependence, is sought.

The way independent living centres themselves are organized and managed is also significant because of the fact that centres are part of a movement that itself places a high value on process. The organizational structures of ILC's are thus expected to be consistent with the philosophy and goals of independent living, though there may be "stylistic" differences between structures and management. These differences simply attest to the unique influence of the respective communities, and the flexibility with which centres have responded to the needs and idiosyncracies of their settings. No style or method of operating is said to be better than another; they are simply different. In terms of organizational style, the Calgary and Kitchener-Waterloo centres are virtually opposite one another with respect to their degree of structure (Lord and Osborne-Way 1987: passim).

In Calgary (CAIL), for example, the word "association" is used rather than "centre" (I will continue to refer to CAIL as a centre in this study, however), and the title of director is not used at all. This is apparently consistent with the group's desire to avoid language and behavior that infers bureaucracy, hierarchy, or formality. In this way, CAIL tries to communicate its desire to be an association of people, rather than a place denoted by the term centre. CAIL's spokespersons refer to this kind of structure as "organic," that is, as horizontal rather than vertical, and as open (Lord and Osborne-Way 1987: 62, 64). The strengths of such a structure, according to CAIL participants, are that CAIL can be responsive and flexible to emerging individual and community needs. The acknowledged weaknesses of such a loose structure, however, include some disorganization, and the possibility that other groups may perceive CAIL as not having clearly defined goals or a clear focus.

By contrast, the Kitchener-Waterloo independent living centre has developed the greatest degree of structure (Lord and Osborne-Way

1987: 64). Characterized by clear, formalized positions and lines of authority, the staff include an executive director, administrative assistant, several key project coordinators, and a full-time bookkeeper. There are bi-weekly staff meetings, and the coordinators are required to submit written reports to the director; in addition, the administrative assistant attends and takes minutes at all staff, board, and committee meetings. Again to contrast, staff at the Calgary centre are responsible for job areas that necessarily overlap (such as information and education, brokerage, peer support, etc.), rather than for specific positions or roles; at the same time each person can also be a member of one of several advisory committees. There is nothing to suggest that such differences in approach as these reduce the over-all effectiveness of the centre's core functions.

The organization and management of independent living centres also involves the interplay between each centre's staff and its board, especially with regards to planning and decision-making. Ideas for new initiatives and approaches usually come from the experience of working directly with disabled people in the community, and so are brought to the attention of the centre's board of directors by the staff. Details of new initiatives are normally examined by a program committee which subsequently seeks board input as potential projects get closer to implementation. Decisions relating to the allocation of resources that pertain to projects are usually made by the board or one of its sub-committees (Lord and Osborne-Way 1987: 65-66). In order for this decision-making format to work effectively, lines of communication must exist and be maintained between those individuals that consume the services, front line staff, and those who are responsible for planning and administration (i.e. board members). Of course, this is much easier said than done:

> Our Committee has not had a whole lot of time to look at the future.... There seems to be an overwhelming response from the community right now..... Our Centre is still evolving... Opportunities for Centre staff to share

> their learnings and experience with board members is an important part of decision-making..... (Lord and Osborne-Way 1987: 65-66).

A means of communicating feedback to those responsible for organizing and coordinating programs are clearly important for the recipients of services, and for ensuring that program or service strengths are enhanced and that weaknesses can be identified and remedied. Interestingly, part of the solution to communication difficulties is in ensuring that board members are in fact disabled consumers; presumably, being able to share experiences facilitates understanding what other disabled persons want or need.

Planning and decision-making therefore depend a great deal on sharing and communicating information at all levels of a centre's structure; staff will attend board meetings (Calgary), or they can meet on a regular basis with the centre's director who then takes information to the board (Kitchener and Winnipeg). Still, data suggest that boards and staff at these IL centres are concerned about the lack of effective planning and the need for long-range planning. There is concern that much of the activity of the centres has been reactive rather than proactive, particularly with regards to the role of the independent living centre in the community-building process (Lord and Osborne-Way 1987: 19-21). Among the issues that are related to planning and decision-making are the degree to which IL centres can best serve cross-disability populations, how the more severely disabled and physically isolated can be reached, and whether the growing population of elderly people, for example, should be made a target for IL centre (and indeed, consumer) activity.

Perhaps a function of the continuing evolution and development of these not yet fully "mature" organizations, there has been a questionning of the relationship between the centres and existing service agencies with respect to the centre's ability to stimulate or encourage consumer direction and individualization (of services) beyond their front doors. Some staff and board members perceive a danger in slipping into a social work mentality in the advocacy role or becoming human service bureaucracies, and in losing consumer and grassroots control when generic services take over (as inevitably they must). Concerning the latter point, the difficulty lies in the fact that outside the centre, in the community, consumer direction and control may become lost.

Long-range planning must therefore of necessity include the training of competent disabled people who can monitor generic service delivery and reach "back" to the independent living centre from the community, and it must include educating the public. Independent living centres thus face the additional challenge of impacting on the consciousness of the larger community. A formidable task, this probably cannot be achieved outside the context of the cross-disability coalition structure or network of consumer organizations that I discussed in the last chapter.

Independent Living Centres as a Social Innovation

For developing and emerging IL centres, it is important to focus on their planned functions, services, and approaches that are consistent with the independent living philosophy, with the community context in which the centres are located, and with a coalition structure that happens to be in place or that is itself developing. My interpretation is that it is the interplay of philosophy, context, and structure that helps create the necessary environment in which further individual and collective empowerment can take place. At the same time, it should be recognized that the independent living centres are themselves an initial outcome of the empowerment process, as well as a further means of empowering people. Of course, the IL centre is in reality only one vehicle of several for enhancing the quality of life of disabled people (and by extension, everyone's).

The on-going development of IL centres clearly represents an innovation in the community-building process. In order for innovative concepts and practices to be adopted, they must be understood and accepted by potential adopters -- for disabled as well as non-disabled people. Effective communication is therefore key to the subsequent diffusion of the independent living concept and model that underlies this particular innovation. While written and published materials will help disseminate knowledge of both the IL concept and the idea of "centre," innovations are evaluated not only on the basis of research but through the subjective evaluations of peers who have adopted the innovation. Face-to-face dialogue between disabled people and supportive individuals, including those from other agencies, serves to expand the understanding and acceptance of both the concept and the practice, and give them legitimacy in the larger community.

Yet, acceptance of any innovation (technical or social) involves more than just effective communication. Potential adopters must also see a relative advantage to the concept, and they must feel that it is compatible with their own values and approaches. In addition, acceptance of innovative ideas in the general community takes time and usually requires some sort of trial period during which time people can observe and reflect on the process "in action" and the results. This is necessarily part of any learning process. An important implication for the establishment of new independent living centres is that they might consider starting with a small number of program and service initiatives, to gradually add others as the ideas become generally more accepted. This of course requires some planning, as well as a more proactive approach to individual and community needs.

As with all social and/or technical innovations, changes will occur as those individuals involved in the emerging independent living centres continue to experiment with the concepts and the principles. Disabled consumers stress, however, that the idea of independent living itself is not sufficient, but that compliance with the principles and functions of independent living (cross-disability, consumer control, promotion of integration, and community-based) are of greater importance and consequence. The point is that while innovation is a constructive on-going process, there is always the danger that people trying to adopt new ideas might lose sight of the original vision.

Thus, the Canadian Association of Independent Living Centres (CAILC) was established at the 1985 COPOH national conference in Montreal to monitor the IL philosophy and practice, so as to ensure the effectiveness and integrity of programs, services, and the centres themselves across the country (COPOH 1985c: 47, Resolution IL 3.85.12):

> Prior to the 1985 COPOH conference, representatives from independent living centres across Canada held a national symposium which launched the Canadian Association of Independent Living Centres, a national coordinating body for centres. This organization was officially recognized and endorsed by delegates to the COPOH conference in Montreal (COPOH 1987d: 49).

CAILC did not hold its first annual meeting until March 1988, however. Primarily a consumer directed organization, the Association was formed to act as a kind of national coordinating body that would create and develop coherent over-all guidelines for policy planning, strategic development of core functions, and for achieving consensus over definitions and goals as additional independent living centres are created across the country. Existing centres apparently see themselves in a positive light in relation to the guidelines established by CAILC (Lord and Osborne-Way 1987: 80).

According to CAILC, however, no single centre has yet achieved status as a full independent living centre according to the essential program components (e.g. information and referral, peer counselling, advocacy, research and planning, demonstration programs, service delivery coordination, and service/consumer networking in such areas as housing assistance, attendant care, transportation, vacation relief, technical aid loans). Lack of uniformity or consensus between centres, and thus the "tension" between independent living/disabled consumer movement goals and the need to innovate, is clearly attributed to the complexities of local situations and the need to be wholly responsive to the needs of local disabled consumers.

The Canadian Association of Independent Living Centres nevertheless envisions a clearly defined role for independent living centres, both with respect to their functions and their relationship to the independent living/disabled consumer movement <u>and</u> consumer organizations (Lord and Osborne-Way 1987: passim). Consumer organizations, like the Alberta Committee of Disabled Citizens, COPOH, or those which provided the initial impetus for the development of IL centres (e.g. Calgary's Action Group or Kitchener's Action League), have important advocacy and monitoring roles with government and community. As COPOH has argued on all of these points,

> In Canada the consumer movement has consistently maintained that a distinction must be maintained between monitoring organizations and those which provide services. Canadian consumers insist that COPOH should retain its role as an independent monitorer of all services affecting disabled citizens including independent living centres.... In Canada, the consumer movement engages in group advocacy and centres concentrate on individual advocacy (COPOH 1987d: 49).

Thus, both CAILC and the Coalition of Provincial Organizations of the Handicapped have insisted that IL centres focus their advocacy efforts on individuals, leaving broader monitoring and advocacy efforts to the consumer groups. CAILC and COPOH have suggested that the two approaches are complementary (crucial for empowerment), but they caution that groups and centres must not attempt to define the same activity as their own lest there develop a conflict of interest between them (COPOH 1985a: 14-15, Lord and Osborne-Way 1987: 22-23, 37-38). CAILC and COPOH maintain that the independent living/disabled consumer movement does not have the resources to advocate on behalf of individuals.

Individualized advocacy is probably a logical and natural extension of the individualized support services that IL centres provide, but potential conflict of interest with consumer action groups that are also part of the larger disabled consumer coalition structure arises when, for example, funding for core service functions is sought. Private and public sector funding is available for programs and services that reach the largest number of people, but not for individuals with their own individualized mixed services requirements. Since it is the programs that get the dollars, it is then up to individuals to figure out how to get services from them.

Because the idea of direct and individualized funding (called individualized dollars) is still a relatively new one in most provinces, IL centres are obliged to pursue program dollars, that is, block funding (Alberta Committee 1987e: Appendix B, Attendant Care Action Coalition 1986: 6-9). In some cases this has meant that IL centre staff and boards of directors have had to deal with both government and service providers "on behalf" of disabled people as a category of individual, something that is obviously antithetical to the independent living model and the IL philosophy. On a positive note, this situation encouraged the development of a constellation of unique service delivery/personal empowerment mechanisms (unified under one model) at one independent living centre in particular (CAIL) that made possible customized or personalized (direct) funding and services.

The Idea of Supported Independence

Perhaps the most interesting and most significant cluster of interrelated innovations that provide empowering alternatives to traditional services available to disabled people are those that have been developed by the Calgary Association for Independent Living. The Association has developed what it calls the supported independence (SI) model, that is, a self-help model that combines the idea of ecological intervention with the principles of the independent living movement (Marlett and MacLean 1987, 1988, MacLean, et. al. 1987a, Marlett 1988: 28 ff).

The independent living approach to community integration, as I outlined earlier in this chapter, stresses consumer control and choice. The individual, no matter how disabled, is assumed to know best his or her own needs (that is, his or her own disability) and able to make decisions. This is quite different from the more traditional (and, hopefully, soon to be outdated) service models that allow control only when the individual has demonstrated competence. Moreover,

> [I]ndependent living [is] a process whereby disabled citizens achieve their desired individual lifestyle by assuming responsibility for the development and management of personal and community resources. The central underlying concepts are risk, responsibility, choice, control, freedom, and self-determination..... [I]f an individual has chosen a particular lifestyle for some management reason then it can be considered an independent lifestyle. An individual requiring attendant care may opt to live in a nursing home where these services are provided so that he/she can devote his/her energies elsewhere.... Some have referred to I. L. as a liberation philosophy (COPOH 1987d: 29-30).

As Irving Zola noted, "independence is not the quality of tasks we can perform without assistance but the quality of life we can life with help" (op. cited in COPOH 1987d: 30). In the words of Connie Oxelgren,

> An immediate plan is to move away from home again. In all probability I will be moving into a nursing home. Though I am not particularly looking forward to this move, it does have an advantage. I will be relieved of attendant hiring and management tasks. This will allow me to put all my energy towards completing my university degree (COPOH 1987d: 64).

Under the supported independence model, control by the individual over his or her own situation is assumed a priori and once the decision is made to take it, actual competence is assumed to follow. Obviously, participatory competence can only be learned and acquired through action and activity; from this perspective, the process has to start somewhere and at some point. As well, the material and social environments are adapted to support the disabled individual in his or her activities, not the other way around. The person's disability is accepted as a given, and so is regarded as secondary. To put it another way, changing rules and procedures, equipment and technical aides, and even the people with whom a disabled person interacts, is more effective with respect to the disabled individual's self-determination in the long run than any attempts at behavioral and physical (e.g. clinical) intervention.

The key to the SI model, according to Marlett and MacLean, lies in the fact that the disabled person is in the "driver's seat," that is, in control, and with the help of his or her support team focuses on building supportive and enabling environments. This involves encouraging self-advocacy, developing peer or natural support networks, accessing individualized funds, and developing "resource safety nets" that permit the individual to manage his or her own staff (i.e. personal care attendants, agency workers, rehabilitation and/or community development professionals, guardians, etc.).

For the SI model to work, however, a number of support or enabling systems should be in place that disabled persons can use to realize his or her independent living/lifestyle goals and, hopefully, greater participation in mainstream community life. As both the means and the outcome of empowerment, they include a consumer-controlled independent living centre with trained staff, the commitment of family and friends, a personal support staff who work in cooperation with funders as well as service providers, an open-minded and flexible local social services management, a service broker, and a volunteer brokerage advisory team of rehabilitation and other professionals who are committed to the principles of independent living. Of particular interest, of course, is the Calgary Association's development and use of both non-professionalized personal support groups (Joshua Committee) and independent service brokerage. It is to a description of these structural innovations that I now turn.

The Joshua Committee: A New Initiative in Personal Support Networks

As I noted earlier in this chapter, many valuable soft services are delivered to disabled people through independent living centres. One of the unique aspects of these centres is that they are controlled by disabled people themselves at both the board and staff levels; another unique feature is the use of volunteer persons who may or may not be disabled. A significant part of IL programming involves disabled people sharing disability-related information, knowledge, and skills with each other. As I discussed in an earlier chapter, disabled individuals (and others) who are consumers of health services can become disconnected from the intricate web of relationships that, as a whole, constitute community. These individuals experience difficulty re-establishing their lives outside the service system into which they have been socialized. This "disconnection" is especially marked for those individuals who have been institutionalized.

However, neither institutions, programs, nor professional service providers can totally recreate the experience of community or respond to the need for meaningful work, income, support services, or even reciprocal relationships. The solutions to these problems call for quite radical change in the nature of the social relationships of disabled persons, and this change must occur first at the grassroots level. Independent living, of course, and the idea of independent living centres is one [illegible] and the Joshua Committee is an integral part of it (the name [illegible] from the biblical character Joshua who caused the walls of [illegible] crumble).

A Joshua Committee is a personal network of support or a group of volunteers* that have been established, either at the request of the disabled person or at the suggestion of a friend, to assist a disabled person lead a lifestyle of his or her own choosing. These committees are unique to the disabled persons around whom they have been developed (i.e. one person = one committee), and their members are active in supervising service staff, coordinating personal care attendants, and distributing funds (Hicks 1985, Lord and Osborne-Way 1987: 51-54). The first Joshua Committee was actually formed in Toronto in 1980 through the efforts of a disabled woman and some of her peers.

By the end of 1985, thirty-five such committees had been formed in Calgary, coordinated by a CAIL staff person specifically assigned to the task. The Calgary Association alone has taken the concept and developed it further; other IL centres have nothing similar. Joshua committees can be made up of a wide range of individuals, including disabled and non-disabled peers, friends, relatives or family, neighbours, and personal care attendants. Medical, health care, or other kinds of social service professionals may also be invited to participate, but their involvement is strictly on a personal basis. Commented the CAIL staff person,

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* See also Aronson 1970, Bott 1957, Mitchell 1969, Powell 1987, Stone and Doucette 1988, Warren 1981.

> The biggest strength of Joshua Committees is that of personal commitment. I think a lot of people get disheartened because although people are there to support them, if they are not paid, they don't come around anymore. These are citizens who are respected in the community and who are coming together and saying "I support you." Just that (effect) in itself, on the person, and on the way society views the person, is really positive (op. cit. in Lord and Osborne-Way 1987: 52).

The strengths of the committees are the personal commitment of its participating members, and their flexibility. This is why the Joshua Committee is referred to as a natural support system. The committee helps the disabled person make decisions for him- or herself; its function and role is not to make decisions for the disabled person, but to respond to the demand for information with which decisions can be made. The focus is on choice: Decisions are made and actions are taken by the disabled person based on information and knowledge that is provided and shared by committee members. The idea is clearly to encourage and assist the disabled person learn, first, how to even ask for information, and then how to process it, to understand the importance of perceiving alternative choices, and to gain skills in the decision-making process.

The committee's effectiveness is determined primarily by its ability to act as a safety net whose very existence encourages and inspires the disabled individual to experiment, take risks, and deal with failure. The committee provides a means of bridging the lack of knowledge and the "zone" of failure by providing knowledge, and by helping the person learn to tolerate failure without destroying his or her innovativeness. The member's moral support is often sufficient; indeed, because community living is not restricted to the hours of "nine-to-five," this support has to be very flexible, and to be effective, supporting individuals must be available and accessible nearly all the time.

As disabled individuals begin to realize their own potential, the liklihood increases that the choices and decisions they will make will be outside the scope of the traditional services and programs available to disabled people. JC members therefore have to be prepared to help identify and create alternatives with respect to access to generic services. By the same token, with a move away from traditional services, funding to provide what the disabled person has chosen may not be readily available. Committee members thus help the individual, through group support, by lobbying for purchasing power to be vested in the individual, and by trying to reallocate acquired funding in ways that give the disabled person more control over what specific services to purchase, who as a personal care attendant to hire (or fire), and so on. However, with regards to funding, committee members do not work alone but hand-in-hand with a service broker.

The organization, procedures, activities, and the interventions of Joshua Committee members on behalf of the disabled individual are not _ad hoc_. On the contrary; there are a number of functions that the committee must carry out if it is to be an effective support structure, and not simply a social or drop-in club at the beck and call of a disabled person. Joshua Committees typically develop what are called individual program plans (IPPs, cf. Hicks 1985: 7-9). These are priorized systems, or "processes" of ends and means whereby individuals are helped to identify their own behavioral and psychosocial capabilities and weaknesses, set specific goals and objectives, develop possible action strategies, and, most importantly, track, monitor, and reflect on their progress and achievements.

Joshua Committees, in effect, guide disabled individuals through the empowerment process in adherence to the principles of independent living. This the committees try to accomplish by, first, establishing and maintaining open and very flexible lines of communication between the disabled person and themselves (internally), and service providers as well as funders (externally). This ensures an awareness of the goals of the disabled person by all concerned, and makes possible the transfer and equal exchange of relevant information on which sound decisions can be made; this arrangement is clearly in contrast to the typical professional-client dyad.

Second, the committees work at coordinating the variety of services that are required and utilized by the disabled person. A single service agency cannot provide all of the necessary supports required by individuals, and so the services of several agencies have to be contracted. Again in contrast to the professionalized helping model, however, it is the disabled person who decides what the needed services are going to be and who (which agency) is to provide them. The purpose of coordination is thus to establish effective and efficient delivery of services, and to provide integrity to an over-all "ecological" support strategy with respect to an individual's program plan.

Thirdly, all professional interventions (ecological, clinical, behavioral, etc.) are filtered and systematized, that is, they are first evaluated by the disabled person and his committee as to their necessity and relevance in meeting his or her community living objectives (e.g. employment, residence, personal relationships, money management, etc.). Only then are outside interventions put together in ways that ensure maximum consistency in over-all approach (and positive) impact on the needs of the individual. Consistency (or integrity) of approaches, of course, facilitates evaluation and monitoring by JC members, involved IL centre staff, and by the individual him- or herself, thus making it easier to track and assess the progress of the person's growing independence (or, alternatively, the lack of it).

Significantly, the focus is not only on personal abilities or deficits, but on the supports needed by the person in his or her chosen environment. This shift in focus is important, because it enables a person to explore a number of alternative environments, arrangements, and support systems, rather than being "fitted" or programmed into a particular one. Unsatisfactory or no longer needed supports and services are dropped and replaced as required.

In other words, a characteristic of the individual program plan is that it is a continuous self-correcting (and learning) process.

Finally, Joshua Committee members and the disabled persons with whom they work seek greater self-accountability. On the one hand, the committee itself is responsible to the disabled person in enabling his or her access to services and programs that are tailored to specific abilities and needs. On the other hand, service providers may be accountable to both their respective departments, agencies or funding sources, and to the disabled person and his or her committee. The effect of such a traditional arrangement, however, is that the disabled individual is neither responsible nor accountable to anyone. The idea of accountability to the individual, an agency, or a funding source has simply meant some kind of justification for continued financial support of whole programs and services whose objectives have seldom reflected the capability or potential of the individual disabled person.

One goal of independent living, of course, is to make the disabled individual him- or herself accountable to service and program providers as well as funding sources, as well as to make <u>them</u> accountable to the disabled person. In the past, the thinking has been that services and programs must be monitored by third parties (i.e. not by disabled people). The implication is that disabled people may misuse funds and purchase poor quality services, or they may be exploited by unscrupulous service providers. It is also implied that people on subsidies should be controlled, and that they do not have the freedom to choose or determine how or how much money should be spent. Self-accountability, and hence independence, means that like everybody else, the individual has complete freedom of choice and dignity of risk in determining the quality of goods and services purchased, and the money spent.

Service and Agency Brokerage: Individual Empowerment and Personal Accountability

The Calgary Association for Independent Living has innovated on a number of fronts with respect to the development of something called the supported independence (SI) model -- both as part of the service development function of independent living centres, and as a systems approach to individual and collective empowerment. The Joshua Committee as a natural support network, as it is called, is clearly a necessary component, or dimension, of the SI model. The Joshua Committee is also a necessary and integral part of yet another innovation in consumer planning and control, namely brokerage.

Like a personal support network such as the Joshua Committee, the idea of brokerage is grounded in the recognition that if disabled individuals are to empower themselves to live as full participants in their communities and in society, some critically important links missing from present social service systems must be put into place. Brokerage and the SI model of which it is obviously a crucial part also emerged from an understanding of how systems do not operate in ways that make them accountable to the people served, and from an awareness of how systems tend to impede the people served from effectively exercising influence in decision-making processes. Brokerage and personal support networks might be considered innovations that encourage the changing or eventual replacement of existing structures and relationships. They serve disabled individuals in ways that are also very much consistent with a new understanding of the rights of disabled people (Marlett 1988). Brokerage in particular is a means of bridging existing services,* and it is in the bridging process that new services might be encouraged to develop to meet new needs.

As described by CAIL's brokers, independent service brokerage operates much like stock brokerage, in that consumers use a broker

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* See also Paine 1971, 1976, Rodman and Counts 1982: 1-33.

to gain access to and manage a portfolio of services that are designed to meet their individual needs. A portfolio might include tutors, schooling, attendants, funding, housing, therapies, prosthetics, and so on. Service brokerage is a technical, mediating support service; it is the technical arm, so to speak, of an autonomous planning mechanism that is community-based and consumer-controlled (Community Living Society n.d., MacLean 1985, MacLean and Marlett 1987b). Brokers assist those who are unable to manage their own services by contracting and negotiating for, and making available things like personal management support, information and training, skill development consultation, individuals interested in becoming partners in support networks (such as Joshua Committees), and so on. Brokers act with, or on behalf of, disabled consumers in negotiating on-going service agreements that facilitate consumer control and independent living. The broker typically works with the disabled consumer, in conjunction with his or her Joshua Committee (if one is used), in seeking funds needed for community living.

As individual funding becomes more and more available, brokers help disabled individuals select support personnel or service agencies from the Association's Service Registry (the DIBS line, i.e. Disability Information Brokerage System, which is a computer listing of over 2000 resources ranging from agencies, personal assistance volunteers, wheelchair repair, to motor van converters). Brokers also assist in drawing up contracts between consumers and service providers, and they establish payment procedures. Combining elements of advocacy, support, information, and referral (i.e. the core functions of IL centres), brokerage is clearly highly compatible with independent living principles. A brokerage advisory committee comprised of CAIL and community representatives ensures the smooth operation of the brokerage process, including the further development of the process itself (through recruitment, training, and supervision of new brokers).

There are several brokerage models that disabled consumers and IL centre personnel have developed. In the independent service brokerage model, developed by the Calgary Association for Independent Living, the broker works only for the consumer/client, not for agencies, the government, or government funding sources. As the name suggests, CAIL brokers prepare service brokerage contracts for services and funding (MacLean, et. al. 1988, Marlett 1988) based on the needs identified by disabled consumers themselves, their natural support networks, or their legal guardians if they are dependent adults. Once the needed services are defined, brokers search for the availability of what is required and prepare cost estimates. Funding estimates are based as much on available generic services as possible, and costs as well as the terms of the service provision are more readily and easily negotiated than would be the case with traditional service structures (Lord and Osborne-Way 1987: 49-50).

When funding is secured, it is allocated directly to individuals and their supports through the broker; the consumers and their networks are therefore placed in a unique empowering position of securing, allocating, and being directly accountable for government dollars. Brokers subsequently maintain contact with both consumers and service providers in order to help monitor the effectiveness of the service package, and to assist in changing the package whenever necessary. In addition to direct work with consumers, brokers are also active in educating existing services (traditional as well as non-traditional) with respect to the needs of disabled people and the importance of direct consumer control and personal accountability.

Another kind of brokerage is agency brokerage, developed by the Vancouver Community Living Society (a group of parents whose children and older dependents were residents of Woodlands, a provincial institution for the mentally handicapped; Community Living Society n.d.). In this situation, the broker is a member of the Society yet works as the technical arm of the referring agency, in this case the provincial institution. In fact, it is the institution/agency that appoints a broker to work with particular individuals and their families. The broker develops what are called general service plans in cooperation with each disabled person's family and the agency, and acquires block funding on behalf of the agency that is subsequently dispersed to the individuals through the agency.

However, the agency rather than the disabled individual (or the family) is accountable to the government (the funding source) for the expenditures for the services that are acquired and contracted. The institution/agency ultimately decides which ones will be utilized, though in the majority of cases it will go with what the broker suggests and what the families want. In turn, the broker is accountable to the disabled individual with respect to providing access to the best possible services and alternatives, and ensuring that services are actually delivered as contracted.

In contrast to the independent service broker, however, the agency broker's prime responsibility and motivation is not the acquisition of funding but rather the development of service plans and the matching of available community resources with individual needs. The agency broker's concern does not necessarily have to be with costs, but with stimulating service providers to enhance their existing services and resources. It is still the broker's task, however, to assess the disabled individual's on-going levels of well-being and growth, monitor the effectiveness of the general service plan, or service package, and to come up with better alternative strategies and plans. The broker's responsibility is to maximize the disabled individual's capacity for self-determination and independent living.

The reason some institutions and agencies use brokers in the first place is that their staff have neither the mandate nor the time to gain knowledge about the full range of existing community resource systems, to identify gaps between needs and services, or to help stimulate the development of missing resources and services. In both the independent service and agency models the broker is a kind of technical expert who is expected to have full knowledge of available generic and non-generic services, but who is also committed to the philosophy of the independent living/disabled consumer movement.

The Basis for Brokerage: The Role and the Process*

Disabled individuals share common experiences in dealing with the govermental and voluntary/private service sectors, and they also experience considerable difficulty, at some point in their lives, in gaining access to even such basic services as community housing, employment, integrated educational settings, in-home supports, life-skills training, technical aides, and so on. These services may simply be nonexistent, of unacceptable quality, or they may not be responsive to the particular needs of disabled individuals. Perhaps an even more fundamental problem is that complete and accurate information about the location, cost, accessibility, and quality of existing service and program options is not easily available. Until very recently, there did not exist a means by which disabled individuals could obtain services directly or directly access needed resources, much less negotiate for them themselves.

This situation has persisted, of course, because no one institution, agency, or organization within the patchwork of social services has been equipped to assist a disabled person and his or her personal support network to develop on-going programs for integrated community living. Fragmented planning has meant that all too often disabled persons are "bounced" from one service to another, from professional to professional, while their needs continue to go unmet. The traditional service sector, then, is not really mandated to assist individuals in planning their integration into the community. Not only is it not equipped for the task, but it lacks the comprehensive outlook, the ability to coordinate with other systems, and the

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* Much of the discussion in this section draws from Marlett and MacLean 1988, MacLean 1985, MacLean et. al. 1987b, 1988, Marlett 1988, and especially Salisbury 1987.

flexibility that is required by disabled people to satisfy their needs over time.

Identifying and putting into place the particular services, professionals, and other resources that a disabled person might need at any given time obviously requires considerable knowledge, skill, energy, personal resources, and a sense of competence -- things that disabled individuals often have the least of but need to develop the most. Likewise, Joshua Committee members or independent living centre staff help individuals identify their needs, are instrumental in formulating program plans, and help coordinate existing services and resources. But they, too, are limited in their ability, expertise, and resources to "pound the pavement," to directly negotiate service or program contracts, or to initiate changes in existing service structures.

What has been needed was a means by which links could be forged between disabled persons, the resources and services available in the community, and funding sources. For these links and arrangements to be truly empowering, they had to be such that the disabled person could be autonomous from service providers and funders, in a position to decide what he or she needed, and be responsible and accountable for services used and money spent (Marlett 1988: 17-18). Since empowerment and self-determination entails learning how to gather information (and what to gather) and how to make decisions, the "means" has to be enabling, not controlling or constraining. That is, both the personal support system (e.g. Joshua Committee) as well as the broker are in the delicate position of working towards, initially, full sharing of control, and later, the gradual transfer of control to the consumer.

The personal support system as well as the broker are themselves autonomous in the sense that they can neither be tied to nor controlled by a direct service system or a funding body. Without autonomy, they would be no more effective than an investment brokerage service, for example, that is offered by a firm directly owned and controlled by a corporation or company such as IBM or General Motors. Agency brokers, of course, are urged to maintain some distance from the service system to which they are attached in order to avoid the possibility of favoring their own agency when referring disabled consumers (MacLean and Marlett 1987b).

Together, an individual's personal support network and his or her broker constitutes what is called "the fixed point of responsibility," that is, a kind of central identifiable body to which the disabled individual can turn for information, advice, continuity of care, and assistance. This fixed point also serves to legitimize the demands of the consumer, since by definition disabled persons are assumed to be unable to know what they want, cannot articulate demands, or do not have the skills to deal with the "outside world." The fixed point is a way of providing the disabled person with a kind of power base that is understood or recognized by government and the traditional service sector. A key assumption underlying the idea of a fixed point is that it will continue to act in its capacity over time, and that brokerage services will consequently remain available to the individual on an as-needed basis. This continuity enables the disabled person to have access to an identifiable body as personal and/or service requirements change (as indeed they will); the on-going presence of a vehicle such as this provides the person with the assurance that he or she can regularly gain access to the opportunities society provides to all non-disabled citizens.

Brokerage systems have a number of unique features that make them especially useful to disabled individuals in the empowerment process. By definition brokerage is a mediating process that enables the broker to network across all system and organizational boundaries in the community, with and on behalf of an individual or group being served. Using a range of technical and professional skills, brokers mediate between disabled individuals requiring services, the people and agencies offering those services, and the structures enabling payment for the services. This flexibility ensures that the needs of individuals, rather than the needs of systems, remain the most important issue. Network involvement in the monitoring of services makes it possible for the broker to keep up to date about matters affecting the lives of those using brokerage; this, of course, is a prerequisite for making appropriate responses to changing needs. Brokerage is thus the technical arm of the fixed point of responsibility, as was mentioned before, that literally extends the disabled person's ability to interact with others in society. It is in this respect that the process is empowering.

As I also pointed out earlier, independent service brokerage is flexible and controlled by the consumer him- or herself. The broker's involvement is engaged only at the discretion of the disabled person and/or his or her personal network. In the case of agency brokerage, the broker's salary is paid by the organization using the broker; in this instance salaries are built into the core funding that is allocated to an individual's fixed point of responsibility. Independent service brokers currently survive on short term and "soft" (i.e. discontinuous) funding, but it is recognized that this is not a viable long term solution (MacLean and Marlett 1987b: 5-6, Marlett 1988: 20 ff, 50-51). One solution has been "fee for service" (typical for brokerage), but since the disabled client is by definition unable to pay, the question is who pays. If the funder pays the broker's fee, the broker becomes responsible to the funder (usually government) and not to the consumer. While this is certainly desirable for funders, such an arrangement could undermine the essential relationship between the consumer and the broker.

How the broker is paid is an aspect of brokerage that is still being developed (MacLean, et. al. 1988, Marlett 1988). It is important that a funding arrangement operates to ensure that brokers are responsive and accountable to the people they serve, and that such an arrangement includes checks-and-balances against professional control. The issue of how brokers are paid also seems to be tied to the issue of how individual disabled consumers are funded. The more individualized, personalized, or direct the funding to disabled persons, the greater their accountability to funders and the greater the relative objectivity of brokers (and so the greater their responsibility to their clients).

The broker's relationship and involvement with the disabled consumer is clearly a paid one in which he or she provides a technical, professional support service. Accordingly, brokers operate on a more general rather than a specific level of the service continuum, that is, they are not too directly involved in individual advocacy, or individual program plan (IPP) development and coordination. Brokers are, however, involved in the development of general service plans. The broker allows matters at the "hands on" level to take their course; brokers should be proactive and reactive, never controlling. The brokerage idea is based on the traditional if overlooked principle (from the point of view of independent living and the supported independence model) that the proper role of the human service professional is that of an "auxiliary" of the disabled person who seeks to arrive at informed decisions while pursuing appropriate goods and services.

Brokers help interpret and explain to disabled persons and their networks the complex and sometimes confusing aspects of various community systems. It follows that the broker does not dictate to people what course of action should be taken in any specific situation. Instead, acting as an auxiliary support, the broker enables individuals to see the range of options and to arrive at their own decisions. As mediators or interpreters, brokers also provide ongoing technical assistance to agencies and organizations by translating disabled persons' personal needs and goals into language that is understood. As a personal agent and technical resource, the broker is in a unique position to help mediate misunderstandings or disagreements between the disabled individual, his or her personal network, professionals, and the various service systems.

As one who facilitates planning and decision-making, the broker tries, of course, to maximize the self-determination and independence of the person he or she serves. The active partnership between the broker and the personal support network of the disabled consumer helps the broker do the job effectively. The broker draws from the information passed on by the network as it monitors services around the individual using brokerage. The broker likewise reflects on the network's insights into the individual's personal situation, and it is this partnership that reinforces the empowerment of the individual. This relationship ensures that the individual remains the central focal point of demand in relation to services in the community, while making his or her own contributions to effective brokerage as well.

I conclude that service (as well as agency) brokerage is a means of putting a range of technical resources at the disposal of the disabled consumer. Properly conducted, the brokerage process should enable the disabled person to develop and act on his or her "vision' for a self-determining life in the community and in society. It is the disabled person who is allocated dollars, who is supported by a personal network made up of family and friends, and who augments his or her capabilities by using the technical and professional supports of a service broker. On the other hand, the individual, empowered by his or her personal network and by the broker, controls the planning and decision-making process while at the same time brings about a needed measure of service monitoring and evaluation.

As a sort of skilled generalist who operates within the broader social and system context, I would suggest that the broker possesses a variety of technical and interpersonal skills, and knowledge of the empowerment process in order to not only get the "best deal" possible for the disabled person, but to enable the person, through an active learning process, to re-contextualize him- or herself in community and everyday life. At the same time, the brokerage process can act as a catalyst that stimulates innovative responses, by others in the community, to a disabled individual's diverse and often challenging needs.

Service and agency brokerage appears flexible because it is designed to be interdependent with the other components or means of delivering services of the independent living model. I suggest that this interdependency of brokerage's operation could prevent it from developing into a large and inflexible bureaucratic structure. Without a healthy degree of openness to citizen input and consumer control, systems tend to expand, giving rise to powerful vested interests that also tend to consolidate power over those served (see, for example, the historical discussion of therapy and rehabilitation in Gritzer and Arluke 1985). By contrast, brokerage, as envisioned by disabled consumers, presupposes individual input and control. It also presupposes the free operation of a number of checks and balances at work among the components in the independent living model (e.g. IL centre staff, IL centre brokerage advisory team, peer support groups, natural support networks).

Checks and balances, usually excluded (or absent) from larger structures, ensure that brokerage remains sensitive to the needs of those involved in the process, and that the brokerage system, in turn, does not become an entity unto itself. Broker accountability, as disabled consumers and others are saying, remains a crucial aspect of the process as it is currently evolving and as it is currently being experienced. I have heard it said that there is the ever-present (and not unfounded) concern that brokers may act in unprofessional and unscrupulous ways to take advantage of the vulnerability of disabled persons by forcing solutions on the consumer by providing service packages that are more convenient to the broker than to the consumer, or by manipulating information that results in even greater dependency rather than empowerment. I can see brokerage becoming as much a double-edged sword as any of the other strategies for community-building.

Summary and Discussion

One of my goals in this chapter has been to outline the new perspective that has emerged over the past decade or so regarding the basis of social innovations with respect to community reintegration as it pertains to disabled people. Simply stated, the concepts and philosophies of supported independence and independent living have become topical bywords for describing strategies of problem prevention, amelioration, and community building, a lay (as opposed to professional) basis for health and social service community efforts. Very basic to this orientation is the view that social programs involving initiatives from professionals and experts, formal agency bureaucrats, and hierarchical planning have either failed to produce significant success outcomes, or have only added to the weight of (disabled) citizen and consumer alienation from the health professions, government, and the public in general.

From what I would like to call the "community as expert" perspective, many new initiatives have been created for which funding and other kinds of support have been sought and made available to establish "partnerships" between informal and formal solutions that address many of the problems of re-integrating and re-contextualizing disabled persons back into general community life. Independent living centres, personal support networks, Joshua Committees, and brokerage models are the emerging (and, to some degree, already established) new "organizing principles" or mediating-alternative structures. Where once patient, client, or target population goals existed, one now finds community support strategies defined by significantly increased citizen participation acting in concert with natural helpers (peers and friends) who are able to supplement or even to supplant experts.

Thus, a sort of dichotomy of formal versus grassroots expertise has arisen in which the proper boundary or balance between the two, with brokers as go-betweens, is still in the process of being worked out and defined. As empowered disabled consumers discover more about the positive functions and consequences of parallel or alternative "enabling" systems in helping them cope with a variety of medical, social, and life concerns, the importance of ensuring that public and private agencies offering services are not destroying or discouraging these enabling systems becomes clear.

The independent living/disabled consumer movement and the empowerment strategies which it has generated symbolizes reaction to the overprofessionalization and the exceedingly high costs of services and institutional care.* The following, then, are some of the premises that I interpret as underlying the supported independence and independent living approaches I have described in this chapter:

1. There are limits to "social policy intervention" styles; i.e. the use of government, professionals, and formal procedures is considered a finite strategy.

2. Grass roots involvement is a key to maximizing community action and local or individual empowerment; such actions can be conducted independently or in some reciprocal relationship (network) with specialized and formalized self-help groups, human service agencies, and other community-based structures.

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* An informal cost-comparison study of costs for institutionalization versus home/community care is provided by Marlett and MacLean 1987; see also Marlett and MacLean 1988: 56, Table 5: "Yearly Estimates of Per Day Costs in Institutional/Community Group Home and Supported Independence." According to Marlett and MacLean, total institutional costs can run from $40,000 to $60,000 per person, group home costs are calculated at just over $33,000, while the costs of supported independence have dropped from just over $37,000 to just under $23,000 per person. These dollar figures include staff, facility, and administration costs. COPOH (1987d: 45) has argued that because of the savings to the taxpayer under the supported independence model, disabled persons earning less than $20,000 should be income tax exempt. This, COPOH argues, would encourage independent living.

3. Recognizing that local individual and community skills and resources contribute to problem-coping, and that many of the social bonds at the local level have been weakened, the need for empowering individuals, families, and social networks should be acknowledged; these would then come to see themselves as significant entities fully capable of contributing to their own well-being.

The first premise is grounded in the notion that communities, regardless of size or composition, have different agendas and value systems, and that in a pluralistic society it is not reasonable to design social (including medical and therapeutic) interventions that are based on models which are not themselves grounded in differential consumer needs and interests. Without such grounding, policy formulations usually miss the mark of their intentions by considerable margins. In reference to what independent living centres are intended to do, for example, I have found there to be a variety of opinion among disabled consumers of just what constitutes a problem or a solution for a particular disabled person; hence, standardized and pre-determined formulae concerning ideal solutions are consciously avoided. The importance and usefulness of locality, variability, and strategy flexibility are emphasized instead. Moreover, the right to reject proferred expertise and traditional service delivery mechanisms is also consciously exercised, and so serves to stimulate the empowerment process.

The second premise recognizes the vast potential of utilizing peers, so-called natural helpers, and volunteers with respect to individual support and care. IL centre staff, Joshua Committee members, and so forth (including, of course, consumer organizations themselves) involve, to a very significant extent, local community volunteers. My understanding is that the implementation and effectiveness of many independent living centre and agency programs appears to rest on an appropriate pattern of referral and linkages with informal helping networks that necessarily include fellow disabled persons. Such linkages or networks seem to be a very efficient means for moving, distributing, or circulating needed goods and services.

The third premise, which I would suggest is related to the second one, concerns the emergent socio-psychological properties and utility of small social networks. The very acts of communicating needs and concerns and sharing information and expertise -- whether involving peers as well as professional helpers -- encompasses the potential for common purpose and a shared sense of justice. There is of course a great deal of overlap and interplay between the situations and problems of disabled individuals, and those of the larger community of which they are part. Innovative service delivery programs or mechanisms can therefore instill a sense of self-confidence among many kinds of users that can, in turn, stimulate newer and even further-reaching demands for services. The value of the consciousness-raising (empowering) functions of many of the independent living solutions or innovations for community-building should be acknowledged.

With respect to the community-building process, I posit that the basis of community depends not only on primary groups, natural or mediating support systems, or on helping networks alone such as what disabled people have created. It depends rather on the dynamic linkages between these and existing groups, institutions, and community structures. The community-building process should be considered synonymous with the conscious "de-colonization" of the "life world" (community), and the bridging, or re-integration, of the life world and the system, as I noted in a previous chapter. The innovations for empowerment and independent living that I discussed in this chapter are thus considered the means by which disabled people individually and collectively can acquire and then exercise their reflexive monitoring skills, and restructure or reconstitute their motivations and interests in conscious ways. This relearning and restructuring is central to the so-called normalization process, and thus to self-determination, and is really what supported independence and independent living as the means and outcome of empowerment is all about.

Institutionalization, segregation, and the categorization of people by ability, social class, ethnic origin or race, gender, age, and so on, have all contributed to the weakening of social integration and community cohesion in general terms. This weakening, in turn, has been a major source of social alienation and isolation that has resulted, unfortunately, in a burgeoning public agency and/or government "problem-solving" load, and in the tendency for professionals to "take over" and impose limited services using highly standardized and uniform definitions of problems and administrative procedures for assessing needs and allocating resources. In typical circular fashion, however, overspecialization, professionalization, standardization, and even well-intentioned public policies further erode the social environmental basis of community, and in fact exacerbate dependency, asymmetrical relations, and alienation.

In the final analysis, the goal of independent and integrated community living that disabled persons envision -- returning the person to the community and re-establishing personhood -- depends ultimately (and necessarily) for its success on a balanced and integrated working partnership between informal or natural support systems and specialized formal systems. Disabled consumers point out that consumer organizations, independent living centres, Joshua Committees and other kinds of social innovations described in this chapter have to be seen as means to certain ends, rather than as ends in themselves. Allan Simpson (1980: 30) stated quite explicitly that,

> The consumer group [or any of the structures I have discussed in this chapter] is not an island unto itself. It must not fall into the trap of becoming a social circle as an alternative to community integration. Rather, reaching out, it must be a sharing part of the community,

> always bridging gaps to enhance consumer involvement and recognition.

Simpson seems confident, as might other disabled consumers, that consumer involvement will extend beyond these mediating or alternative structures to direct participation in the political process itself. Thus,

> Growth through the consumer movement should equip many leaders with the skills to run for political office, and to offer their unique understanding of human needs, of the democratic decision-making process, and the integrity and honesty of a proven politician. Only when individual consumer involvement is established by legislation will the consumer movement have reached its pinnacle and become part of the establishment (Simpson 1980: 36).

It is indeed the institutionalization of discourse, the expansion of the public realm via public policy formulation, and legislation (e.g. Kallen 1989: 219, Chart 3, and passim) that will further enable the community-building process. In true dialectic fashion, the movement and the community influences and changes each other, and continues to do so. In the next chapter, I briefly examine the impact the independent living/disabled consumer movement has had on Canadian public policy. I also discuss the movement's approach to equality and human rights in its attempt to secure and protect some of its achievements, and to ensure a future voice for disabled citizens and others in the on-going process of community-building.

Chapter 7

Towards Community Integration: Equality Rights and Reasonable Accommodation

Participation in the independent living/disabled consumer movement, in consumer organizations, and experience with different enabling structures such as those I discussed in Chapters 5 and 6 has equipped many disabled individuals with the skills needed to participate in the democratic decision-making process at the individual, group, community, national, and international levels. Action-oriented disabled individuals have also noted the importance of establishing more independent living centres or similar such community structures, and to lead the way with policy initiatives concerning such things as integrated transportation systems, meaningful employment alternatives, dignified security income, minimum wage protection, integrated housing with appropriate forms of attendant or personal care support systems, and so on.

Further community participation necessarily calls for the involvement of disabled consumers in the political process itself. The 1990s now offer a significant opportunity for the independent living/disabled consumer movement to establish its principles of self-determination and independent living, and for turning these concepts and principles into practical realities for the entire community. Employment, health, tax reform, transportation, housing, education, family needs, and so on are clearly pan-community concerns -- not just the concerns of a few. That society, for example, is rapidly moving from a public-service and professional monopoly in the human and social services to a greater private-public mix requires that all citizens be more critically aware of how their needs (present and future) are going to be met. The apparent trend towards the privatization of social services means that issues such as funding, responsibility, accountability, coordination of research, etc., will also loom large in the future.

Indeed, politically active disabled consumers are no longer concerned just with the immediate needs of only disabled people, but have over the past decade acquired a more global, holistic, and integrated outlook, one that now takes into account community economic development as well as long-term social and health planning (Derksen 1980, Simpson 1980; cf. Canada, Health and Welfare 1988). One might speculate and say that the empowerment process has become as outward-directed as it once perhaps was inward-directed. An integrated and holistic outlook, I would argue, is the heart-and-soul of the community-building process. As Dobell and Mansbridge (1986: 28) explain with regards to the social policy process, also an integral aspect of this process,

> Social policy-making suffers, it is argued, when its major focus is seen to be exclusively the needy, the poor and the powerless. Instead, social policy should address the total community, and its objective should be the prosperity and well-being of all citizens. NGOs [non-governmental organizations, e.g. consumer organizations].... will achieve greater policy influence to the degree that they succeed in achieving identification with an informed citizenry.

From the perspective of disabled citizens, part of "getting in on" this process has involved coming to the realization that they have a right to represent themselves in the community and to participate in the decisions that directly concern and affect them as individuals, and then doing something about it. Both political participation, self-representation, and an integrated outlook are unquestionably part-and-parcel of self-determination. Disabled citizens simply do not want legislators and policy makers to identify their needs for them in the same way that traditional providers of care have done in the past (COPOH 1982, Obstacles 1987: 85-86).

In this chapter I focus on equality rights and the Canadian Charter of Rights and Freedoms, the basis for a variety of anti-discrimination legislation and policy developments whose intent is to enable disabled citizens to participate more fully in Canadian social and political life. More specifically, my aim will be to describe the independent living/disabled consumer movement's own formulation of a theory of equality that individual disabled citizens collectively insist give substance not only to the rights and freedoms contained in the Charter of Rights, but that enable their own empowering and community-building efforts as well.

I will also discuss how the movement has tried to incorporate various concepts and approaches such as substantive equality and the notion of reasonable accommodation into a broader empowering theory of equality. The idea behind substantive equality and reasonable accommodation is to ensure as accessible a social environment as is physically and technically possible, in which disabled citizens can have the confidence to participate despite their physical or mental impairments. In the context of community-building, the notion of "unity in diversity" is important, since disabled citizens are equal to other citizens without having to be the same as them. As I will elaborate later, this requires that their differences in fact be recognized and accommodated.

Before turning to a discussion of equality rights, discrimination, and some of the relevant legislation, however, I would first like to briefly discuss some policy developments pertaining to disabled citizens (but ultimately to the whole community) that have taken place in the 1980s.

Some Recent Federal Government Initiatives

The extent to which the independent living/disabled consumer movement has been successful in developing its particular approaches to equality rights and in reaching out to the general community might perhaps be reflected by government policy initiatives in response. In 1985 Canada's participation in the United Nation's Decade of Disabled Persons was confirmed (Appendix 3, Item 1). Since then, the federal government has created a permanent Secretariat (Status of Disabled Persons Secretariat) to support federal initiatives that influence the quality of life of disabled persons. The purpose of the Secretariat is to perform a "watchdog" function over federal departments and agencies, and to raise the consciousness of the public as well as government officials to the ways in which disabled citizens could be assisted in their quest for full citizenship. The Secretariat is also supposed to act as a kind of catalyst in efforts to translate policies into reality.

Inspired by the efforts of the Special Parliamentary Committee on the Disabled and Handicapped (a standing committee whose members had worked closely with consumer organizations across Canada)(Sub-Committee on the Disabled and Handicapped 1987), the government announced a set of organizing principles whose purpose was to guide immediate as well as future policy and planning initiatives (Government of Canada 1987). The principles are participation, access, and awareness. They were enunciated in recognition of the fact that, first, disabled persons should have the same opportunity to participate fully in all of the educational, employment, consumer, recreational, community, and domestic activities that characterizes everyday society, and second, that the entire community is responsible for the necessary changes that will give disabled citizens as wide a variety of choices of participation as are also enjoyed by the non-disabled (ibid., 1).

Participation

Between 1985 and mid-1988 the federal government, in the face of the Charter of Rights and Freedoms (especially section 15, the equality rights section) and at the behest of organized disabled citizens, took a number of important steps towards realizing or putting into practice these policy principles. With regards to participation, one of the first steps was to increase funding for the Disabled Persons Participation Program to $3.2 million per year (a five-fold increase over previous years). This program provides much-needed funding support for disabled consumer organizations, including advocacy organizations (local and provincial levels) and, to a limited extent, independent living centres (block funding for some services and programs). The Canadian Labor Code was also amended in 1985 to prohibit the discriminatory practice of paying disabled persons less than the minimum wage. Likewise, by broadening the definition of disability for income tax purposes to include people with intellectual and psychiatric disabilities, the value of the income tax deduction was increased. This had the effect of enabling some 250,000 disabled consumers to qualify for the deduction, an increase in total numbers from previous years.

By far the most comprehensive and far-reaching policy initiative undertaken in 1986 was Employment Equity legislation (Appendix 3, Item 6) and the Federal Contractors Program (Employment and Immigration Canada 1986a,b). The purpose of Employment Equity legislation, of course, was to promote the employment of disabled persons in the federally-regulated private sector and Crown Corporations. The latter, for example, were required to submit annual action plans (for the approval of the Treasury Board ministers) comprised of the identification and removal of employment barriers, the establishment of three-year numerical targets (by major occupation groups) to increase the total number of disabled citizens hired, and the creation of a new management category (with its own numerical targets).

By 1987 these requirements for Crown Corporations had been extended to cover all departments within the federal public service as a whole (for a profile and discussion of the workforce that includes disabled persons under employment equity legislation, see Appendix 6, Item 1). Similarly, the Federal Contractors Program was established to create further employment opportunities in private sector firms seeking to do business with the federal government. Those companies seeking contracts with the government for goods and services valued at $200,000 or more are required to sign a certificate committing themselves to implementing employment equity programs, subject to verification of this commitment by the government (Treasury Board Secretariat 1988).

Along with these policy initiatives in the area of participation, a number of federal government departments have begun to formulate their own policies and programs, or are beginning to modify their services (Government of Canada 1987: [illegible]-10). The Department of Transport, for example, has been working on accessibility standards in the form of regulations that address the requirements of disabled persons using air, rail, marine, road, and other modes of transportation that come under federal jurisdiction (Obstacles 1987: 63-71). The departments of Health and Welfare and the Secretary of State are cooperating on the development of guidelines for the funding of independent living centres across Canada. This represents a "first" in moving towards a much-needed coordinated national approach to facilitating the implementation of independent living philosophies and programs.

Likewise, Veterans Affairs and Canada Mortgage and Housing are developing proposals for the provision of accessible housing for elderly and disabled veterans (and others who qualify) to reduce premature and inappropriate institutionalization. Finally, Canada Employment Centres through its "Revitalization Project 20-9" are providing technological aids such as infra-red communication equipment, image enlargers, audio cassette players and recorders, as well as reader assistance for disabled persons using Employment and

Immigration's self-help services. Canada Employment and Immigration (CEIC) is also developing policies to ensure telecommunication access to its services (Obstacles 1987: 25-26).

Access

With regards to access -- the second of the government's three organizing policy principles -- one of the main program and policy initiatives has been the expansion of the Court Challenges Program. Administered by the Canadian Council on Social Development, the purpose of the program is to cover all challenges to existing federal laws that are considered to conflict with the equality provisions of the Charter of Rights and Freedoms (discussed more fully below). More specifically, the Justice Department is producing and distributing law information packages that provide disabled citizens with information about the justice system. This apparently includes efforts to educate the public about the requirements of disabled persons in the justice system. Related to developments in the legal sphere, legislation has also recently been introduced (suggested amendments to the Canada Election Act) that removes restrictions on the right of mentally disabled persons to vote. Bill C-79 tabled but not yet law (mid-1988), also ensures that physically disabled persons have improved access to polling stations (Government of Canada 1987: 10, Obstacles 1987: 3-5).

With the creation of the Status of Disabled Persons Secretariat to help federal departments and agencies improve access by disabled persons to social and economic opportunities, formal consultation mechanisms have also been adopted by Treasury Board, Statistics Canada, as well as by Health and Welfare Canada, to name but several (Government of Canada 1987: 4). Treasury Board, for example, maintains ongoing consultations with an advisory committee of disabled persons that advises the President of the Board on all matters related to the employment of disabled persons within the federal public service. Statistics Canada consulted extensively with COPOH and its provincial affiliates in carrying out its

Health and Activity Limitation Survey in 1986 and 1987, and Health and Welfare Canada is likewise consulting with organizations of disabled consumers, their representatives, and hired consultants to identify new directions for the current (1988) federal-provincial-territorial review of the Canada Assistance Plan (CAP) and the Vocational Rehabilitation of Disabled Persons Act (VRDP)(Obstacles 1987: 29-30, 57-58). I should perhaps mention that the VRDP, supported by the CAP, is considered by the consumer movement to be the single most important piece of legislation affecting education and employment of disabled citizens (Simpson 1980: 26).

The government also financed, at a cost of $720,000 over two and one-half years, the creation of the Disability Information System of Canada (DISC) at the University of Calgary's Walter Dinsdale Centre. Disabled persons providing other disabled persons with first-hand access to current information is an important process which the government has evidently been persuaded to support by the consumer movement. On another level, it is significant that in late 1985 the Treasury Board issued a directive that all federal facilities be upgraded to ensure physical accessibility to the level of the so-called Barrier Free Design Standard (BFDS) developed by Public Works Canada at an estimated cost of $110 million over ten years (Government of Canada 1987: 10-11). In order to continually improve on existing BFDS guidelines, Public Works is funding the Canadian Standards Association (CSA) to develop new technical standards on barrier-free design; the CSA consults regularly and on an on-going basis with disabled persons and consumer organizations.

Awareness

According to disabled consumer organizations such as the Alberta Committee and COPOH, public education and awareness are quintessential to creating a climate in which positive social and economic change can occur. In advocating their own integration into the mainstream community life, disabled persons are creating an awareness of the need for concerted social action. The consumer movement has been successful in getting the federal government involved in taking initiatives with private sector umbrella organizations such as the Canadian Chamber of Commerce and the Canadian Manufacturers Association, with a view to increasing employer's awareness of issues like reasonable accommodation in the workplace.

The government has also been persuaded to provide technical (and some limited financial) support for an annual National Access Awareness Week that began in 1988. In 1986, the federal government commissioned a comprehensive census of disabled persons in Canada (at a cost of $6.4 million over three years) whose goal was to help consumer organizations raise awareness about the scope and nature of their concerns (Government of Canada 1987: 5, 11-12). These data, argue disabled citizens, should go a long way in aiding policy planning processes in both the public and private sectors.

Developments at other levels, no less significant, include: A push for the more positive portrayal of disabled citizens in government publications (Treasury Board), new provisions for disabled students under the Canada Student Loans Program, the development of an extensive data base on disabled people in different countries (External Affairs), the development of an information package to sensitize employees who deal with the public (RCMP), the distribution of information on hazardous products to disabled consumers (Consumer and Corporate Affairs), and so forth. All of the public sector initiatives I have summarized here are significant for the reason that they represent both the outcome of empowerment efforts by disabled people and the further means of empowering disabled people. Community-building, as I have said, is a dialectical process.

The Struggle for Charter Protection

The patriation of Canada's constitution on April 17, 1982 not only marked Canada's final assertion of independence from Britain, but it also heralded a new era which provides constitutional protection for the rights and freedoms of all Canadians. The Canadian Charter of Rights and Freedoms which forms Part I of the Constitution Act (1982) prescribes the political, legal and egalitarian rights regarded by Canadians to be essential to Canadian society (Appendix 3, Item 2). Section 52 of the Act declares the Constitution to be the supreme law of Canada. This means that all the laws of Canada must conform with the principles and standards articulated by the Constitution. Those laws which do not comply with constitutional standards can be struck down by the courts as being unconstitutional.

One of the most significant sections of the Charter of Rights and Freedoms, that which has received the most attention and debate as to its impact is section 15, the equality rights section. The potential social and political impact of section 15 caused Parliament to impose a three year moratorium on the operation of this section to enable Parliament and the provinces to conduct a legal audit to ensure that various federal and provincial laws did not contravene the equality guarantees. Section 15(1)(2) of the Charter finally came into force on April 17 1985, and it was (and still is) the conviction of many groups and individuals, including disabled consumers, that the legal review carried out by governments between 1982 and 1985 accomplished very little and produced legislative changes that amounted to mere cosmetic and tokenistic gestures. Many equality issues, those pertaining to disability as well as those pertaining to other characteristics, have subsequently ended up or will end up in the courts for resolution.

The Charter of Rights, and with it, the equality rights section, of course, are products of a great deal of drafting and re-drafting, and are a kind of end result which reflects considerable input from a large number of interest groups and citizens. Prior to the final

Constitutional accord assented to by the Prime Minister and the provincial First Ministers, the Special Joint Committee of the Senate and the House of Commons on the Constitution of Canada (also known as the Hays-Joyal Committee) convened hearings in 1980 and 1981, and invited interest groups to provide the committee with their views on the kinds and types of rights and freedoms the Charter should protect. The committee considered about 1,000 written and oral sub-missions in all [Minutes and Proceedings of Evidence, 1st Sess., 32nd Parliament, 1980-81].

Initially, of course, the Joint Committee did not support the inclusion of persons with disabilities in section 15(1) (the omission of disabled persons was deliberate). It was simply assumed that the needs of disabled citizens were already being adequately addressed by existing federal and provincial human rights legislation. As well, it was feared by some that the inclusion of disability in section 15(1) would force public sector expenditures of large sums of money to accommodate the rights of disabled persons. It is curious, in retrospect, that disability was the only ground which caused the committee to consider dollar cost as a factor in its deliberations of extending constitutional protection to a designated, or enumerated, group.

According to Lepofsky and Bickenbach (1985: 333), strong arguments for a so-called handicap amendment actually came from three forums. First, the arguments were part of a more general public debate over patriation, and were put forth in various public forums, in the media, and in letters and petitions aimed at legislators. The second forum was of course the Special Commitee of the House of Commons on the Disabled and the Handicapped, an all-party committee struck in 1980 to inquire into the status and needs of the country's disabled persons. The committee heard from about 400 witnesses during hearings held through the summer of 1980 about the need for expanded legal protection against disability-based discrimination; again, the arguments were strongly and consistently in favor of constitutional (rather than mere legislative) provisions to this effect.

Thirdly, and finally, the case for stronger and more comprehensive rights of disabled people was formally articulated in briefs and presentations to the Special Joint Committee. Here, three principal advocates for the amendment appeared before the committee: The Coalition of Provincial Organizations of the Handicapped, the Canadian Association for the Mentally Retarded (a federation of action groups), and the Canadian National Institute for the Blind. Organizations such as the Canadian Labor Congress, the Royal Canadian Legion, the Canadian Human Rights Commission, and even the Canadian Jewish Congress joined in support of COPOH, CAMR, and the CNIB for the expansion of section 15(1)(2) entitlements (Minutes and Proceedings of Evidence, Vols. 10, 11; noted in Lepofsky and Bickenbach 1985: passim).

Disabled citizens protested loudly themselves, of course, and pressured politicians to reverse the committee's decision not to introduce the so-called handicap amendment. COPOH, just mentioned, appeared before the Special Joint Committee and argued strenuously that the inclusion of disability rights in the Charter would not only afford greater legal protection for the rights of persons with disabilities, but would also symbolize Canada's commitment to disabled persons as first class citizens (Minutes and Proceedings of Evidence, Vol. 12: 26-44; noted in Lepofsky and Bickenbach 1985: passim). These arguments were also advanced when Canada, together with other nations, prepared to proclaim 1981 the International Year of The Disabled Person.

During the hearings in 1980 the Special Joint Committee was thus confronted by the fact that physically and mentally disabled persons in Canada constitute a significant and numerically large (though often hidden from view) disadvantaged minority, that disabled persons are regularly victimized by intentional and unintentional acts of discrimination (discussed fully below), and that overt and more subtle forms of discrimination constitute a major barrier to full participation in mainstream Canadian life.

In testimony before the committee, for example, the Chief Commissioner of the Canadian Human Rights Commission (Gordon Fairweather, Minutes and Proceedings of Evidence, Vol. 5: 17; noted in Lepofsky and Bickenbach 1985: passim) stated that over 20 percent of all complaints to the Commission dealt with alleged employment discrimination against disabled persons. Fairweather noted in particular that an unemployment rate of almost 80 percent afflicted disabled persons. More particularly, the Special Committee was presented with evidence that showed that discrimination on the basis of disability was reinforced by existing provincial legislation regarding group homes and sheltered workshops, for example, coupled with municipal zoning bylaws, apparently had the effect of segregating disabled people. There was also evidence of exceptions to minimum wage legislation that permitted the paying of even lower wages for a disabled person's labor. As well, the Special Committee learned that blind persons could not serve on juries, that certain disabled persons were not entitled to welfare benefits, that disabled children were segregated from mainstream education institutions, and even that the federal Immigration Act discriminated against immigration applicants.

The pressure upon the government to accept and enshrine constitutional guarantees for disabled people was therefore, in the words of disabled consumer advocates, overwhelming and unequivocal (Minutes and Proceedings of Evidence, Vol. 12: 30, statement by COPOH; see also COPOH 1985c: 1, human rights resolution 6.78.4). Put simply, equality rights for the disabled were deemed no less important than they were for other minority groups enumerated in section 15(1). In January 1981 Jean Chretien, then federal Minister of Justice, responded to the demands and the evidence of the disabled community, and that of others, by announcing that section 15(1) would, after all, be extended to include the equality rights of persons who are mentally or physically disabled. This was to be the last minority category enumerated under the section. Moreover, the phrase "or mental or physical disability" was also inserted in section 15(2)'s list of designated minority groups for the purpose of affirmative action programs.

The final adoption of the handicap amendment was clearly a significant step (Kallen 1989: 16). Canada is apparently the only country in the world that has specifically, and formally, accorded constitutional (legal) protection to rights of disabled persons. Canada (on the surface, at least) has therefore more than fulfilled its international obligations with respect to the rights of disabled persons [e.g. the 1975 United Nations Declaration of the Rights of Disabled Persons. In Appendix 3, Items 3-5, I have included key examples of international declarations and human rights instruments pertaining to disabled people; see also Kallen 1989: 5-12 for a useful discussion of the Inter-national Bill of Human Rights and Canada's response to the Bill].

Section 15(1) of the Charter of Rights reads as follows:

> Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability.

Under section 15(1), the term equality consists of four clauses, each of which represents a particular aspect of equality. "Equality before the law" refers to the application and administration of the law. That is, the law must apply equally to all persons; no one stands above the law. In general, equality before the law is concerned with how the law is carried out and not with what the law actually says or does. This type of equality is sometimes referred to as procedural equality. By contrast, "equality under the law" deals specifically with the content of laws and how they treat people. Laws which single out or classify on unreasonable, arbitrary, and unfair grounds could be characterized as constituting an inequality under the law. A particular law, for example, that prohibits blue-eyed persons from becoming doctors may be considered a clear denial of equality under the law.

From the point of view of disabled citizens "equal protection" and "equal benefit" of the law are the clauses which offer the greatest potential in extending the scope of section 15(1) (Peters 1987b). These clauses can be used to not only advance equal opportunity but equality of results as well; this means that people must not only be treated equally, but that additional steps must be taken to ensure that people benefit equally. Peters gives the example of an educational institution that makes its premises accessible to students with disabilities in order that they may enroll in the courses of their choice provides those students with an equal opportunity to participate. That same educational institution, however, that provides additional services such as sign language interpreters, alternate media and technical aids, etc., also provides equality of results by ensuring that disabled students can benefit to the same extent as their non-disabled counterparts.

It is thought that the "equal protection" and "equal benefit" clauses of section 15(1) have the potential of placing an onus on governments (and perhaps others) to accommodate the unique needs of disadvantaged persons. This concept, of course, receives further support from section 15(2) which endorses the development of affirmative action programs that have as their object the amelioration of conditions of disadvantaged individuals and groups.

For all intents and purposes the Canadian Charter of Rights and Freedoms is still in its legal and political infancy; the specific ramifications of the equality rights provisions have yet to be fully unravelled (Department of Justice 1985, Government of Canada 1986, see the essays in Smith, et. al. 1986). Complicating matters is the so-called Meech Lake Accord (the currently proposed constitutional amendment, 1987).*

Towards a Theory of Equality: The Disabled Citizen View

What follows is an overview, which I admit is incomplete and probably simplistic, of the notion of equality from the point of view of the disabled consumer movement. Peters (1987b), on whose legal work and perspective** I base much of the following discussion, suggests that a distinction should be made between formal and substantive equality. Representative organizations of the independent living/disabled consumer movement such as COPOH (and its affiliates) have therefore felt it essential that a theory of equality be developed that reflects the movement's vision of full

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* There is concern, perhaps valid, that certain sections of the proposed amendment will have a negative impact on the rights of specific ethnic and non-ethnic minorities. It has been suggested by women's groups, the disabled, and by other non-ethnic minorities originally enumerated under section 15 of the Charter that their rights would be considerably weakened by the Accord's focus on the rights of Canada's "founding majorities" (section 2(1) a, b), and by its specific lack of reference to certain other groups (sec. 16)(COPOH 1987a). It has also been argued, for example, that the Accord will even further entrench a hierarchy or "pecking order" of minority inequalities (and rights) that even the Charter of Rights perpetuates (Gadacz 1988, Kallen 1988, 1989: 181-186, see also Cairn 1988). Representatives of ethnic and non-ethnic minorities are hopeful, nevertheless, that when (and if) the Accord does become part of the Constitution it will include a provision ensuring that all statutes, including the Constitution itself, will be interpreted in light of the Canadian Charter of Rights.

** Yvonne Peters is legal counsel with the Canadian Disability Rights Council (formed in 1988), which is mandated to take on test cases and initiate litigation to clarify the equality provisions of the Charter of Rights as they pertain to disabled persons (see COPOH 1989e: 7).

participation and equality of persons with disabilities. Disabled citizens have also asserted that the task of constructing a framework for equality should not be left in the hands of lawyers, judges, and even politicians, but that disabled people themselves must participate.

First of all, a coherent theory of equality is said to be founded on certain assumptions, values, and principles. Equality as a concept does not evolve in a vacuum; it is a product of definite moral and political ideals and values. It is therefore important to be aware of the various political, social, moral, and philosophical forces that influence the development of such a concept. Gold (1983: 132, op. cited in Peters 1987b), for instance, has stated that

> A particular conception of equality cannot be said to be right or wrong. The most that one can say is that it does or does not fit with a particular political or moral theory. As such, it is not surprising that equality is a political ideal around which revolves the most profound ideological controversies.

Peters suggests that a civil libertarian may view equality as the right to be left alone to pursue his or her goals without state interference. Alternatively, a feminist view of equality may adhere to the principle that to be equal is to be non-subordinated to male dominance. A communitarian perspective on equality, notes Peters, may hinge on providing benefits that enhance the collective well-being of all members of a community.

The courts, including the Supreme Court of Canada, have rejected a narrow and technical interpretation of equality rights in favor of a purposive approach (Smith 1986: 356-360). In light of Peters' discussion, this is something disabled people agree with and wholly support. The courts have eschewed a restricted view of the language employed by the Charter in favor of a more liberal approach that supposedly breathes life and meaning into the different sections by considering the value of a particular right or freedom that is protected. Something called a purpose and effect test is therefore applied to determine the validity of a law that is contrary to the spirit of the Charter.

To illustrate this point, Peters (1987b) cites the case of R. v. Big M Drug Mart [1985 1 S.C.R. 295]. The Supreme Court declared that the federal Lord's Day Act was invalid and thus had no force or effect, because it infringed on the religious freedoms guaranteed by the Charter. Had the court determined that the law in question possessed a secular purpose, the court would have then considered the effect of the law on those persons alleging the breach. Thus, according to the Big M Drug Mart decision, a law may be rendered unconstitutional not only because of a discriminatory purpose, but also because of a discriminatory effect (see also Pentney 1988: 22, n. 26b).

Similarly, the independent living/disabled consumer movement has attempted to distinguish between formal and substantive equality in order to argue that both should be within the ambit of legislative and judiciary interpretation -- at least as far as section 15(1) of the Charter is concerned (Peters 1987b: 12-14). The notion of formal equality concerns the similar or identical treatment of individuals regardless of their differences. Using gender to illustrate her point, Peters argues that under a theory of formal equality the desire to create a gender neutral and non-sexist world would focus on abolishing the differences between males and females, men and women. While there are many differences that could be eliminated because of their sexist and oppressive nature, treating women exactly the same as men would only have the effect of excluding such important issues as rape, prostitution, and wife abuse that are of unique concern to women (and to society) from equality considerations. Clearly, the focus should not be on gender [disability!] differences, but on the differences that gender [disability!] makes or creates. Applying a theory of formal equality would not address historical patterns of political and socio-economic inequalities that are part of women's or any supposedly disadvantaged group's experience.

A similar result, says Peters, is produced were a theory of formal equality to be adopted in dealing with disabled people's rights. To treat disabled persons precisely in the same manner as non-disabled persons would completely disregard the various structural and systemic discriminatory barriers that exist in the community and in society that are of deep concern to the disabled consumer movement. The case of <u>Huck v. Canadian Odeon Theatres Ltd.</u> [1981 2 C.H.R.R. D/521, also Re: Saskatchewan Human Rights Commission and Canadian Odeon Theatres 1985 18 D.L.R. (4th) 93] likewise serves to illustrate this point. Michael Huck was treated exactly like all other patrons wishing to see a movie in an Odeon theatre. However, because he used a wheelchair he was forced to view the movie from in front of the first row of theatre seats. Although Odeon Theatres treated Huck identically to other patrons, identical treatment created a negative effect because he is different in one respect from a non-disabled person or from other patrons.

The Saskatchewan Court of Appeal agreed with this analysis and ruled that identical treatment does not necessarily result in equal treatment. Measures such as reasonable accommodation and programs such as affirmative action (e.g. employment equity, etc.) would probably find little favor under a formal approach to equality. In a society that welcomes gender, cultural, social, religious and other "differences" between people (e.g. the idea of unity in diversity), such a formal approach to equality would seriously undermine the goals of liberal pluralism. From the perspective of disabled people there would certainly be little to gain from supporting a formal approach to equality.

The "equal protection" and "equal benefit" clauses of section 15(1) and the affirmative action provisions of section 15(2), together with the "purpose and effect" test that the courts have applied, suggest that another dimension of equality exists and should be recognized.

From the perspective of disabled citizens, applying neutral standards will not eliminate inequality and oppression. A theory of equality must recognize that there really are differences between people and that not everyone is the same. Equality, in other words, does not mean "sameness." Factors such as powerlessness, exclusion, and disadvantage are of course the direct consequence of the subordination of certain groups and the domination of others, and the application of so-called neutral standards implies "sameness" or conformity to specific values and ideals.

I would offer the comment that with regards to the application of standards in general, most human rights statutes in Canada now recognize that discrimination can be both intentional (direct) as well as have an adverse effect (indirect, or unintentional) on people (Tarnopolsky and Pentney 1985: 4.29 ff). This distinction has enabled individuals who have been adversely affected by a procedure, program, policy, or law because of their "differences" to seek legal redress for the harm that was suffered. One can therefore argue that one of the purposes of the equality rights section of the Charter is not only to ensure that people are treated in a "like manner," but also to recognize the inequalities created by disadvantage or adverse effect.

My impression from Peters (1987b) is that disabled citizens would perhaps argue that the notion or idea of substantive equality does not imply a double standard. Clearly, one of the goals of disabled people is to be integrated into the community. This involves taking the same risks and, at the same time, assuming the same responsibilities as other citizens -- regardless of their individual or so-called categorical differences. A substantive approach to equality does not negate this goal, according to them. Rather, and more to the point, such an approach provides a means by which to assert such demands as reasonable accommodation, affirmative action programs (to some extent), special tax deductions (e.g. COPOH 1987b, 1987g, 1989c), and significantly greater access to the physically constructed environment.

Thus, a theory of substantive equality legitimizes the goal of ensuring equality of results; both formal and substantive equality have a place in section 15 of the Charter of Rights and Freedoms. As I noted above, equality "before" and "under" the law implies a form of procedural equality. This means that the law must apply to and must treat everyone fairly. The guarantee of procedural equality is based on the notion of formal equality, that is, everyone has the right to expect that the law will be applied to all persons in an equal manner. To bring a challenge under the Charter in this regard, an individual must indicate that the law, as it applies to them, is discriminatory on grounds of arbitrariness, unfairness, and unreasonableness.

By contrast, substantive equality would come into effect where a claim is made that a particular law perpetuates a certain socio-economic disadvantage. In a situation such as this, section 15(1) of the Charter sets out a number of grounds which are also found in most provincial human rights statutes that may serve as a guide in identifying those groups in society who experience adverse effect discrimination. Other grounds such as political beliefs, citizenship, marital status, and (arguably) sexual orientation have also been cited as possible bases for substantive equality claims.

Following the work of Peters (1987b) and others, the disabled community recognizes that it is not enough to make a claim for substantive equality on the basis of one of these grounds or on any another enumerated in the Charter. But disabled citizens do argue that members of groups that have been victimized by discrimination (e.g. stigmatized and stereotyped on the basis of a group or individual characteristic) and that suffer disadvantage and powerlessness should receive the protection of a substantive (or effect) approach to equality under the Charter of Rights.

Thus, Peters (1987b) makes the point that to advance a claim for substantive equality under section 15 one must first show that one is a member of one of the enumerated groups that are recognized by the Charter, and so is specifically protected by it. Second, an individual must be able to demonstrate that he or she has suffered disadvantage worthy of a substantive equality remedy. Essential to community-building, I would agree with those writing on behalf of disabled citizens (such as Peters) that a comprehensive theory of equality requires both formal and substantive approaches. As members of Canadian society we are all entitled to formal equality, while at the same time citizens who can show that they are being disadvantaged should also be entitled to substantive equality that takes into account some of the inherent (and welcomed) social, cultural, and physical individual differences between citizens.

Discrimination and the Law: A Basis for the Concept of Reasonable Accommodation

Lepofsky and Bickenbach (1985: 328) have pointed out that equality rights expressly for disabled people is a recent development which does not have its roots in the common law. According to these authors there is no general common law principle affirming the entitlement of disabled people to equality of rights under law. During the past ten years disabled Canadians have therefore made major strides in attaining equality by securing legal recognition of their community and citizenship rights in human rights legislation. Through considerable efforts, disabled citizens have finally succeeded in acquiring legal protection of their human rights at both provincial/territorial and federal levels. During the 1980s the federal government, along with several of the provinces, amended human rights legislation to ensure that such protection also extended to persons with mental disabilities (e.g. the Canadian Human Rights Act; Canadian Human Rights Commission 1987, Pentney 1988: 69).

The inclusion of persons with disabilities in human rights statutes means that, in theory at least, discrimination on the basis of disability is prohibited in such areas as employment, housing accommodation, and access to goods, services, and facilities. With respect to the Charter of Rights and Freedoms, the equality rights section has filled a gap in Canadian human rights law, and applied specifically to disabled people, is "a genuinely new and unprecedented right in Canada" (Lepofsky and Bickenbach 1985: 331-332, original emphasis).

In my view, the fact that disabled persons have obtained both statutory and constitutional protection of their rights over the past two decades represents an unequivocal accomplishment. Statutory rights to equality under the law without discrimination on the basis of physical disability were, for all intents and purposes, non-existent before the 1970s. As disabled citizens have come to discover (COPOH 1989e), a great deal now still depends on how existing power structures, including the governments and the courts, will interpret and apply these legislative protections and constitutional guarantees. Disabled persons must therefore actively continue their efforts to press for the particular kind of equality they feel will help eliminate their often shared experiences of stigma, oppression, and exclusion from mainstream community life. Identifying the kinds of discriminatory barriers to integrated community living that exist and proposing methods of eliminating discrimination is one obvious place to begin.

My reading of COPOH and other materials suggests that disabled citizens identify and confront several types of exclusionary and discriminatory barriers which are of concern to them with regards to human rights legislation and policy formulation (see also Baker 1985: passim, Lepofsky and Bickenbach 1985: 324-326). So-called social bias discrimination, for example, denies a particular benefit to an individual solely because of ignorance, discomfort, or hostility aimed at the group or category to which the individual supposedly belongs or with which he or she is identified. Such attitudes have largely been responsible for the development of segregated services, and for preventing full participation and integration into the community. Social bias may also manifest itself through stereotyping or stigmatization. Poverty, low levels of attained education, and lack of self-worth -- the consequences of discrimination -- are of course factors that perpetuate the notion that disabled persons are helpless, incapable and dependent, and thus by implication, inferior to able-bodied persons. Of course, the barriers provoked by social bias have nothing to do with a disabled individual's ability and/or competence. Rather, a negative attitude about a particular trait connected with an individual or category of individual constitutes the basis of exclusion.

Standards as applied in law or elsewhere, seemingly neutral on their face, can also operate to exclude certain classes or categories of individuals. A "neutral standard" barrier establishes a general rule or condition that has, unintentionally, a negative impact on a disabled person's access to equal opportunity. Unlike some social bias barriers, neutral standard barriers are not intentionally aimed specifically at excluding persons, but they nevertheless impede a disabled person's access to equal opportunity. Examples might include: A standard telephone which is not compatible with hearing aid equipment; a request about a potential employee possessing a driver's license (which cannot be obtained by visually impaired persons); a requirement that a potential employee pass a medical physical examination which obtains information pertaining to an individual's physical health which is not relevant to the job in question.

A third barrier that I can suggest, namely that of "failure to accommodate," arises when two factors are present: First, except for an individual's impairment, the individual possesses the qualifications necessary to perform the job in question; second, that efforts were not made to actively accommodate the individual's limitations created by his or her impairment. An example might be that of a deaf university student. The student would without question benefit from classroom participation, and no neutral standard would otherwise bar the student. However, the institution's or the student's inability or failure to provide interpreter services, combined with the student's communication impairment, would serve to prevent the student's full participation.

Disabled citizens also cite "insurmountable impairment" barriers as those which are caused by an individual's disability that cannot be rectified to permit full participation in a program, service, employment situation, and so on (Baker 1985, passim). Absent drastic alterations, no degree of accommodation could reasonably provide the benefits of programs and services to the impaired person. Accommodation is virtually impossible since the impairment, whatever it might be, removes an essential capacity for benefitting from whatever the program, service, or employment possibility might offer. In this situation, alternative programs, services, and accommodating structures as an altogether different dimension to accommodation, would be sought.

To these four barriers might be added an important fifth, namely "neglect" of differences. My interpretation is that by this disabled citizens mean that exclusionary barriers exist primarily because "society" ignores or neglects differences between people. Society, as they recognize it, is composed of people exhibiting a wide variety of differences, which include linguistic, cultural, and religious differences, as well as educational, physical, and biological differences. Programs, services, policies, and laws which treat people as if they were identical thus serve to maintain the domination and interests of a small group by further exacerbating the discriminatory barriers I noted above. In reality, differences may not be perceived, they may be ignored on purpose, or it may be felt that, for utilitarian reasons, they need not even be addressed. In my view, this is how "differences" between people have often been dealt with in law and in public policy.

Finally, a discriminatory barrier identified by Kallen (1989: 75-77) that is not at all an obvious one is "discrimination of silence," or discriminatory acts of omission. Discrimination of silence is where "majority members -- those with the legitimate power to do something -- choose to say nothing and do nothing about discrimination against minorities." Majority members such as academic researchers, social scientists, educators, law enforcers, policy makers, and others continue to violate the rights of minorities, for example, by discouraging research on particular topics (e.g. homosexuality), and by insisting that stigmatized minorities are either deviants or categorically different from others in society (e.g. sociology of deviance, abnormal psychology, child psychology, rehabilitation medicine, special education, gerontology, etc.). Whether those "in power" do nothing, cover up, or continue to justify differences between people because they are afraid of stigma by association, face-to-face encounters, or of exposing the invalidation myths on which policies are founded, their (in)actions nevertheless continue to violate fundamental principles of human rights (Kallen 1989: 75).

Thus, to inject real meaning into the goal of eliminating the various kinds of discrimination encountered by persons with disabilities, I concur with Peters (1987a) that the concept or idea of reasonable accommodation must be recognized and developed. The term reasonable accommodation, which I discuss in greater detail below, refers to measures which are designed to enable a disabled person to overcome barriers resulting from either his or her disability, or from the environment. Reasonable accommodation is seen as a kind of equalizing force that ensures that a disabled person is no more burdened than his or her non-disabled peers when participating in normal community living. However, because reasonable accommodation is allegedly associated with large expenditures of public money as well as "inconvenience" to society in general (and business in particular), the idea has been negatively perceived. As a background to the concept, however, I wish to first provide an overview of discrimination and laws that pertain to it.

Discrimination and the Law

To understand how the concept of reasonable accommodation can be useful in reducing or eliminating the effects and consequences of discriminatory behaviors (barriers) I just described, I want to explain what is commonly understood by the term discrimination. It is interesting to note that it has only been in the last twenty years or so that the scope and impact of discrimination on disadvantaged groups has received concerted attention. The last two decades have seen the introduction of human rights legislation and the establishment of human rights commissions to administer and enforce the legislation (Tarnopolsky and Pentney 1985: Chapters 2, 3, 14, and 15). At the same time, the existence of human rights legislation precipitated the need to develop theories of discrimination to assist in the interpretation of such legislation. There seems to have developed a sort of evolution of an understanding of discrimination that has tried to probe the social, economic, and political forces underlying such practices, behaviors, and policies.

Discriminatory behavior can be divided into two general categories, or types: Intentional (direct) and unintentional (indirect)(compare Kallen 1989: 71). Initially, human rights legislation focused on prohibiting intentional forms of discrimination for the simple reason that it was obvious and relatively easier to identify. Canadian courts have therefore, in the past, given human rights legislation a very narrow interpretation. Direct discrimination is frequently motivated by ill will, malice, or prejudice, which is harboured by an individual against other individuals or groups (Tarnopolsky and Pentney 1985: 4.29). This form of discrimination occurs when an individual consciously and deliberately restricts or denies opportunities to certain persons who happen to possess a certain characteristic. The chief element which must be proven in a complaint of intentional discrimination is that the perpetrator intended to discriminate. Most human rights commissions have developed a fair track record for handling complaints of this type (e.g. Canadian Human Rights Commission 1987).* However, it has to be kept in mind that

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* Edward Hore, writing in <u>Saturday Night</u> magazine (September 1989, pp. 25-28), has all but condemned the commissions for the inordinate length of time it takes them to resolve cases (despite huge budgets), for the large costs that are incurred (usually by the

remedies for this type of complaint usually only benefit the individual complainant, and do little to resolve broader, subtler, and more insidious forms of discrimination that are a great deal more pervasive in society.

As human rights law developed, it became clear that focusing solely on intentional, or direct, discriminatory practices and behaviors did little to remove the barriers to equality of opportunity. It was recognized that policies, practices, and procedures (e.g. legal, employment, etc.) themselves constituted barriers, either in and of themselves, or when carried out. Unintentional, or indirect, discrimination is also referred to as adverse effect, institutional, and systemic discrimination (Tarnopolsky and Pentney 1985: 4.34 ff, Hughes 1985: 228, Kallen 1989: 72-73, 80-100). An individual's intent and motivation is no longer the sole factor in determining whether discrimination has occurred. Rather, it is the harmful effect that a particular program, policy, or practice may have on a group of individuals that becomes important. Thus, a policy or practice which is seemingly neutral on its face can be determined to have created a negative impact on a certain category of persons. The recognition of the harmful effects caused by unintentional discrimination requires that social institutions and systems be monitored and evaluated.

One of the earliest cases to address the effects of unintentional discrimination was rendered in 1971 by the United States Supreme Court in <u>Griggs v. Duke Power Company Limited</u> [401 U.S. 424 1971]. The Duke Power Company had an employment policy of hiring both black and white employees. However, to be considered for or to

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respondent), for inadequate investigations of often invalid complaints, and for their obvious political connections. Hore suggests that commissions should do nothing more than recommend cases to Crown prosecutors who would decide whether a case should go to court or not, and developing legal aid for those who need it. Hore's point is a good one, in light of the need to often go beyond the individual case to address institutional and systemic discrimination.

obtain a promotion employees were required to possess a grade XII certificate and pass an aptitude test. Griggs alleged that such requirements were not employment related and that due to socio-economic factors, such requirements had the net effect of eliminating a disproportionately higher number of black individuals than other people. The U.S. Supreme Court agreed with Griggs, and held that practices or procedures which were neutral in their face, and which do not constitute a business necessity, cannot be maintained if they perpetuate discrimination against a category or class of persons.

Importantly, the Griggs analysis has been adopted in a number of Canadian cases (Tarnopolsky and Pentney 1985: Chapter 4; see the essays in Smith, et. al. 1986). Of particular note are two cases decided by the Supreme Court of Canada in 1985 (Pentney 1988: 14-17, 21-32, Hughes 1985: 228-229). The case of O'Malley v. Simpson-Sears [1985 2 S.C.R. 536] as well as Bhinder v. Canadian National Railways [1985 2 S.C.R. 561] endorsed the practice of interpreting existing human rights statutes to include prohibitions of unintentional forms of discrimination. At issue in O'Malley, for example, was whether a complainant had to prove that there was an intention to discriminate before an allegation of discrimination could be substantiated.

O'Malley, a Seventh Day Adventist, was reduced from full-time to part-time work because her employer, Simpson-Sears, required her to work Saturdays. The company restricted her hours because she could not work Saturdays, which they deemed an essential requirement for a full-time position. The court subsequently rejected the notion that the Ontario human rights code only prohibited intentional discrimination, and it adopted the view that the code also protected persons from unintentional or "adverse effect" forms of discrimination. The requirement to work Saturdays in order to secure full-time work was found to be a form of adverse effect discrimination in that the requirement affected a person differently from others by imposing a particular obligation or penalty. It is interesting to note, too, that the judgement also discussed the duty of an employer to provide some form of reasonable accommodation for those employees adversely affected by an employment policy.

The reasoning articulated in the O'Malley decision was likewise adopted by the Supreme Court of Canada in the Bhinder case, but with an entirely different outcome. Bhinder was decided under the Canadian Human Rights Act, and involved a man of the Sikh religion who worked in a CN coach yard. Canadian National's hard hat policy (making the wearing of a safety helmet mandatory for employees working in the coach yard) came into direct conflict with a fundamental precept of Bhinder's religion, namely that a Sikh male must always wear a turban, over which nothing could be worn. Bhinder would not compromise his religious beliefs by wearing a hard hat, and so was forced to terminate his employment with CN.

My analysis is that the main issue considered by the courts was not the employer's attitude toward Sikhs, but the effect of the hard hat rule on a class of persons because of their religious beliefs. While the court acknowledged that adverse effect discrimination was prohibited by the Act, Canadian National's rule was upheld on the ground that it was a <u>bona fide</u> occupational requirement (BFOR) as described by the Act itself. Thus, while the O'Malley case was decided under the Ontario Human Rights Act and the Bhinder case under the Canadian Human Rights Act which encompasses federal jurisdiction, the Supreme Court issued a clear message declaring that both intentional and unintentional forms of discrimination are prohibited by both provincial and federal human rights statutes.

<u>Defences to Allegations of Discrimination</u>

I do not doubt that intentional and unintentional forms of discrimination have taken their toll in preventing the participation of persons with disabilities in their communities and in society. In my view, discrimination of these sorts create social and economic barriers that alienate and oppress persons with disabilities. It turns out, however, that an alleged act of discrimination even under human rights legislation may not necessarily entitle the complainant to a remedy.

Provincial and federal human rights statutes contain something called an "exception clause" (usually pertaining to employment) which actually permits the contravention of anti-discrimination provisions set out in the legislation. Such a clause refers to the "reasonable occupational qualification" (ROQ), or more commonly, the "bona fide occupational qualification" or requirement (BFOQ/R) clauses in a statute. Qualifications may be on the basis of age, gender, marital status, and perhaps physical and mental disability (Tarnopolsky and Pentney 1985: 4.46-4.50, 9.22-9.27, Pentney 1988: 17-20). Their purpose is to provide employers with a defence to charges of discrimination where the employer can demonstrate that the "offending" practice or policy is necessary to the performance of a task or job.

The BFOQ clauses suggest that employers are allowed to intentionally discriminate on otherwise prohibited grounds. The BFOQ clauses in provincial human rights statutes often directly mention specific limiting characteristics, such as age, gender, marital status, and physical ability. The BFOQ clause found in the federal Canadian Human Rights Act, however, takes a slightly different approach. Employment practices exempted under the Act are not connected to a specific characteristic at all; rather, the Act merely states that any limitation or specification expressed by the employer must be a bona fide occupational requirement.

Despite differences between federal and provincial human rights legislation, employers are still obliged to meet certain requirements before being able to claim a BFOQ (or BFOR) defense. A case that is often cited is Ontario Human Rights Commission v. Borough of Etobicoke [1982 1 S.C.R. 202], decided by the Supreme Court of Canada in 1982 (see Tarnopolsky and Pentney 1985: 9.26, Hughes

1985: 231-232). The case involved a fire-fighter who was manditorily retired at age 60, which was in violation of the Ontario Human Rights Code. The respondent argued that firefighting was a demanding and rigorous occupation, which qualified age as a BFOQ. The Court said that to meet a BFOQ defense, the employer is obliged to show, first, that the requirement or limitation is based on an honest and genuinely held belief, and, second, that this particular employment requirement is related in an objective sense to the performance of the job. The employer, in this instance, had to provide some kind of factual evidence demonstrating or proving that persons over the age of 60 cannot fight fires effectively.

According to Supreme Court decisions, however, it is not advisable to prohibit discrimination against certain classes or categories of persons in all instances. There might be some situations in which a distinction based on a characteristic <u>is</u> justifiable to ensure satisfactory job performance, among other things. For example, an employer of taxi drivers might reasonably deny employment to persons who are blind, even though that would, obviously, constitute discrimination on the basis of physical disability. But in order to justify discrimination against an entire category of persons (i.e. blind persons), the employer must show that practically any person who can be identified as a member of that category, possesses a characteristic that prevents him or her from performing the necessary or essential duties of the job in a satisfactory way.

Stereotypical assumptions are not condoned, however. An employer cannot assume, for example, that no woman will be able to perform strenuous manual labor even if, arguably, men on average have greater capacity for physical work. It is still necessary to show, as in the Etobicoke case, that there is a "problem" with all members of a class. Impressionistic evidence is not sufficient to establish a case (the example of blind taxi drivers aside). Onus of proof is apparently on the employer and the evidence, if sufficient, must establish that few if any members of a particular category can meet the requirements of the job.

It has been argued by disabled citizens that implicit in establishing an occupational requirement is the requirement that employers make some kind of reasonable effort to accommodate an individual who would otherwise be subject to discrimination. To-date (1989), most (provincial) human rights legislation, even that amended or revised since the Charter of Rights became law and including the Canadian Human Rights Act, do not possess specific provisions prescribing a duty to provide reasonable accommodation (COPOH 1989e). Reasonable accommodation would seem to be a kind of affirmative action because the concept requires positive action on the part of an employer (or someone providing a service) to make reasonable accommodation to a known physical or mental limitation of an otherwise qualified employee (or a member of the public).

Before an employment requirement can be deemed to be reasonably necessary, an employer must first show that providing reasonable accommodation is impossible or impractical. An employer, for example, could easily show that the exclusion of blind persons from positions as taxi drivers as being reasonably necessary in that the provision of some form of accommodation is impossible (and from the point of view of the safety of the public, undesirable!). However, an employer who excludes all persons who use wheelchairs because the worksite can only be accessed by climbing stairs would probably not meet the "reasonably necessary" element because it might be possible to make structural renovations and alterations to the worksite. An employer must be able to show that a specific characteristic of an otherwise protected category of persons can be predicted to almost always lead to employment failure, and/or that accommodations for such persons would be unreasonable, or impractical in terms of material costs, safety, and so forth. The Bhinder case shows that reasonable accommodation may not always be possible, and that discrimination is justified in law.

With respect to costs and other requirements of running a business, the Supreme Court in O'Malley stated that where it is shown that a rule has caused discrimination the onus is on the employer to make an effort to accommodate the needs of employees, short of "undue hardship" in the operation of that business. Significantly, the judgement in the O'Malley decision also included a statement to the effect that "no right is absolute," and that "rights must be limited in the interest of preserving a social structure in which each right may receive protection without undue interference from others" (op. cit. McIntyre, J. in Peters 1987a: 18, Kallen 1989: 6).

In other words, an employee can expect an employer to accommodate his or her religious beliefs -- or disability. At the same time, an employer should not be expected to provide accommodations that are unreasonable, that could result in a disruption of business, or that involves undue expense. A balance must be struck between these two positions, and it is the notion of reasonable accommodation that, in theory at least, might provide it (Tarnopolsky and Pentney 1985: 9.27-9.33, Ratushny 1986).

Reasonable Accommodation: Definitions and Legal Issues

Achieving equality for persons with disabilities so that they may live independently and be integrated into the community cannot be attained by simply ensuring that disabled persons are treated the same as non-disabled persons. This deceptively simple proposition received overwhelming support from the Saskatchewan Court of Appeal in the case of Huck v. Canadian Odeon Theatres (already noted above), which I briefly describe here (cf. Kallen 1989: 196-197). Michael Huck used a motorized wheelchair as his primary means of mobility. He attended the Odeon Theatre in Regina with the intention of viewing a movie. Huck gained access to the theatre and was sold a ticket in the same manner as all other patrons. However, when he entered the viewing area he was told by theatre staff that he would either have to transfer from his wheelchair into a regular theatre seat, or park his wheelchair in front of the front row of theatre seats.

Huck complained to the Saskatchewan Human Rights Commission and alleged discrimination on the basis of physical disability, and on the grounds that the theatre's seating arrangement did not provide spaces that could accommodate a wheelchair. Odeon Theatres argued that they did not discriminate against Mr. Huck because he was not denied an opportunity to view the movie, and that the theatre had in fact granted him a privilege by permitting him to park his wheelchair in front of the front row of seats. The Saskatchewan Court of Appeal rejected the theatre's arguments by stating that a physically reliant person does not "acquire" an equal opportunity to utilize facilities or services which are of no use to him or her; identical treatment does not necessarily mean equal treatment or, for that matter, lack of discrimination.

The Court of Appeal stated that if Odeon Theatre's interpretation were correct, the owner of a public facility who offers washroom facilities, for example, to a disabled person that is of the same kind offered to the public generally, or offers any other service notwithstanding that it cannot be used by a wheelchair reliant person, will then be found to have discharged his or her obligation under the Human Rights Code. From that perspective, no changes would ever have to be made! The theatre's interpretation, of course, was found to be incorrect.

Achievement of equal opportunity therefore depends on a great deal more than just equal treatment or equal sevices and programs for all. Reasonable accommodation may be regarded as a kind of "equalizing device" which ensures that equal access translates into equal results. Thus, transcribing printed text books into braille or unto audio cassette simply enables a blind student and a sighted student to access the same material and to learn, or compete, on a more realistic and equal footing. Though an integral part of human rights law, the concept of reasonable accommodation is nevertheless a young one in Canadian human rights legislation, so that a concrete and legally useful (i.e. useful in law and policy) definition of the concept is still developing (Tarnopolsky and Pentney 1985: 9.27-9.33, Hughes 1985: 239-240).

According to Peters (1987a),* the phrase reasonable accommodation as it pertains to persons with disabilities first appeared in employment regulations issued pursuant to a section of the U.S. Rehabilitation Act of 1973. The concept of accommodation was gradually broadened into a generic term that came to encompass the removal of architectural, transportation, and communication barriers. A 1983 report issued by the U.S. Commission on Civil Rights, which Peters cites and draws from, attempted to set out a working definition. The report stated that reasonable accommodation means "providing or modifying devices, services or facilities, or changing practices or procedures in order to match a particular person with a particular program or activity" (op. cit. in Peters 1987a: 24-27, Hughes 1985: 238).

This working definition, as suggested by the U.S. Commission, was premised on two orienting principles. The first principle espouses the notion that a disabled individual requesting a service or applying for an employment opportunity would otherwise be qualified were it not for a physical or mental limitation. The meaning of "otherwise qualified" was addressed in a number of U.S. cases. In one case discussed by Peters, a hearing disabled nurse sought admission to a college degree nursing program in order to fulfill eligibility requirements for certification as a full registered nurse. In this instance, the court held in favor of the college who rejected her application, on the grounds that the college could imposed necessary or essential physical requirements for its nursing program. The court determined that the candidate could not safely participate in the nursing/clinical program without extensive modification of the program, and that the ability to hear was a necessary requirement; the court did not, therefore consider the student to be "otherwise qualified." Reminiscent of the Bhinder decision, the court also

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* The following discussion draws primarily from Peters (1987a).

determined that some requirements and practices could legally exclude disabled persons if they were determined to be necessary and essential, or that modification to an existing program would be unreasonable, impractical, or impossible.

In another U.S. case illustration noted by Peters (1987a: 26), an employer refused to absorb the costs of an assistant reader who was hired by some maintenance workers employed by the Department of Public Welfare; the reader was engaged to facilitate the paperwork that the job had come to entail. The employer argued that the blind workers were not "otherwise qualified" as they did not possess the ability to read printed material, and that the accommodation necessary (e.g. paying the costs) was for them a hardship. The court, however, held that with the assistance of a reader, the blind employees met the requirements of the position in all respects in the same way as sighted employees, and could thus be considered "otherwise qualified." The court went on to hold that the cost of providing a reader represented only a fraction of the Department's administrative budget, and that the department had failed to meet a defense of "hardship." Paying the costs of a reader would thus have been a reasonable accommodation to the needs of the blind workers.

The second orienting principle underpinning the concept of reasonable accommodation as put forth by the U.S. Commission on Civil Rights is the notion of individualized assessment. Arguably, unlike other protected characteristics, such as gender and race (or ethnic origin), disability is not a homogenous or static characteristic. A variety of physical and mental conditions, impairments, and limitations may be classified under the broad rubric of "disability" (I discussed this in Chapter 2). Within each classification, in turn, are sub-classifications which encompass a wide range of abilities, skills, and aspirations. In light of these facts, Peters (1987a) suggests that it is therefore impractical, perhaps even impossible, to devise a uniform formula for providing reasonable accommodation to persons with disabilities.

Peters, as do other disabled citizens, argues that the kind of accommodation that an individual requires will depend largely on the degree and nature of his or her disability, on his or her's coping strategies, and, of course, on the essential requirement of the job or program in question. One approach might be to determine under what circumstances reasonable accommodation is not possible (from the point of view of the employer or service provider). Following these two orienting principles, disabled citizens in the United States as well as in Canada have argued that, for the concept of reasonable accommodation to be embodied in policy and put into practice, the following are crucial questions necessary to operationalize the concept (Peters 1987a: 27):

1. What are the requirements of the program or employment opportunity? Can the essential requirements be distinguished from the arbitrary or unreasonable requirements?

2. What are the skills and abilities of the disabled individual? Is the disabled person otherwise qualified, but for a physical or mental limitation?

3. Is it possible to alter or modify requirements to accommodate the limitations caused by an individual's disability?

4. Is the accommodation necessary, feasible, or does it fundamentally alter the nature of a program or employment opportunity, or is it financially burdensome?

The Canadian Human Rights Commission has developed guidelines which prescribe the relationship between the Canadian Human Rights Act (e.g. section 14(a), concerning the BFOQ/R clauses), and employment practices. Implicit in the guidelines is the duty of an employer to provide accommodation when he or she offers an employment opportunity to a person with a disability. The guidelines identify criteria which may assist in determining when reasonable accommodation is impractical. An example of the guidelines illustrating this reads as follows (Canada Gazette, Part II, January 13 1982 but op. cited in Hughes 1985: 240, and in Peters 1987a: 28):

> Where an employer finds that he or she cannot make reasonable accommodation in order to offer an employment opportunity to a handicapped person, and before he or she [denies] such employment opportunity based on a bona fide occupational requirement, the employer shall support his or her findings based on evidence that:
>
> (a) No method of accommodation exists that would permit the handicapped person to perform the job in a safe and satisfactory manner;
>
> (b) To make an accommodation would impose an undue hardship involving either financial cost or business inconvenience to the employer; or,
>
> (c) To make an accommodation would create a predictable safety hazard for the employees or the general public.

Though these guidelines are binding upon the Commission and upon any tribunal that hears or reviews a complaint under the Canadian Human Rights Act, they are not binding on the courts. According to disabled citizens (Peters 1987a), this fact, together with the Supreme Court's ruling in the Bhinder case that a BFOQ/R does not always include a duty to accommodate, seriously diminishes the effectiveness of the federal guidelines.

Implementing Reasonable Accommodation

There are of course a number of different ways by which the idea of reasonable accommodation has come to be embodied in both the law and public policy. I would suggest that largely as a result of significant efforts by the disabled consumer movement by way of lobbying efforts, appearances before parlaimentary committees, and the consultation process, the federal government finally introduced employment equity legislation in the summer of 1986 (e.g. beginning with Abella 1984, Parliamentary Committee on Equality Rights 1985, COPOH 1985c: 18, the Employment Equity resolution 3.85.29, Government of Canada 1986; see Appendix 3, Item 6 for the Act itself). The aim of this legislation was to ensure that designated groups, including the disabled, could achieve a degree of representation within the workforce.

Employment equity has been defined to include special measures as well as the accommodation of differences. One of the tools for enforcing commitment made in the legislation itself is the powers contained in the Canadian Human Rights Act (Greschner 1988). However, because the Bhinder decision essentially rejected the requirement to accommodate in all cases, disabled consumers doubt that the Human Rights Commission has the ability to carry out its purported enforcement mandate (Peters 1987a, COPOH 1989e). Nevertheless, Employment and Immigration Canada prepared a Guide for Employers which defines the terms "special measures" and "reasonable accommodation"; they provide some insight as to how these terms will be applied at the federal level (Employment and Immigration Canada 1986a,b, 1987a,b).

Employment equity includes not only the removal of barriers, but also the implementation of special measures (such as affirmative action) and the application of the concept of reasonable accommodation. Special measures such as targetted recruitment or special training initiatives are aimed primarily at correcting, over a specific period of time, employment "imbalances" that are a consequence of past discrimination (Government of Canada 1987: 6-9, Pentney 1988: 32, 37 ff, Employment and Immigration Canada 1988a,b; see Appendix 6, Item 1 for facts and figures pertaining to the employment equity workforce with regards to the participation of disabled persons, at least in the public sector).

These special measures are intended to hasten the achievement of fair representation in the work force of qualified women, Native people, visible minorities, and persons with disabilities. In most jurisdictions employers must base special measures on a thorough work force analysis. Employers are also advised to consult with the relevant federal or provincial human rights agency prior to carrying out the program, so that they can be in a position to assure employees and managers that a particular special measure is indeed an appropriate and necessary strategy (see Kallen 1989: 208-210 for a brief but useful discussion of employment equity and an associated concept, contract compliance).

According to Employment and Immigration Canada's definition, reasonable accommodation requires that adjustments to employment policies and practices be made so that no individual is denied benefits, is forced to compete at a disadvantage for employment opportunities, or is blocked from carrying out the essential components of his or her job because of race, color, gender, or disability. Human rights tribunals have placed employers under a duty to be flexibile in meeting the needs of employees; it is no longer acceptable for employers to assume a priori that all employees will "fit in" regardless of their special needs, or that they cannot be accommodated without exception.

Reasonable accommodation can involve such measures as redesigning job duties, adjusting work schedules, providing technical, financial, and human support services, and upgrading facilities (e.g. Rioux 1985: 628-634, Peters 1987a: 33-34).* More specifically, there

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* A Globe and Mail article (October 23 1989) noted that "some employers mistakenly believe that hiring disabled employees means a truckload of extra technical devices." Instead, "usually minor adaptations, specialized training and a little sensitivity" will

some six possible types of accommodation that can be introduced in the workplace and the work setting:

> Environmental. These may include improved lighting, adequate or improved ventilation, reduction of temperature fluctuations and changes, lowered noise levels, etc.
>
> Physical. Here, the use of adjustable tables, relocation of switches, use of interchangeable light or sound signals (for the deaf or visually impaired, might be considered.
>
> Minor Worksite. This would encompass process flow modifications, rearrangement of equipment or machines, and some organizational restructuring.
>
> Job Structuring. This form of accommodation may involve task modification, task elimination (entirely or in part), task reassignments, or recombinations of tasks. The latter may assist in providing additional employment opportunities at lower skill levels, additional promotional lines, job enrichment, or situations designed to meet the specific needs of disabled employees or qualified disabled applicants.
>
> Support Services. Examples of this type of accommodation may include the use of readers, sign language interpreters, part-time helpers, and personal care attendants.

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integrate disabled workers "almost painlessly." It is suggested in the article that 80% of disabled workers need few or no special concessions at all. Building, office layout and facility modifications that are required can be funded by cost-sharing agreements between the federal and provincial governments, and by grants from Canada Employment and Immigration.

> Rearrangement of Work Schedules. In some instances it may be necessary to rearrange hours of work to meet certain needs. Such rearrangement may include flexible hours, compressed work weeks, job or time sharing, or part-time work hours.

COPOH (1987g: 2-6) has suggested that reasonable accommodation of perhaps other types can sometimes benefit employees of all kinds. The provision of allowances for child care expenses, for example, when employees take company-sponsored courses not only removes a barrier that blocks many women, but likewise assists any employee faced with sole parenting responsibilities. Even tax exemptions, deductions, and credits for low-income earners, or those with expenses that the majority in society would not have, are a kind of accommodation in that they make available cash that can then be put back into the economy, rather than having to be obtained through transfer payments.

Policies promoting reasonable accommodation are frequently incorporated into comprehensive affirmative action plans. Nevertheless, Peters (1987a) notes that reasonable accommodation and affirmative action are two distinct measures. Affirmative action plans are usually implemented as a remedial measure to redress patterns of past discrimination against disadvantaged groups. The aim of the program involves altering the composition of certain "sectors" of society such as employment and education by means of a quota system, goals, timetables, or other preferential treatment that serves to achieve the desired rate of participation by members of a class or category that has been injured by discrimination (see also Tarnopolsky and Pentney 1985: 4.80-4.81, Pentney 1988: 37-41).

By contrast, reasonable accommodation is not geared towards achieving a particular rate of participation by disabled (or other) individuals. Rather, the objective of reasonable accommodation is to ensure that capable individuals are not denied employment or education (or other) opportunities because of physical barriers or because they cannot meet non-essential (and thus arbitrary) program or job requirements. The duty to accommodate has become an integral component of non-discrimination law, whereas affirmative action is one strategy (not disallowed by law of course) for overcoming a history of discrimination against certain categories of people.

According to writers like Peters (1987a), disabled citizens further distinguish between reasonable accommodation and accessibility. The latter refers to changes that employers can undertake to make the personnel process, the work site, and other auxilliary services available to persons with disabilities. Removing environmental barriers in areas such as physical access, transportation, and communication benefits disabled people as a group so that as individuals they can take advantage of educational or employment opportunities with the assistance of reasonable accommodation. Accommodation, by contrast, refers to modifications which allow disabled employees to perform the essential duties of the job for which they were hired.

Although the distinction between accessibility and accommodation can be somewhat blurred, the elimination of environmental barriers for greater physical accessibility generally entails a comprehensive strategy involving building codes and equipment standards designed to assist disabled persons as a group. My reading suggests that accommodation as envisioned by disabled advocates is a policy directed specifically at the unique needs of the disabled individual.

Reasonable Accommodation: The Political Response

Various consumer organizations initiated a variety of efforts to amend, among other legislation, the Canadian Human Rights Act to include language that explicitly declares that employers and service providers have a duty to provide reasonable accommodation. In early 1986 Gordon Fairweather, then Chief Commissioner of the

Canadian Human Rights Commission, submitted a letter to John Crosbie, then Minister of Justice, which outlined the view of the Commission regarding the Bhinder case (cited in Peters 1987a: 34). The Commission recognized, of course, that the Bhinder case was decided after the 1982 amendments to the Act, but the Commission nevertheless advised that there was still a risk that the new language would not be considered a significant change, and that the courts may still not recognize accommodation. According to Fairweather's letter, the Commission's position stressed that amendments are crucial to make it absolutely certain that "to refuse to make reasonable accommodation for special needs or obligations related to a prohibited ground of discrimination" would in fact be a discriminatory practice.

In the spring of 1986 the federal government undertook a review of the Canadian Human Rights Act and invited human rights experts and interested individuals and groups to submit their views on needed changes to the Act. In June 1986, the Coalition of Provincial Organizations of the Handicapped submitted its brief to the federal Department of Justice; the brief dealt with a number of issues, but chief among them was an appeal to amend the Act to include a duty to make reasonable accommodation. In a report entitled "Toward Equality" (1986, The Response to the Report of the Parliamentary Committee on Equality Rights), the federal government dealt with the issue of reasonable accommodation as put forward in the Parliamentary Committee's recommendation number 80 (Parliamentary Committee on Equality Rights (1985: 131). Recommendation 80 reads as follows:

> We recommend that the Canadian Human Rights Act be amended so that employers are obliged to make "reasonable accommodation," that is, such special provisions as would not cause undue hardship to the employer in response to the needs peculiar to those classes of employees that are protected from discrimination by the terms of the Act.

The government's response subsequently agreed in principle that the suggested amendments were necessary, but it indicated that further considerations were necessary to determine the best way for amending the Act to include the required changes (Government of Canada 1986: 63-65). Since the release of the government's statement COPOH made several inquiries to the Department of Justice; although assurances have been given as late as 1988 that amendments are forthcoming, specific amendments have not yet been proposed (COPOH 1989a, 1989e).

My interpretation is that the independent living/disabled consumer movement in Canada considers the concept of reasonable accommodation of more than passing importance in giving life and substance to the statutory recognition and constitutional guarantees afforded the rights of disabled people in general. The concept serves as a catalyst for ensuring that disabled persons can really enjoy equality of opportunity. Disabled consumer organizations have determined that disabled persons are often barred from obtaining employment, not necessarily because they are not qualified or incapable, but because they encounter barriers within the system that could be reduced or eliminated altogether. The suggestion has been made by them, and others, that legislation which does not enforce reasonable accommodation, such as the Canadian Human Rights Act and various provincial statutes, renders the rights of disabled citizens such as those given to them under the Canadian Charter of Rights and Freedoms to be empty, hollow promises and platitudes (Parliamentary Committee on Equality Rights 1985: 129-135).

COPOH and its provincial affiliates, including the Alberta Committee of Disabled Citizens, have been active in developing a comprehensive strategy designed to expand and advance the concept of reasonable accommodation. Disabled citizens have advocated that the term reasonable accommodation, first of all, should be given a broad social interpretation and should include, but not be limited to, adjustments or modifications made to the environment, the work site, the job structure, and the work schedule. It should include providing techical aids, mechanical or other devices, and personal support services that increase or supplement an individual's capability of participating in community life. Accommodation is a means of assisting "otherwise qualified" individuals to meet stated job requirements, where it is recognized that the right to employment is essential to integrated community living.

Secondly, disabled consumers suggest that to avoid the inevitable limitations imposed by confining or restrictive language, the duty to accommodate should be assessed on a case-by-case basis. Assessment should take into account factors such as the various forms of relevant accommodation available, the degree of benefit extended to the disabled person by the accommodation, and the size and financial position of the company, employer, or service provider. Thirdly, unlike affirmative action and accessibility, which are strategies and means by which benefits can be granted to disabled people as a whole, disabled persons argue that the implementation of reasonable accommodation should be tailored to meet the unique needs of the individual disabled person. Individual abilities, coping mechanisms, and individual aspirations should be taken into account.

From the perspective of disabled consumer advocates, a number of legislative and policy changes can be suggested. All human rights legislation, for example, should contain explicit language prescribing a duty to make reasonable accommodation for the benefit of those persons protected by the legislation. The onus should therefore be placed on the employer or community service provider to demonstrate that requested accommodations might be unreasonable or would produce an undue hardship. Advocates further argue that an interpretation of the Charter's equality rights section 15(1)(2) should include reasonable accommodation as a key concept (cf. Smith 1986: 373-375). They suggest that guidelines or regulations governing the development and implementation of affirmative action (section 15(2)) and employment equity programs should also require participating organizations to develop policy statements and practices that not only reflect but incorporate the concept of accommodation.

COPOH (1987g: 4-5) felt that it would not be unreasonable, for example, to provide tax incentives to employers who provide accommodation in excess of a (predetermined) amount of money. Finally, COPOH put forth the idea that a data base could be developed that would help facilitate the selection and implementation of forms of accommodation appropriate to their different contexts. Specialized knowledge, for example, could be obtained of the organizational structures of public and private sector employers, labor relations issues, analysis of job and task descriptions, and of the availability, cost, and quality of technical aids, devices, and personal support services.

Summary and Discussion

My argument is that there has been an improvement, albeit only a gradual one, in the provision of goods and services to disabled people in society in recent years. Nevertheless, there remain a great many unnecessary barriers that inhibit disabled persons from participating as fully as possible in their communities and in their society. This situation was quite effectively demonstrated in the "historic" 1981 Obstacles report of the Special Parliamentary Committee on the Disabled and Handicapped. This particular document identified a significant number of key obstacles to integrated community living, and made some practical suggestions that would help overcome them. A rather wide range of recommendations contained in the report called for legislative, fiscal, and administrative action by the federal government in almost every significant sphere of community life, including employment, transportation, housing, education, recreation, and others. The Committee's report likewise dealt with the importance of prevention of disabilities, research and development, and perhaps most significantly, the changing of attitudes.

Complete equality of accessibility to goods and services is simply not possible in reality. As a result, the independent living/disabled consumer movement has worked to develop the concept of reasonable accommodation as the basis for anti-discrimination law, for the reason that, as Ratushny (1986: 257) states, the concept is perceived as serving a realistic middle ground "between doing nothing and doing everything." The concept of reasonable accommodation is not only an acknowledged fundamental element in the guarantee of non-discrimination for disabled persons (Tarnopolsky and Pentney 1985: 9.27), but is a means of letting the wider community know what the needs of disabled citizens are.

The concept refers to a legal duty or responsibility to take positive action to accommodate the unique needs of the disabled in the workplace, and in the provision of services, facilities, or dwelling places in the wider community. It can also be used as a defence to an allegation of unintentional, or adverse effect discrimination, if reasonable attempts to satisfy this responsibility can be demonstrated. According to Pentney (1988: 21) the combined effect of the O'Malley, Bhinder, and other cases that I noted in this chapter has been to establish the following two propositions in Canadian human rights law:

(a) adverse effect discrimination and the duty to accommodate short of undue hardship are applicable to the various Canadian human rights codes;

(b) the scope of adverse effect discrimination as well as the duty to accommodate is limited by factors that are inherent in the concepts (i.e. business rationality, undue hardship), and also by external factors (i.e. the BFOQ defense).

The first proposition is significant because it is supposed to increase the protection offered by anti-discrimination laws and make them easier to administer. Complainants and Human Rights commissions will examine the impact of policies and practices rather than getting involved in the tedious process of gathering circumstantial evidence relating to the individual complaint. I would suggest that the "adverse effect" approach to discrimination is thus useful in enlarging the remedial scope of human rights law in both quantitative and qualitative ways. A rule, policy, procedure, or practice which can be proven to have an adverse effect on an individual because of an assumed group-based characteristic will usually affect others who are "similarly situated." The remedy sought in an adverse effect case will thus benefit the single complainant as well as others who supposedly share the relevant characteristic (Kallen 1989: 202).

At the community level, the focus in an adverse effect case is on the ongoing and continuous effect of a policy or practice that is part of an employment, education, or service provision system. If that impact is adverse to the interests of individuals because of a group-based characteristic, the remedy should logically be directed to changing some of the community structures. It is for this reason that the O'Malley and other decisions mark, on one level, a turning point in anti-discrimination law. The concept of reasonable accommodation is also incorporated into human rights law in the O'Malley decision. In my view, the duty to accommodate is an integral and vital part of "equality" as that ideal is defined by many disadvantaged groups, including of course disabled citizens.

The second proposition mentioned above refers to the impact of a required accommodation on the employer's or service provider's (the "respondent") business or enterprise. It is acknowledged that the question of whether a measure of reasonable accommodation will impose an "undue hardship" on an employer cannot be resolved by focussing only on the claimed expense or inconvenience involved. There has to be a consideration of a "balancing" of rights in the interest of preserving a community structure in which the rights of both employer/public and employee/citizen receive protection. A claimed hardship that will be caused by an accommodative change must be measured in light of the benefits gained by the complainant as well as others who might benefit in order to determine whether the change really constitutes a burden.

Undoubtedly, anti-discrimination law has been made rather complex in light of these developments. The full implications for an adverse effect approach to discrimination, for the law, for those who administer it, and those who benefit by it, are not likely to be known for some time to come. My conclusion is that the most dramatic immediate impact of the various case decisions will probably be in respect of access to community services and facilities, for the reason that most human rights codes have not incorporated specific defenses that are equivalent to the BFOQ in employment. Besides, none of the cases discussed directly concern disability; the cases have involved questions of religion (O'Malley and Bhinder), and age (Etobicoke). So far, only Huck has directly addressed the issues of adverse effect and reasonable accommodation with respect to disability.

From the perspective of COPOH, those disabled consumers COPOH represents and perhaps others, reasonable accommodation means taking such steps as are considered reasonable (though necessary) to not preclude individuals with disabilities from participating fully in every aspect of community life, particularly in employment, with resultant benefits going to both the disabled person and to the community as a whole. Important factors of individual and public safety, developing technology, and economic considerations must, in addition, be considered together in determining the extent and degree to which disabled persons can be accommodated.

The development of the reasonable accommodation concept, at least as disabled citizens have tried to develop and advocate it, is in large measure a direct result of their concern with the operationalization and enforcement of section 15(1)(2) of the Charter of Rights. As some have suggested (Ratushny 1986: 257), in the end the courts are likely to fall back on the general criterion of "reasonableness" in defining the boundaries of corresponding rights and duties imposed by the equality rights provision. Because the courts may perhaps not be the most appropriate forum for balancing such factors in the long run, for a variety of reasons, disabled citizens advocate defining reasonable accommodation on a case-by-case basis, stressing flexibility and sensitivity to particular situations. COPOH, among other organizations, has made the argument that statutory amendment (of the Canadian Human Rights Act, et. al.) is a necessary a priori step in developing a framework of standards in such areas as transportation, communications, housing, education, and in employment.

Indeed, as I noted in the introduction to this chapter, various federal government departments are already active in regulation-making pertaining to accessibility standards in private housing, public facilities, and transportation (without statutory amendments having taken place). While these developments may not be wholly satisfactory, disabled citizens stress the need to continually shape equality in the context of individual and public needs, evolving technology, changing consumer and labor market conditions -- without loosing sight of the fundamental notions of basic human dignity and without compromising the principles of independent and integrated community living.

With regards to the implementation of Charter equality rights, one of the most significant developments in the area of affirmative action has been the enactment of the federal Employment Equity Act (1986). The idea of employment equity derives from an understanding of the O'Malley and Bhinder decisions, namely that of adverse effect, unintended, or systemic discrimination. The purpose of the Act is to reinforce the notions that, first, equality means more than treating persons in the same way, and second, that equality requires special measures and the accommodation of differences. The Act thus imposes an obligation on employers to not only identify but to eliminate employment practices that have discriminatory effects by putting into place positive policies and practices that accommodate persons in designated groups.

In my view, the Employment Equity Act illustrates the importance of the purposive approach in the interpretation of human rights law, and combines formal and substantive approaches to equality rights (something disabled citizens advocate) -- at least in the area of employment. There is recognition of the validity of affirmative action as one solution to overcome adverse effect discrimination (Black 1985). The Federal Contractor's Program, which came into effect in September 1986, is an initiative that complements the Employment Equity Act; its purpose is to try to extend federal law into both provincial jurisdictions and the private sector. It will also be interesting to see how section 15(1)(2) of the Charter of Rights will enable disabled people to seek equality not only in the workplace, but in the general community.

Overall, human rights legislation in Canada aims at the elimination of actions based largely on stereotypes. Individualized assessments are required, rather than decisions based on stereotypes about groups. The leading cases decided during the early part of the 1980s that I cited throughout this chapter make it clear that identical treatment is not necessarily equal treatment if that treatment fails to account for relevant differences. A BFOQ or an undue hardship defense of alleged adverse effect discrimination requires, essentially, an individualized assessment. In most situations it will therefore be necessary to look at the needs of specific individuals. My interpretation is that the idea of individualized assessment is a crucial one for understanding the thrust of the independent living/disabled consumer movement's advocacy of the notion of reasonable accommodation in the context of community integration.

My conclusion, however, is that disabled citizens do not seem to be arguing for equality rights based on membership in an identifiable minority category alone. Kallen (1982, 1989: 46), however, has argued that a contentionist (and integrationist) social reform movement such as that represented by the independent living/disabled consumer movement will pursue individual as well as categorical rights claims:

> Individual-rights claims represent demands for recognition and protection of the individual human rights of minority members. Such claims may seek specified changes in constitutional and/or statutory law. Categorical-rights claims represent demands for collective redress against the adverse impact of systemic discrimination upon the minority as an entity. Such claims may seek the implementation of affirmative action programs designed to remedy group inequities. Categorical claims do not rest on assumptions about cultural distinctiveness or alternative lifestyles; thus, they can justifiably be put forward by representatives of minorities with and without a viable cultural base.

As well, a minority category such as the disabled,

> .... represents a conceptual or statistical classification of a population based on one or more criteria ..... that may or may not give rise to a sense of collective consciousness or to minority organization. Minority categories are more likely than minority groups to be represented empirically by dispersed, fragmented population aggregates whose members' only common attribute is the stigmatizing label imposed upon them by majority authorities (Kallen 1989: 43).

Kallen (1989: 46) thus makes a distinction between minority categories and categorical claims, and minority groups and collective rights claims. She defines the latter as based on a distinctive ethnoculture or subculture. In Kallen's framework, members of an ethnoculture or subculture, for example, constitute a minority group which possesses an institutional infrastructure that enables it to maintain and transmit the cultural values, cultural orientation, and lifestyle of its members from generation to generation. Perhaps unlike a minority category, a minority collectivity is more likely to have a collective consciousness and an organizational basis for movement activities (ibid., 43).

Kallen's conceptual distinctions between minority "group" and "category," and between "categorical" and "collective" rights claims are a useful heuristic as far as disabled consumers are concerned. I agree with her that the distinctions may not be clear-cut and mutually exclusive, and that there may be several important exceptions that help blur the distinctions. One could thus argue that the disabled have taken on some of the characteristics of a minority collectivity, possibly blurring the distinction between collectivity and category.

While the disabled might remain a vaguely-defined or difficult-to-define statistical entity and a dispersed or fragmented population, there is no question that over the past decade or so there has also emerged a collective consciousness, an institutional infrastructure, as well as a broad organizational basis for movement activity. For many, there might also be value and lifestyle differences that set them apart both from other disabled individuals and from the non-disabled that possibly no degree of integration into mainstream life could reduce or mitigate. While there is no single culture of disability, of course, there has developed an experienced sense of collective or common identity based on a cross-disability orientation. In addition, the structures developed by disabled people can be both parallel and alternative (possibly blurring the distinction between contention-social reform and revitalization movements). Moreover, these enabling structures are there to transmit a sense of identity, knowledge, and the movement's philosophy and principles to successive "generations" of disabled individuals.

I think that the disabled consumer movement shares important features of both contentionist and revitalization movements, that disabled people's rights claims are collective at the same time as they are categorical and individual, and that its empowering structures offer alternatives to the value orientation and organizational forms of majority cultural and institutional norms and forms as much as they parallel them. Indeed, I want to make the point that the idea of community-building that is at the heart of the disabled consumer movement is always one that works for the transformation of the existing social order and <u>its</u> conformity to, or legitimation of, "minority" values, and lifestyles. To put it another way: What is contention in community-building if it is not an attempt to revitalize the existing social order and community structures, and what is integration if it is also not the mutual legitimation of value and lifestyle differences? For disabled citizens, integration means not only participation in the social, economic, and political life of the community, but also the community's full acceptance of disabled people.

Disabled citizens have argued that in attempting to remove barriers to integrated community living that include adverse effect policies and so forth, reasonable accommodation should not be defined in a way that sets up a separate category of the disabled. It is not appropriate for accessibility standards to require programs, services, or facilities which are "separate but equal" <u>unless</u> separation is the only reasonable way of providing them: According to the independent living model's principle of integration, "specialized services if necessary, but not necessarily specialized services." Otherwise, attempts to accommodate would only create additional barriers to the full participation of disabled people in community life. It is also fully recognized that certain individual rights are of no consequence unless enjoyed in community with others (Tarnopolsky and Pentney 1985: 16.27).

The rights afforded to individuals should, of course, benefit and protect collectivities or categories as wholes. The movement's focus and insistence on individualized assessments, on the unique needs of individual disabled persons, and on a case-by-case approach with respect to reasonable accommodation might perhaps serve to distinguish the disabled consumer's approach to equality rights and the Charter from that of other non-ethnic and/or ethnic groups enumerated in section 15. Women, ethno-cultural minorities, religious minorities and others seem to be asking to be treated equally as members of groups or collectivities.

As I noted in Chapter 2 and elsewhere in this study, disability -- unlike skin color, ethnic origin, gender, and perhaps sexual orientation -- is neither a homogeneous condition nor one that is always temporally "fixed." Rather, disability is socially and historically defined, is based on perception and social environment, is a function of available (and ever-developing) intervening technology ("hard" as well as "soft"), and is individually experienced. It is because of this that disabled consumers seem reluctant to characterize themselves as a group except in the most general way and then only in relation to the common experience of stigma and disenfranchisement. It is also because of this that they consciously (and cautiously) distinguish reasonable accommodation from affirmative action and employment equity.

Reasonable accommodation is part of the community-building process that focuses on the unique needs of individuals. Affirmative action and employment equity, on the other hand, are comprehensive policy strategies aimed at categories of individuals that end up including some and excluding others. Significant human and equality rights case law developments notwithstanding, disabled citizens are therefore cautious about the "similarly situated" phrase that is used in adverse effect discrimination cases. The argument is that laws and public policy must never be applied in such a way that differences (or similarities) between citizens determine how those laws and policies are applied.

A ruling or policy of "similarly situated" may end up treating existing conditions as given, and to use them to determine whether individuals are similarly situated or not.* Stereotypes, social designations, labels, and categories -- things that human rights legislation has tried to eliminate from legal or policy decision -- may instead be perpetuated. My conclusion is that individualized assessment as the focus of reasonable accommodation, and reasonable accommodation as a practical interpretation of equality in community life, are both important means by which full participation and integration into community life can be achieved.

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* The Supreme Court of Canada decision in Andrews v. Law Society of BC (February 2 1989), in this non-disability related case, indeed rejected the "similarly situated" test. Black and Smith (1989: 651) comment that "it [discrimination] can be as serious a denial of equality to treat people identically when it is inappropriate as it is to treat people differently when that is inappropriate."

Chapter 8

Conclusions: Personhood and Consumerism as Issues in Community-Building

A "new" "minority" group has been making its presence felt in our society. Certainly not insignificant in terms of numbers, its members represent one in about every thirteen Canadian citizens. They are, as I have referred to them in this study, the disabled, who historically have been relegated to the position of second-class citizens. Until very recently they remained hidden from view in institutions or special housing, sequestered from the able-bodied public and the larger community. This was accepted by most as proper and legitimate for persons whose damaged bodies or minds and spoiled identities serve as a vivid reminder to the rest of us of the fragility of the human physical state. In a society that demands uniformity and "sameness," and that worships physical health and beauty, the physically and mentally disabled have been regarded and treated as virtual outcasts from mainstream social and community life.

In this dissertation I discussed some of the forms of oppression and discrimination experienced by disabled people, individually and collectively. I also tried to describe their various attempts, through the independent living/disabled consumer movement, to recontextualize and reintegrate themselves into society and into community life. One of my purposes in this study was to examine a few of the major social issues of the 1980s, 1990s, and beyond, that have emerged in such disciplines as social anthropology, sociology, and human rights law. I noted that common to these and other related fields of inquiry is the study of such issues as personal and collective self-determination or self-realization, social movement and empowerment, social reproduction, community-building, and so forth.

I also wanted to argue that these issues are well within the purview of the anthropological enterprise: The striving to recontextualize the disabled person, to deconstruct and demedicalize his or her disability as a "condition," to reintegrate, in Habermas' words, the system and disabled people's life worlds, and to reaffirm the value of his or her's full community partnership and citizenship, are shown to be different facets of the same thing. What they have in common is the conscious and purposive renewal or building of something called community. The task of anthropology as I see it is to tie these facets together, and to examine the processes by which they are connected.

I have suggested that the dis-integration and de-contextualization of the disabled person is not fundamentally different from what is experienced by certain language, religious, ethno-cultural, gender, age, and other so-called minorities. The pursuit of community and personhood clearly involves the process of overcoming all sorts of externally (structurally) imposed and internally (motivationally) reinforced language, cultural, color, gender, and age handicaps -- not solely physical or mental ones. Handicaps are recognized as essentially socio-cultural consequences, that is, "translations" of perceived objective facts (physiological, cultural, etc., differences between people) into meaningful and shared social designations and labels. Accordingly, the relevance structures (i.e. society's normative institutions) through which the translation process operates must be dismantled or rebuilt.

Social and cultural renewal and community-building involves two kinds of activities, namely mental and physical/structural ones. The empowerment process (or social movement), as I have tried to articulate it in reference to the independent living/disabled consumer movement, is an action process that strategically and consciously combines these mental and structural activities in order to (a) change current attitudes (e.g. by providing counter-images of ability), and (b) to revise existing structures (e.g. by changing, encouraging, and initiating new practices, behaviors, and interactions).

Taking the lead from Giddens' theory of action, the central thesis of my study has been that changes in the ways people interact with one another will generate changes in social categories and structures, and perhaps transform them. Because the relationship between action and structure is necessarily a reciprocal one, engaging in new practices and interactions should, over time, transform the very social and community structures against which social movement or these empowerment efforts are directed.

Thus, partially motivated by other disadvantaged minority groups who have organized, fought for, and won new personal (and collective) freedoms for themselves, disabled citizens are clearly no longer satisfied with their second-class, second-best status. They are no longer content to accept a kind of community that has, by omission or commission, pushed and/or kept them out of the employment market, out of public buildings and public transportation systems that are not accessible, out of educational systems that are not designed to accommodate them, and into a health care system that has depersonalized them as individuals.

From this new perspective, successful coping with impairment and disability necessitates more than merely learning to live with recurring pain, limited mental and/or physical functions and abilities, and frustration. It means, instead, learning skills and gaining new knowledge to pursue the kind of lifestyles in which the disabled person him- or herself actively works to not only confront and challenge dominant societal attitudes, but also to develop and put into place new enabling structures that are founded on a vision of personal independence, community integration, and uncompromised personhood. In the first half of this chapter I elaborate on the idea and significance of community, and discuss the relation between it and the notion of personhood.

Personhood: A Prerequisite for Community-Building

For a great many disabled citizens it is not disability that should be the focus of attention, but rather the social and community structures, and the social (and work) environment, in which disabilities occur and that continue to produce and maintain disability. This community (or ecological) perspective is, of course, central to the disabled consumer independent living model. From this perspective, too, the concept of reasonable accommodation that I discussed in Chapter 7 can be appreciated as a means by which disabled persons can gain just a little more control over their environment, however limited it might be. The concept can also be appreciated as a means, or as a starting point, from which the organizing principles of social life can be reconceptualized and perhaps reconstituted.

I would like to suggest that the basis of the community-building process that disabled people are engaged in is self-determination, which in turn is linked to the notion of personhood. Just as action, for example, is linked to structure by way of social movement (a process), so is agency necessarily linked to action by a particular conception of what a "person" is (disabled or non-disabled). What a person "does" is going to be determined largely by what he or she thinks he or she can actually do; this in turn will be determined by what he or she has been taught or socialized into believing is expected or possible. The notion of person is therefore normative, like-wise processual, and highly ideological. The notion, furthermore, is bound up with what is deemed significant about ourselves as capable and mutually-recognized human beings.

In the context of community life, first of all, different conceptions of personhood can be enabling as well as constraining. Within limits, we are "self-legislatively, self-defining creatures" (Rorty 1987: 69). The process of self-definition, however, involves a learning process that takes place within the context or limits of pre-existing social categories and structures. What a person "will do" may therefore be determined by rejecting what he or she has been taught or has experienced, and by imagining different possibilities. Vision, I think, is an intrinsic part of rejecting any limits imposed upon the process of self-definition, and is realizable only in association and communication with others (Tinder 1980: 21-22, Community Living Society, n.d.: 6-7).

Community, then, is both a means of questioning and rejecting pre-existing social categories and structures, and an outcome of self-actualization and self-fulfilment. It is essentially a vision of a context or process that further enables, as much as possible, the process of self-definition. It has been argued, correctly I think, that participation in community life therefore satisfies the deep human need and desire for self-determination and self-actualization (Plant 1974: 62). Perhaps, following Freire, community-building is our ontological vocation. In the relational and psychological sense of community as I defined community in Chapter 1, I would further argue that community-building is in fact an on-going process of self-definition for the participants.

Tinder (1980) has taken this idea one step further. He suggests (ibid., 80) that community "is not in the nature of an order that is changeless and that members must simply accept or quit." Rather, community is defined as a <u>process</u> of participation, communication, and inquiry through which personhood is discovered and continually created:

> The familiar idea that community consists in agreement of any kind, that it consists, for example, in common acceptance of a narrow and stifling set of customs inherited from the past.... grossly distorts human nature and obscures the ideal of community. It tends to reconcile human beings to social conditions under which <u>they are far less than they should be</u>.... Community can live only if people insist again and again, by speech and occasionally by violent resistance, that not any kind of

> unity that habit, circumstances, or a momentary elite can induce everyone to accept is a community. Only co-operation in the most serious human concerns -- <u>and this means above all in the exploration of being</u> -- calls forth a community (Tinder 1980: 31, emphasis added).

Nothing characterizes the essence of empowerment better than this. Thus, "community is unsettled and must call upon the creative resources of its participants" (ibid., 80); human beings are essentially critical and questioning creatures, and so community is a kind of ever-shifting context for their inquiries. Anything less than that would constrain and stifle the process of self-definition and self-determination. Tinder (1980: 34) makes the further insightful comment that,

> Entering into community is not linking a completed self with others; rather, it is forming the self in association with others...... [A] human being, unlike an object of experience such as a stone, is not finished and wholly present in his empirical nature. He must be formed and discovered through the clarification of consciousness that takes place in inquiry or communication.

If human beings are not "finished" and are continually being formed, then by definition community is itself "inherently unfinished." Community, following Giddens, is therefore "ever a process, never a product," or as Tinder (1980: 81) himself states, "it is not the product of the activity but is the activity itself." COPOH's Allan Simpson is saying essentially the same thing, when he suggests, in reference to individual involvement in disabled consumer organizations, that the means is perhaps more important then the solution, or outcome. The relationship between individual realization and community is thus a very close one; this is perhaps why disabled citizens see no inherent contradiction between independent living and community integration. Independent living is only possible in the context of relationships and communication, and is itself an ever-evolving and unending process.

Conflict, of course, exists; the so-called limits of self-definition (i.e. the restraining conditions of self-determination and self-actualization, and therefore of community) can be manipulated or are imposed. Different conceptions of personhood, of community, and of society can therefore clash. According to Rorty (1987: 72), however, any particular conceptualization or definition of what constitutes a "person" (and so of community) might not function to provide a basis for resolving conflicts among competing interests and claims for rights and duties, because the concept itself embeds and expresses those conflicts. Personhood and community, it seems, like Giddens' structure, are probably best expressed as a duality. They are simultaneously the means and outcome of competing values and interests.

Disabled citizens' claims for equality before and under the law, equal protection of the law, equal benefit of the law without discrimination (e.g. the Charter of Rights and Freedoms, and other human rights legislation), as well as reasonable accommodation (including employment equity, affirmative action programs), all presuppose or are based on certain conceptions of personhood, of what a "person" is. Inherent in the claims is also a vision of community. Significantly, issues of human rights, equality in law, and even public sanction of specific programs and services geared towards an identified (or enumerated) category of individual are issues of how different groups in society view each other, whether their conceptions of "person" coincide or whether they differ, and which view dominates.

As Rorty (1987: 68) has pointed out, societies and communities which "weigh" the conditions for personhood differently will therefore be structured differently. It is the implicit conditions for personhood (i.e. the limits of community) that will be contested, and that subsequently determine the interactions and behaviors that constitute structure, and thus the nature of community life.

Consider, for example, the following presuppositions, or conditions, for what would constitute a "person" (Rorty 1987: passim):

- persons are capable of critical reflective rationality;
- persons are autonomous agents, capable of self-defined and self-defining choices;
- persons are capable of forming and modifying their own beliefs, desires, and actions;
- persons are capable of entering into mutually affective and effective relationships.

A great deal depends on the degree to which consensus, or agreement, in society over the truth of these presuppositions, or conditions, exists, and so whether they are accepted, or denied: Indeed, the various structures of domination experienced by disabled people and other minorities will probably reflect this acceptance, or denial. The degree to which these presuppostions are accepted will therefore determine whether and to what extent (Rorty 1987: passim):

- persons are going to be treated as ends (subjects) or as means (objects);
- persons are connected to a range of social, political and material goods;
- persons may have or exercise specific rights and duties, or responsibilities and obligations, of participation in decision-making, representation, and governance;
- persons may participate in public life, actively forming or at least modifying the social and political policies and institutions that shape their own lives.

Structurally, of course, in the sense used in this dissertation (i.e. interactions and behaviors), the idea of "person" ensures that we are taken seriously and respected. The notion also ensures that we have rights (ontological as well as instrumental) which both allocate and limit the exercise of power, and that structural conditions exist that enable us to pursue our interests and goals of self-realization. Absent these presuppositions, rights, and structural conditions, of course, some persons will not be considered or treated as persons at all. That is, they will be treated as means (objects), will be disconnected from social, political and material goods, will be differentially denied responsibilities and obligations shared by others, and, by being denied the opportunity to choose or construct their own system of values, will have the least input into shaping the social and cultural policies and institutitions that in turn shape their own lives. Disabled people have until recently been the classic example of "non-persons" in the sense discussed above, though they have not been the only ones (cf. Kallen's (1989) Label Me Human).

The imposition of handicap, whether physical, mental, linguistic, ethno-cultural, gender, or age-based, thus reflects the serious lack of agreement over and denial of some of the rather fundamental presuppositions of personhood. The disabled, for example, have long been thought incapable of reflective rationality, incapable of forming or articulating their own beliefs and desires, and were deemed dependent and unable to act with others in a common world. Evidence to the contrary has been down-played and even denied, and has instead been interpreted as deviance. In fact, the process of social and cultural dis-integration and de-contextualization is in fact justified by these negative presuppositions, and is further reinforced by institutional structures, practices, and conceptual machinery.

The medical/rehabilitation model is an obvious example of this: The model is evident in the way clinics, hospitals, special institutions, workshops, government departments, and their programs and services, are organized and delivered. The process of reintegration and recontextualization (community-building), from the point of view of the handicapped, involves asserting the positive aspects of the presuppositions that constitute personhood (or showing that the negative ones are illegitimate) by creating alternative, parallel, or mediating structures that prove participatory competence, responsibility, autonomy, and that demonstrate a capacity for self-determination.

Again absent current structures that enable disabled consumers to demonstrate competence and pursue self-determination, parallel or alternative structures become necessary. The particular model, or vision, of community living and citizenship that disabled consumers have in mind is not, of course, one of parallel structures or an alternative lifestyle. Other minorities probably would not want it that way either. Rather, as part of the process of reconstructing society, the function of parallel/alternative structures (e.g. independent living centres, personal support networks, consumer organizations and coalitions, brokerage systems, etc.) is to provide workable alternatives to normative structures that are considered to be founded and operating on "false assumptions."

As parallel/alternative structures providing valuable services, the assumption is that disabled people (or others) are capable of being directed by their own conceptions of their own identities and by what is important to that identity, that they are indeed capable of acting with others, and that they are community-context sensitive. These structures may be temporary or permanent, depending on the continued need for them, and on the extent to which normative structures themselves begin to change.

As part of a vision of community and citizenship, the idea of enabling structures and all that they entail seems to underscore the rather important point that persons, no matter how pathetically deformed, however constitutionally or socially deprived, are nevertheless able to form a system of practices that define their own lives. They are equally the creators of their stories that are their lives, to paraphrase Rorty (1987: 70). Furthermore, this vision of a new citizenship is based on the understanding that persons are self-defining and self-legislating only as members of a community defined by shared practices. The different enabling structures created by disabled citizens bring people together; the case approach (an element of the medical model), the institution, and specialized services, by contrast, marginalizes and alienates them. Parallel and alternative structures such as the ones created by disabled people serve to unify; the normative structures of society serve instead to fragment.

Self-determination, therefore, is not individualistic or atomistic, but rather communitarian. Individuals become "persons" to their fullest potential only in relation to others. From this perspective, too, it is easy to see that today's emphasis on group, collective, and even categorical rights (viz the Charter of Rights and Freedoms) is an expression of the desire to finally realize or achieve what has been a duality of social life all along: One's self-realization is possible only in the context of group life, while at the same time group life facilitates the development of the "person." It is in this new vision of community and citizenship, with its empowering and unifying structures, that the duality of social life can be finally realized. Integration and participation, as expressions of an equal citizenship and a shared community, will have become a reality -- not merely a reasonable accommodation.

Barriers to Community: The Production and Maintenance of Disability

As I have discussed, the dynamics of the struggle to build community have turned on three areas, namely the production and maintenance of disability, "official" definitions of disability, and the medical/rehabilitation process itself. Efforts to change perceptions and attitudes, lifestyles, and to create and put into place new enabling structures have, of necessity, included a priori critical evaluations of the sources of disability. I feel that one very positive outcome or contribution of the independent living/disabled consumer movement is that there has been a deep questioning and a consciousness raising of how and why disability occurs, and "what" it is in our social system and cultural practices that keeps producing impairments and disability.

There has been a growing awareness of the effects of personal lifestyles, kinds of employment or types of jobs, the quality of working life, the politics of health and welfare administration, the state of the physical environment, and so forth, on the overall physical and mental health of all citizens. In efforts to rebuild community, as it were, disabled consumer groups have urged greater research and development in the area of disability production (cf. Obstacles 1987: 92-96, and Health and Welfare Canada 1988).

Clearly, eliminating stereotypes, destigmatization, changing attitudes and labels, and so forth is only one side of the coin: All the best intentions, positive attitudes, reasonable accommodations, human rights legislation, and regulations geared towards the disabled either as individuals or as a category are of no real consequence if social, technical, and other forces continue to produce disabled people. A partial list would have to include acquired occupational diseases and accidents, the psychosomatic and mental illnesses related to work and personal stress, the incapacitation caused by road and highway vehicle accidents, diseases of early childhood, the effects of environmental pollution, and even the illnesses brought on by, or associated with, unemployment and poverty.

Occupational health and safety administration and welfare/income security legislation are identified as two significant loci for the production and maintenance of disability. In the following discussion, I will give greater attention to the latter.

With respect to occupational health and safety, first of all, Reasons et. al. (1981) have thoroughly documented the nature of the dangerous and often fatal hazards associated with different kinds of work and occupation types (Appendix 7, Item 1 lists the kinds of violent injuries workers sustain on the job). Their research, moreover, has done much to expose the politics and economics of industrial management, occupational health and safety administration and the related regulatory process in Canada which, according to them, have both directly contributed to the ideology of blaming the victim and supported the myth of the "dumb worker" (cf. the discussion in Brown 1977: 97-111, 117-127).

A second area of disability creation, not surprisingly closely related to occupational health and safety, lies in the area of production and work organization. The classic syndrome in late or advanced capitalist society is illustrated by speedup on the assembly line and reduction of the work force, which is achieved by increased automation, the de-skilling of workers, and job/task breakdown. These are the characteristics (or results) of scientific management, or Taylorism, which according to Sass (1988: 14),

> produces the aggregates which make up the workforce -- shift workers, women, injured workers, unemployed, etc., -- and causes the pitting of members of a family one against another: husband and wife, father and son, father and daughter; resulting from scheduling of work affecting non-work time. Thus shift work or scheduling of work has an enormous effect on marital breakdown, alcoholism, drug abuse, etc., showing up in work last, because all is sacrificed by the worker to maintain the employment relationship.

From Marx's first writings on alienation with respect to the psychic and economic costs suffered by workers, to recent work on the social epidemiology of hypertension (recognized in law as a disabling impairment, cf. Pentney 1988: 70), the dynamics are the same: People are not machines. When pushed to behave as though they are, they not only become increasingly prone to work-related accidents, but they begin to seek refuge in alcohol (alcoholism as well as substance abuse is recognized as a disabling condition by the Canadian Human Rights Act; see also COPOH 1987b, and Kallen 1989: 88-89), become addicted to tranquilizers (or worse), suffer neurotic conflicts, abuse their children and/or spouses, and so on. In turn, the social crises of inflation, recession, and cutbacks in services provide a kind of rationale for increasing the pressure "to produce," and a fiscal excuse for refusing to treat the physical, mental, and spiritual wreckage that results.

It is equally important to consider the so-called lower visibility areas of disability production and maintenance, for example, poverty. Since the late 1970s welfare, disability pension, and old age security payments have remained at unacceptable near-starvation levels while the cost of food, housing, and energy has continued to increase at a somewhat phenomenal rate. The so-called middle class has thus been set against the poor, for the middle class is expected (by virtue of the tax structure) to pay for any increases in supports to the poor, the disabled, and the elderly. Due generally to an overall lack of funding the consequence is the continuing chronic malnutrition of the poor and elderly, with its attendant consequences of chronic respiratory diseases, insufficiently fed (and sometimes single) pregnant mothers, malnourished new-borns, rapidly deteriorating health, increased incidence of new disabilities, and aggravation of existing chronic disabilities.

The relationship between poverty and living on a fixed income (such as the retired, the elderly, as well as the disabled), and higher rates of mental and physical disability is an established one. It is the continued production of disability through the maintenance of poverty by virtue of the welfare and social security system that is, apparently, less recognized (e.g. Piven and Cloward 1971, Gordon 1988: 611-619). The administration of our welfare and disability income systems, not unlike occupational health and safety administration, is therefore identified as a significant locus of the production and maintenance of disability, and is one that likewise requires substantial reconstruction. Likewise, over-all health care administration has been singled out as a major policy problem and economic concern (Economic Council of Canada 1986: 37-41), particularly in light of a drastically, and rapidly, changing demographic profile of our society (with respect to the aging of our population).

It is interesting to note that the majority of early federal social assistance/welfare/income security legislation and programs (e.g. prior to the 1966 Canada Assistance Plan) were in fact aimed at the elderly and the disabled: The Blind Persons Act (1937), the Allowances for Disabled Persons Act (1954), the Old Age Assistance and Security Acts (1952), and even the Vocational Rehabilitation of Disabled Persons Act (1952) are some examples. The VRDP, to be fair, was different from other legislation; it was initially designed as a social service program emphasizing the vocational rehabilitation of physically and mentally disabled persons. The program's aim was to facilitate the entry of disabled individuals into the work force (even though it seldom succeeded), and to that end it provided medical, social, and vocational assessment, counselling, training, maintenance allowances, protheses, tools, books, and equipment. The CAP, of course, was intended as an integrated, comprehensive, and general assistance program (cost-shared between the federal and provincial governments) that would be useful to all kinds of citizens.

Unfortunately, both CAP and VRDP have been "tarred with the welfare brush," although this orientation is less pronounced in the VRDP than in the CAP (COPOH 1987b: 9). The welfare world, of course, is not one that fits well with the disabled consumer philosophy; in many instances disabled consumers have spoken out against the (additional) stigmatization of being on welfare. Many of the welfare-associated delivery systems treat disabled persons either paternalistically or as the "undeserving poor." Indeed, social services in Canada have been heavily influenced by the view that poverty is the result of "flawed character," that it is the individual's (read: the victim's) own fault.

The traditional response to poverty (and thus to disability) has been to rehabilitate, or "fix," the person so that he or she can enter the labor force in order to earn their own income (ibid., 9). This has led to the case services approach to social (as well as medical rehabilitation) services, an approach in which systemic or structural problems are discounted or simply ignored. Case services are problem-oriented, and focus primarily on adjusting the individual to fit the existing environment; there is also an unduly heavy emphasis on employability.

The VRDP and the CAP, as I noted in passing early in Chapter 7, are currently under review. For their time the VRDP and CAP were progressive pieces of legislation, in that they recognized that (non-institutionalized) disabled people required resources in order to live within the community. Despite some of their serious limitations, they still remain the major legislation governing the provision of services to disabled people. By participating in the current (1987-1989) review of the VRDP and the CAP (COPOH 1987b: passim), disabled citizens hope to bring the fiscal arrangements affecting them into line with the current realities of their social situations.

Since the passage of the VRDP and CAP, disabled people have somewhat altered their position within society; witness the development of consumerism and independent living as movements, deinstitutionalization, the emergence of IL centres, and so forth. Over the twenty or so years that the Acts have been in existence, ideas about the role of persons with disabilities (conceptions of personhood) have also changed (supposedly), as have models of progressive social and other services affecting disabled people.

In other words, the fiscal arrangements which affect disabled people have not kept pace with the changes, nor are emerging community needs being met. This view, fortunately, is shared inside and outside the consumer movement. In particular, COPOH and other organizations involved in this fiscal review have argued that the federal government lacks an appropriate legislative framework to share (with the provinces) the cost of services designed to specifically meet the non-medical needs of disabled people (brief by the Canadian Council on Social Development, op. cited in COPOH 1987b: 3). Disabled consumer advocates suggest that there needs to be a movement away from the current emphasis on case services, as noted above, towards what they call a public/social utility community service model (COPOH 1987b: 10). Examples of public/social community utilities would include libraries, museums, day care facilities, family planning services, walk-in medical clinics, friendship centres, and so on.

Unlike the focus on the individual person which is characteristic of the case services approach, the public/social, or community, utilities approach is directed toward improving the quality of community life, where the emphasis instead is on improving the environment in which the individual operates. Users of a public/social utility-type service do not have to prove illness or disability, poverty, or any other kind of "problem." Users approach the service(s) as citizens, not as patients, clients, or cases; likewise, services are used at the option of individuals (based on their needs and requirements), or on the basis of their status (age, disability, etc.). There is, of course, no diagnostic testing, such as needs, means, or income testing. Disabled citizens (read: users) are arguing that there must be greater support for more public utility-type services for disabled people (and others), and that this type of service delivery should be eligible for support from existing fiscal arrangements between the provincial and federal governments.

The upshot of this, of course, is that disabled citizens hope that one of the outcomes of the current review of the VRDP and the CAP will be the public recognition of independent living centres as a legitimate and bona fide public and community service utility. As described in Chapter 6, IL centres work to improve the quality of life for disabled individuals by assisting them to take greater control of the management of their own lives. IL centres provide training, counselling, brokerage, personal support services and many other non-medical kinds of services that can empower individuals to learn the management functions necessary to live independently in the community. It bears repeating, of course, that independent living does not mean the performance of physical tasks, but refers to the control of the decisions that are associated with everyday life. As such, the argument is that IL centres should receive funding because they deliver services which are themselves eligible for CAP funding (COPOH 1987b: 15).

With respect to community-building, disabled citizens have therefore stressed the importance of adequate funding, the development of new and innovative approaches to social assistance and service delivery mechanisms, and the creation of opportunities for meaningful vocational train[illegible] VRDP and the CAP have been soundly criticized for being [illegible]-oriented and, by isolating services available under their [illegible]tive programs from available generic services, for not sufficiently integrating disabled people. In other words, disabled citizens argue that all disabled people must have adequate opportunities to develop their skills and talents in the community regardless of perceptions of their abilities, educability, and employability.

Narrow perceptions about what constitutes gainful employment, occupations, and education for disabled people -- and what disabled people are capable of -- must not restrict the choices for the available funding or fiscal arrangements. Comprehensive education and training provisions obviously need to be buttressed by a variety of social assistance and income schemes (Obstacles 1987: 31-40, COPOH 1987b: 5-6). Disabled people should not be restricted to using certain types of services or receiving certains kinds of income assistance just because the service or funding has traditionally been offered that way. Clearly, flexibility to meet emerging needs and solutions is required.

The issue of an adequate income is perhaps even more pressing than that of the availability of education and training programs and provisions (COPOH 1987g). Like other citizens who derive their incomes from employment, assistance recipients such as disabled persons require funds that are adequate enough to secure resources needed for economic security, personal growth, and inclusion in mainstream community life. Low levels of support are a disincentive mechanism that encourages dependence on the social assistance system. Many of the services and much of the funding provided under the CAP and the VRDP, for example, could be useful in assisting disabled individuals to develop independent living as well as employment skills; however, because the CAP is essentially welfare legislation, only those on social assistance are eligible for those services and funding (COPOH 1987b: 5-6).

Disabled citizens rightly point out that they find themselves in a position of double jeopardy. On the one hand, because of existing barriers to full participation in economic life (e.g. systemic discrimination), it is virtually impossible for the majority of disabled persons to find renumerative employment. On the other hand, low levels of social assistance that are designed to encourage re-entry into the work force actually works to prevent re-entry (COPOH 1987b: 22). In actual fact, disabled citizens argue that a situation of triple jeopardy exists: Currently, social assistance does not take into account the extra cost of disability in a realistic way. Here, they are making reference to the costs associated with being disabled, e.g. personal care attendants, technical aids, transportation, prescription drugs, etc., that may not be totally covered under a program, service, or funding budget provision.

Thus, systemic discrimination bars disabled persons from participating in the workforce, and necessitates their dependence on social assistance; social assistance rates are kept low in order to force people back into the workforce; the rates, low for disabled persons, are also expected to meet the extra costs of disability (COPOH 1987b: 22). It is this no-win situation that has continued to produce, and maintain, disability.

It is clear from my discussion above (and in Chapter 2) that, from the point of view of health and welfare administration, for disability to even exist, to the point where the injured and disabled worker, the unemployed disabled person, or the incapacitated elderly person can get help, his or her disability must be officially recognized (Stone 1984). While an individual's own subjective and psychological definition of disability is of course important in understanding the progress of that individual in the so-called rehabilitation process, it is significant that others do the defining as well. It is these other definitions that are clearly more fateful and more consequential, for they determine whether there is going to be help in the first place, and what kind of help it is going to be.

Disability definition can of course be considered from a variety of points of view. Medical definitions refers to the abstract degree of physical or mental health of the defined individual; capacity to function is the criterion used here. Pure medical definitions are rare, however. They are usually mixed, in real-world situations, with social and cultural role definitions, in which the capacity to perform a role is the criterion. Paralysis from the waist down will affect a university lecturer and a steel worker in different ways, for example. It is the steel worker in this case who will probably need an entirely new occupation to become reemployed. Legal definitions of disability, on the other hand, based on both medical and socio-cultural definitions, determine whether an individual qualifies for entry into certain programs or for funding that enables the individual to acquire vocational training and subsequent placement in a new job.

Social role definitions, on the one hand, seem to involve the conditions of the labor market, while legal definitions, on the other hand, are the outcome of political struggles that determine whether laws, programs and funds are made available. When the labor market tightens, for example, the medically disabled might enter the social role category of the unemployable. In economic hard times, it is less likely that even the state will maintain the status quo in terms of allowing legal definitions of disability to go unchallenged and unchanged. The tighter the budgets for programs, the stronger will be the pressure on policy makers to make legal definitions that require adequate and dependable state financing. In any case, the important issue of definition has come up time and again in the review process of the VRDP and the CAP.

The definition of disability that is used in the VRDP is, in some respects, broad enough to include a wide spectrum of people with many kinds of disabilities. It is interesting to note that alcohol and drug addiction programs can be funded through the VRDP, though this has been challenged on the basis that alcohol and drug dependency is self-induced. Disabled citizens defend this type of program funding, however, reasoning that this dependency is not necessarily self-induced, and that, in any case, the dependency is a disabling condition. Their defense of this kind of funding is also based on the reasoning that alcohol and drug dependency might, unless proven otherwise, have a systemic or structural etiology (e.g. occupational, the work setting, and so on). They argue, furthermore, that it is dangerous to base program funding on such subjective criteria as who is "deserving" or who is not (COPOH 1987b: 4-5).

Under the VRDP, the definition of a disabled person hinges chiefly on the concept of employability (clearly a social role). For purposes of the Act, a disabled person is defined as "a person who, because of physical or mental impairment, is incapable of pursuing regularly any substantially gainful occupation" (op. cit. in COPOH 1987b: 5). The obvious operative concept in this definition is "gainful occupation." This concept, unfortunately, serves as a gatekeeper for entry into training programs; those individuals perceived as not being capable of eventually securing gainful occupation will not considered eligible for VRDP support. Under the Act, furthermore, a "substantially gainful occupation" means the pursuit of the following: The practice of a profession, self-employment, home-making, farm work, sheltered employment, and home industries (COPOH 1987b: 6).

Disabled citizens have of course criticized the Act for including home-making and sheltered workshop employment in the same definition of gainful occupation. With respect to home-making, they argue that until home-makers receive UIC benefits and/or are part of a federal pension plan as other wage earners, this category would seem to encourage discrimination against disabled women who may wish to improve their education to get into another profession (PUSH-Ontario brief, op. cited in COPOH 1987b: 6). Likewise, sheltered workshops have always been considered a form of exploitation by the independent living/disabled consumer movement, where support of these segregated environments is wholly opposed in any case.

In other words, eligibility for VRDP (and other) support should not depend on narrow perceptions of ability, or what constitutes a gainful occupation (based, obviously, on socio-cultural and legal definitions of disability). All citizens should have the opportunity to improve themselves and learn new skills; "often training and exposure to new environments can open up doors for individuals and create possibilities hitherto unimagined" (COPOH 1987b: 5). The VRDP, furthermore, excludes individuals who are workers' compensation recipients, those who are already employed, and those who are not pursuing vocational objectives. Many disabled people become employed through affirmative action programs, and so are placed in primarily entry level positions that pay the minimum wage (ibid., 5). Though working, they are doing so at subsistence levels, and so should still have the option to upgrade their qualifications. The effect of exclusion is to, again, maintain a preconceived socio-cultural definition of disability, and to turn it into a self-fulfilling prophecy.

Similarly, the definition of vocational rehabilitation contained in the VRDP means "any process of restoration, training, and employment placement, including services related thereto, the object of which is to enable a person to become capable of pursuing regularly a substantially gainful occupation" (op. cit. COPOH 1987b: 7). Again, this definition, once applied, effectively rules out those individuals who wish to pursue work in the voluntary sector (e.g. those working in independent living centers and elsewhere), those who wish to pursue an advanced university education at the graduate level, and even those who seek careers in music, fine arts, the performing arts, and so forth (COPOH 1987b: 6, 9).

Spokespersons of the independent living movement have argued repeatedly that more comprehensive education and training program provisions should be included in legislation such as the VRDP, that these provisions need to be supported by adequate funding, and that the formulation and implementation of acts such as CAP and VRDP must, to be effective, be based on a new kind of citizenship and community living model. I suggest that this new model of citizenship and community membership must be based on new conceptions of personhood, such as I discussed earlier in this chapter

There is evidence that disabled citizens still have a long hard struggle ahead of them: The VRDP, the main legislation affecting disabled citizens, was originally administered by the Department of Labor, and later by the Department of Manpower. It was subsequently administered by Employment and Immigration Canada, but true to the medical/rehabilitation model of disability, shifted to Health and Welfare Canada in the mid-1970s. The effect of this shift, unfortunately, has been to reinforce the misconception that disability issues are health and welfare issues (statement of the Canadian Employment and Immigration Advisory Committee, op. cited in COPOH 1987b: 8). There have been attempts within the last two years to have a revised VRDP administered, once again, by Employment and Immigration Canada. Again, a social/structural problem has been trans-formed into an individual/medical one. As a result of these changes, how can disabled people be viewed in any way other than as patients, clients, or, worse, sick people?

The Promise of the Disabled Consumer Movement: Self-Determination as a Universal Right

My intention in the previous section of this chapter, specifically in reference to the production of disability, was to reinforce and reemphasize a key point that I made in Chapter 3, namely that the market assumptions and relations of the capitalist mode of production, while efficient and useful on one level, come with a cost

-- a human cost. The purpose of my discussion of the social context of disability, with reference to situations and contexts that produce disability or in which disability occurs, was to draw attention to the problematics of work and the production process, and the ideals of self-determination, as well as personhood and community.

What is occupational health and safety administration and welfare or income security legislation (including such legislation as the Vocational Rehabilitation of Disabled Persons Act and the Canada Assistance Plan) if not "the means" by which market assumptions and relations are maintained, albeit indirectly? The VRDP and the CAP themselves reveal how close in fact are the connections between the idea of skills and labor as commodities, the emphasis on employability, and that of blaming the victim and the marginalization of the so-called non-productive worker. Consider as evidence of these connections the definition process and the eligibility criteria set out by these Acts, as I discussed them above.

I would argue that legislation and administration of this kind is not really a defense or protection against the victimization of individuals or categories of individuals, but in a sort of perverse way actually promotes it. Thus, the VRDP and the CAP (only two of many other examples; another would be Workers' Compensation) unfortunately maintain a kind of false opposition between two conceptions of the proper role of human beings in economic and political life -- that of producer and consumer.

The opposition between producer and consumer might also be framed as the (false) opposition between the needs of (capitalist) production (work) relations and the needs of individuals. To put it yet another way and to take it one step further, there is an equally false opposition between two views of human capacities that legislation like the VRDP and CAP maintains: One views human beings as self-developers (as "bundles of capacities and powers"), and the other views humans as infinite consumers, or as "bundles of appetites seeking satisfaction" (Leiss 1988: 93-100). The VRDP and the CAP treats these as opposites or as incompatible views, in the sense that they create and try to maintain a separation between an individual's capacity used in the work/production process, and the individual's ability to develop his or her capacities outside the production process.

In this view, individuals have no personal stake in the production process; they own neither the means of production and what they produce, nor do they have anything to say about the relations of the market or of production themselves. Accordingly, people have no value apart from their ability and willingness to sell their labor. Put simply, the fiction is maintained that production, market, and work relations do not permeate all community relations and that they are also somehow separate and distinct from other spheres of life.

These are, of course, false oppositions. There is, in the social context that produces and maintains mental and/or physical handicap (or any kind of handicap for that matter) an implicit denial of the fact that work/production is really the reproduction of social relations in the satisfaction of personal and individual needs, and that market relations embody a reciprocal recognition of social identity and social role. As I already discussed in some detail in Chapter 3, production and consumption are really two aspects of the same thing; likewise, what is required to maintain market and production relations need not be at the exclusion of the pursuit and satisfaction of personal as well as community needs. In fact, it is market/production/work relations that provide the impetus and incentive for personal growth and development (Leiss 1988: 90-91).

Thus, I suggest that the issue of consumerism as I presented it in this dissertation is really the integration of the critique of market and production relations, and the development of personhood in the context of community. Consumerism is one of the means by which community relationships and identities can be reappropriated and reoriented, in which the consumer becomes the central or major factor in the production process itself. Consumption, in this sense, is "a significant domain of human creativity and satisfaction -- as an expression of individuality, as a source of diverse and genuine satisfaction, and even as an end in itself" (Leiss 1988: 102).

Consumerism is thus intimately bound up with independent living, self-determination, and self-actualization -- or personhood. Yet, if personal and collective independence and self-determination is possible within the context of market and production relations and, indeed, if it depends on such relations, how then is it possible to address the negative consequences and impact of capitalist market and production relations on individuals?

Interestingly, an answer might be found in the post-World War II development and growth of human rights consciousness, and in the parallel historical relationship between "rights" and "property" (Claude 1976, Macpherson 1978, Leiss 1988: 103-109, 135-137). With the spread of a developing capitalist market economy from the late 17th century onwards, an increasing emphasis on private property became the incentive to labor-power which the market economy, and market relations, came to depend on. Not all individuals competed successfully in the open market, however, nor were all individuals able to accumulate property which was supposed to provide their security. The market assumption (the liberal ideal of autonomous individualism) that all were capable of participating equally in pursuing their interests and objectives as free individuals turned out to be a false one.

Thus, those who accumulated property came to control labor-power, and the rights of those who sold their labor as their only means to life was ultimately reduced to trying to secure the rights of access to the means of labor controlled by others. The right not to be excluded from the means of production has, since then, become critical in an intensified wage-labor system such as that found in industrial capitalism. However, having rights of access even to the means of labor has become problematic by virtue of changing market conditions. In keeping with the liberal ideal that every person is entitled to a fully human life and the opportunities to develop his or her potential, the right not to be excluded from the relations of production (equal employment rights) has, since World War II, been transformed into the right to an income (welfare/social security rights). More recently, the right not to be excluded from the accumulated productive resources of society has likewise been transformed into the right to share in the control of these resources or of production itself (e.g. rights of self-determination, equality rights, consumer rights).

According to Claude and Macpherson, the development of the idea of property has gone hand-in-hand with the development of rights. I would agree that the development of the two concepts are clearly rooted in each other. In property, for example, there has been a change (a) from public property and a right to revenue based on social status and moral contract, to (b) private property as a right <u>to exclude others</u> and a right to labor based on legal contract, to (c) the right to access the means of labor, i.e. the right to be employed and <u>not to be excluded</u> from the accumulated productive resources of society. Interestingly, the right "not to be excluded" (from access to, or the use of..... something) is in fact the definition of public property.

With respect to the development of rights, on the other hand, there have been changes from (a) rights protecting individuals against the powers of the state (e.g. freedom of speech, religion and conscience, from arbitrary arrest, and the right to contract), to (b) rights as a means of participating in state affairs (e.g. right to vote, freedom of assembly and of association), to (c) rights guaranteeing a person protection by way of intervention or obtaining benefits provided by the state (e.g. rights to medicare, social assistance, education, employment, income, an adequate standard of living, equality rights, anti-discrimination law). One conclusion that can be drawn is that historically, in the context of capitalist market and production relations, there has in fact been a development towards rights "not to be excluded" from protection and/or benefits provided by the state.

Thus, as Leiss (1988: 104-105) observes from his analysis of Macpherson's work on property,

> The key change in the meaning of property in the twentieth century is a process of "broadening." The dominant earlier notion of the right of an individual or corporation to exclude others from the use of things is by no means abandoned, but competing notions have been added, especially the claim to a right of access for everyone to a minimum share of resources. This share is in effect an entitlement to a stream of revenue that is sufficient to sustain every person at a decent level of existence, whether this stream of revenue is generated by earning an income at paid employment or receiving various kinds of welfare benefits from the state. This is the idea of property as a universal right, a right "to the means of a fully human life," that is to say, (a) a right to a share in political power to control the uses of the amassed capital and the natural resources of the society, and (b), beyond that, a right to a kind of society, a set of power relations throughout society, essential to a fully human life.

The conclusion is that political power becomes the most important kind of property (Leiss 1988: 105), and that, significantly, access to political power as a kind of "public property" must be ensured by the state. This is a rather crucial development in both the history of capitalist market relations and the growth of human rights consciousness. An implication of this conclusion, following Leiss' analysis of Macpherson, is that the state comes to assume many of the allocative functions that before were managed within the context of market relations (or compensates for what was "missing" in these relations). This is fact is what may already be occurring.

In what is a rather provocative analysis, Leiss (1988: Chapter 4) discusses the development and nature of a quasi-market society in the context of a critique of both capitalism and socialism, and in the context of a developmental evaluation of OECD countries (including Canada) and major socialist nations. As a so-called hybrid social formation emerging on a global scale (increasingly rapidly since the end of World War II), a quasi-market society, according to Leiss (1988: 119) is one in which "fully-developed market relations exist side-by-side with a state apparatus that oversees the national economy and takes responsibility for major social programs through transfer payments."

What is significant here is that although the main features of quasi-market societies maintain the essential centrality of market and production relations in the lives of individuals (thereby perpetuating inequalities in the distribution of wealth and income), the negative consequences and impact of these relations and inequalities are somewhat alleviated by mechanisms of income redistribution, transfer payments, and welfare or social assistance entitlements. One effect of these public sector expenditures and involvement is that the extreme polarization of wealth and poverty as would occur under unregulated capitalism is avoided. At the same time, however, this commitment to market forces still provides the motivation and incentive for individuals to pursue their goals of self-determination and personhood in the contexts of both production as well as consumption. According to Leiss (1988: 141-142), in fact, the institutional make-up of a quasi-market society would promote "consumerism as the single most important zone of gratification in the lives of individuals."

My position is that it is in this context of a movement towards a public property and a positive theory of market relations (state intervention) that the current review and critique of the Vocational Rehabilitation of Disabled Persons Act (VRDP), the Canada Assistance Plan (CAP), and the issue of adequate income and program funding by disabled citizens, among others, can be appreciated (cf. COPOH 1987a and 1987b, and Kallen 1989: 185 for a brief discussion of minority-group fears raised by the Meech Lake Accord over continued funding of national/provincial cost-shared programs).

Similarly, the advocacy of the public/social utilities approach that is directed towards improving the quality of community life, and the bid to gain public recognition of independent living centres as legitimate public/community service utilities (funded by the state, of course) might be recognized for what it is: The claim for the universal and public right of self-determination for all people. What is self-determination and, indeed, community-building, if it is not the pursuit and fulfilment of consumer ideals, and the creation of the very conditions by which the satisfaction of individual and community needs can be met? Thus,

> We may pick up again what is a very old idea, the idea that used to prevail before the market economy converted us all into consumers: the idea that life is for *doing* rather than just *getting*. You may ask, can the right to such a full and free life of action and enjoyment be made an individual property, i.e. a legally enforceable claim that society will enforce in favor of each individual? There is no intrinsic difficulty about this (C. B. Macpherson *op. cit.* in Leiss 1988: 106-107; original emphasis).

From the perspective of community, disabled citizens and, for that matter, all consumers would heartily agree with C. B. Macpherson: There is no intrinsic difficulty about this.

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APPENDIX 1

Item 1. Fieldwork and Methodology

Fieldwork and Methodology

[1]

In this section of the appendix to the dissertation, I want to show how my research problem as I defined it in Chapter 1 and my focus on particular issues emerged from the fieldwork experience. I will also note the links between my focus, the issues, and the relevant areas of social science theory. Finally, I will devote some space to describing what other kinds of research might have been conducted within the same independent living/disabled consumer setting.

The Alberta Committee of Disabled Citizens was one of three organizations with which I began research. I initially interviewed three key Alberta Committee individuals.* Questions and the ensuing discussions revolved around the Committee's structure, its organizational dynamics, the board of directors, the membership, human rights-related issues, the relation of groups such as the Committee to the broader consumer movement, definitions of disability/handicappism, independent living and integration as concepts and as strategies, women's issues, ethnicity, the role of government as arbiter of citizen's interests, events in Alberta, the status of consumer organizations in other provinces, and more.

By late 1985 I decided to focus exclusively on the Alberta Committee, for reasons already discussed in Chapter 1. Throughout that year, 1986, and partly into 1987, I attended a number of social and business functions, board meetings, and two annual general

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* Semi-structured interviews were conducted in May, June, and October of 1985, with Nancie Krushelnicki, then ACDC's managing director, Irene Feika, board member and past president [COPOH's national chairperson and ACDC's managing director in 1989], and Edna Coffin, then the organization's secretary-treasurer. All materials were eventually transcribed, yielding 287 pages of edited text. A copy of the transcribed interviews was given to the Committee and is now in its possession.

meetings where many of these same issues were discussed. I also made several trips to Calgary, especially to the Walter Dinsdale Centre/Calgary Association for Independent Living (now called the Walter Dinsdale Centre for the Empowerment of Canadians with Disabilities). On these occasions, I collected information and spoke with people there, though I conducted no interviews.

During this period, I was introduced to some key players, for example, Jim Derksen (COPOH), Henry Enns (COPOH), Leroy Thompson (Calgary), and Michael Huck (Edmonton). I had met Leroy Thompson, active with the disabled consumer movement in Alberta since the early 1970s and founder of several consumer organizations, at Committee board meetings in the fall of 1985. His increasing ill health precluded any possibility of talking in detail with him about my work, however. Leroy passed away April 5 1986. I had the opportunity to work with Jim Derksen in 1986, when he delivered a paper on hiring practices at a session on employment equity I had organized that was part of the 1986 Canadian Sociology and Anthropology Association annual meeting. In January of 1987, I was first introduced to and later worked with Michael Huck. We initially participated in an employment equity information session sponsored by the Alberta Committee, and held at the Terrace Coast Inn in Edmonton.

Through interviews, discussion, and reading Alberta Committee and COPOH materials, a number of key issues and themes emerged. They were the following: The notion of independent living; social and community integration; consumerism; the independent living/disabled consumer movement (which was linked to 1960s civil rights movement in USA); the demedicalization of disability; and deinstitutionalization of disabled persons. The growth and development of various means or strategies of independent living, for example, IL centres, brokerage, peer support groups, networks, consumer groups, coalitions, and so on were consistently referred to.

The principles of independent living were also expounded, for example, accountability, the idea of dignity of risk, and the notion of personhood. Later, legal concerns were discussed in reference to problems in such areas as transportation, housing, education, and employment, for example, equality rights, rights of the disabled as individuals and as a collectivity, and employment equity/affirmative action. The concept of reasonable accommodation as a means of social and community integration was also mentioned from time to time.

The question I was faced with was how to make sense of these recurrent themes. Into what larger context could I put them in which they would be intelligible to me as an anthropological researcher? To what larger issues, if any, were they connected? Would in-depth work on each or any one of these recurrent themes be warranted? Or would a macro-approach tying them together in a larger framework be preferable? More importantly, my concern was whether the latter approach, were I to adopt it, would reflect appropriate respect for the disabled consumer experience.

Related theoretical issues that emerged were the obvious ones: Political economy of consumerism (production-consumption relationships under capitalism); self-determination as a political/rights issue (which I thought I could link, or contrast, with a discussion of Native rights); social movements (contrasting older with newer approaches); and the idea of community-building and social reform in the context of social/cultural change in general. I also became interested in situating collective action in the context of action theory itself (with respect to the relation between action and structure). Here, I was interested in the relations between the actions of organized disabled citizens, the organizational structures they were creating, and the vision of reintegration into mainstream social and community life that they were pursuing.

I introduced Giddens' notion of structuration to help explain the organizing efforts of disabled citizens. I found the idea of structuration useful as sensitizing device and as a theoretical construct, but very difficult to operationalize and apply. Indeed, how is "agency" really carried out, that is, by what process were disabled consumers building their organizations and their movement? I subsequently introduced the idea of empowerment (explained in Chapter 1), and suggested that it puts the "action" back into agency. I linked empowerment to self-actualization and self-determination, and in turn linked the latter to conscious social and cultural change. This, for me, came to constitute the essence of social movement. In treating social movement as a general process of change (social reproduction?), I interpreted the activities of disabled citizens as community-building efforts. Community, as I discuss in Chapter 1, is the idea of a society and of social relations in which all citizens may participate and live in order to pursue and develop to their fullest potentials and abilities.

I made the decision to expand upon the themes and issues of the disabled consumer movement that emerged from my initial field research in an interpretive-theoretical discussion. This meant looking at the larger socio-cultural patterns and institutional processes at work in specific relation to the issues, and to see how they were tied together in a larger framework that gives them meaning -- from an anthropological frame of reference [action, structure, social movement, social and cultural change, idea of community].

The data/theory relationship was a two-way one from the start of my research: Beginning with basically a grounded theory approach, my involvement and immersion into the life of participants in the consumer organization (the Alberta Commitee) led to the discovery of the themes I noted above. (I initially wanted to do something about equality rights, but was not clear at the time what the salient issues were from the point of view of disabled citizens). Once I became more fully aware of what the themes and issues were, and how pervasive they were, I searched the social science literature for revelant theory that was useful in shedding light on their meaning.

Social science literature exists, of course, for the study of social movement, for empowerment, Giddens' theory of structuration, action theory, self-actualization/self-determination, consumerism, stigmatization, deviance theory, and so on. All this was helpful, of course, and I saw my task to be the synthesis of key points in order to interpret and make sense of the actions of disabled citizens.

Once the relevant theoretical material was identified and I was formulating my theoretical approach, I kept returning to the Alberta Committee to search out more data related to the themes and to keep abreast of developments in the group, in Calgary, with COPOH, and what was happening on the national scene. Formulating my theoretical approach was an on-going process: The idea of community-building, for example, was not pursued until mid-1989.

Early during this process my attention was also drawn to the Committee's sizeable archives and library: Contained therein were large numbers of research reports, studies, briefs, and other material produced over the years by the group itself as well as by COPOH and other organizations. Not surprisingly, a great deal of this material had specifically to do with each of the themes noted above (independent living, consumerism..... and other issues relating to the disabled consumer experience that have remained more or less constant over time). I restricted myself to examining the themes as they were discussed and treated in the documentary materials. I discussed aspects of this material, the issues, as well as my findings (i.e. my theoretical treatment) with some of the Committee staff. Committee staff and others, however, were not formally interviewed on these topics.

I would like to make it clear that in my approach I take for granted and/or assume a number of things: I take as given, for example, that organizing activity is both the outcome of the empowerment process as well as the means to further that process. I likewise take for granted that written materials produced by disabled citizens (as the finished product) are evidence of empowered action having already taken place. I also assume that the particular set of shared experiences that motivate organizing activity and even the production of texts, documents and similar such material, are intentional and reflexive activities. Finally, I have taken the view that a politicized view of the phenomenon of disability is not necessarily illuminated by emphasis on the experiential meaning of disability (that is, a focus on what it personally feels like to be disabled may not provide complete insight into the socio-political, structural, or cultural meaning of disability; Shapiro 1980: 88-89, Kaplan 1984: 33).

The approach I have taken contrasts, I think, to what a descriptive-interpretive study might have entailed. Such a study could include an investigation of one or several independent living strategies (for example, the development and operation of a brokerage model, the formation of a self-help group or peer support system). A more detailed organizational study of a disabled consumer group, network, or coalition structure might have been carried out. The disabled lifestyle, however defined (e.g. the coping strategies of disabled people and the observation of daily routines), and how independent living skills (however defined) are acquired, learned, or developed might also have been the focus of empirical research. An observational study of a community independent living setting would also have been among the options. A study of one of these aspects of the consumer experience (cf. Brooks 1983) might then have provided the empirical foundation for a more general and theoretical discussion of independent living, empowerment, and the community-building process.

[2]

In the section above I tried to show that my research problem and my focus on particular themes and issues were derived from the fieldwork experience and guided by broader theoretical concerns. In Chapter 1 of my dissertation I explain and justify my subsequent reliance on and use of Alberta Committee, COPOH, and other disabled consumer organization documentary materials. In this section I want to (a) reiterate that my selection of the materials I came to use was not arbitrary or haphazard. I also want to show (b) that I understand the nature of documentary source material in general, with respect to their usefulness as well as limitations.* I will discuss the general nature of textual and documentary material first.

Not all of our knowledge of people, events, social relations, and social processs comes directly from personal or immediate experience -- even fieldwork experience. Statements in documentary form, whether as news, data, and information therefore stand in for an

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* The use of textual material has advantages and disadvantages. As primary data they can be accessed and checked time and again -- by the original researcher or others who might wish to pursue alternative interpretations of the same material. At the same time there are some limitations in their use. It is recognized that these materials are produced by a specific segment of the disabled community. While they are credible and legitimate data in their own right, they may not be representative of how the entire disabled community feels or how other disabled people (action-oriented or otherwise) may articulate or share the philosophy of consumerism and independent living.

The use of materials produced by a segment of a larger constituency is of course subject to the same caveats as the final use of solicited interview materials or other primary data put together by the anthropologist field worker. For the goals of my study these materials are necessary. The accounts of a few individuals and certain movement organizations are perhaps the only record of analyses of social, economic, and political relations that are perceived to impact on disabled people in general, an articulation of a philosophy, and explanations of organizational and other kinds of activities that have occurred in the movement's and organization's past or that are planned for the future. This material is not accessible in other ways given the temporal and other limitations of fieldwork. Consensus of viewpoint among activist individuals and organizations, of course, cannot be presumed, just as it cannot for the larger society.

actuality that is often not directly accessible, that has happened at a different time, or that was not or could not be observed. The socially organized activity and practice of reporting and recording is acknowledged as an interpretation and a reworking of actual events (including the conscious process or activity of reporting and recording itself, for these are also "events"). In many organizational contexts, the making of factual records, the writing of reports, and the production of different kinds of documents are continuous activities that are an essential part of what the organization does. The "organized" character of an organization might well depend on documentary practices, which coordinate, provide continuity, monitor, and organize relations between people both within and outside a particular setting in which the practices occur. Thus, the resulting documentary forms constitute "the observables" (i.e. records), from the researcher's perspective, of things unobserved by the researcher.

A number of generalizations concerning documentary/textual materials might therefore be made (Smith 1974, 1984, Lindkvist 1981). First, it must be recognized that documents/textual materials are an outcome of the conscious organization of a particular kind of experience and knowledge. Whatever is constituted as social "fact" from the point of view of the authors of the texts, the facts are constructed and organized in certain ways in the process of writing and recording. They might be seen as a kind of "petrified meaning" whose purpose and intent is to help structure the reader's interpretation as he or she reads the material. This kind of organization of knowledge and its communication, of course, depends to some extent on a primary intersubjective participation in a social world known in common to both author and reader.

Second, documentary materials are situated in complex social relations, and have the property of helping organize social relations. That is, there is a relationship between the documents and the normative order: they are a sort of medium between the organizations/authors that produce them and the larger society.

Though grounded in the normative order, the documents represent a reconstitution, reworking, and reinterpretation of elements of it. In reinterpreting the normative order, they help (re)organize the social relations between their individual and/or collective authors and the larger society, or intended audience. The relation of the documents/author(s) to a context/audience is thus important, and it is recognized that there is a complex, two-way, relationship between the two.

A third generalization that can be made, following from the second one, is that the documentary materials "do" or perform "work." Once written or produced, the materials continue to actively do the work of the organization from whose context they originated. To be useful and effective as a means and form of communication, their content must not only be clearly identified with the authors/organization which produced them, but should transcend the specific time/space of their production as well as be uniform across separate and diverse settings to which they might be applied or in which they may be read. In a sense, the textual materials reinforce the operating rules, assumptions, and philosophy of the organization under which they are created and disseminated. A critical reading of such materials might entail revealing and elaborating what those rules and assumptions are, and what the philosophy is. It is, in other words, this kind of latent content of the material that textual analysis could focus on.

Any single document or text should be recognized as the outcome of a cumulative and holistic process. A fourth generalization might be that, as a particular means of communication documents are recognized as instruments of influence. That is, both the form and content of textual material is assumed to be shaped by the individual or collective author's intent to influence, on whatever level and in whatever direction, a reader or an audience. To put it another way, an intended reader or intended audience can influence how a document is written or even put together. Evaluating a document or a set of documents for use in research would therefore include consideration of (a) the relationships of the documents to their readers, and (b) how the documents are themselves put together and organized. In both dimensions, inferences can perhaps be made regarding the meanings, values, motives, or intentions of the author(s).

A textual/content analysis would try to do a number of things. It might involve trying to reveal the intentions or mental life of the communicator, or to make propositions about the effects or consequences of the communication (text). It is recognized, however, that while there is no single correct interpretation of a text, it is possible to make reasonable interpretations. As well, messages, or the contents of a document, do not have a single meaning even to one reader. Nor do meanings need to be shared -- they are always, and only, relative to the author(s).

Finally, it is acknowledged that textual material may indeed be a "consensus outcome" between a number of authors. That is, there may be an original intention or a single message to be communicated, but there might also have been quite different opinions about what form it should take or its possible effect. Other versions are always possible, and indeed a potential problem with "final outcomes" is that multiple drafts, corrections, alternative wordings by more than one author, and so on may be obliterated and simply no longer exist. Whether or not an author has achieved his or her intention in communicating a particular message (i.e. a particular meaning) through his or her document can, of course, only be inferred.

In this dissertation I do not attempt a textual/content analysis of the documents I use. There is much about them that I must take for granted in order to proceed. Writing, recording, record-keeping, and documenting are indeed a major part of what disabled consumer organizations (ACDC, COPOH) do, by definition. There is little debate that their documents are an outcome of conscious organization of experience and knowledge, and that they are also "consensus outcomes." Documents generated by the staff at independent living centres, peer support groups, and even by brokers, on the other hand, are entirely different because what they do is different. Significantly, however, it is the consumer organizations that have tried to pull the information together to provide accounts of what IL centres, brokers, networks, and so on actually do. Theirs is indeed an information collecting, disseminating, and documenting role.

There are a number of different kinds of documents that disabled consumer organizations generate. Their differences as well as their similarities relate to what I see are three different social and cultural functions of communication in general: (1) monitoring the environment (accumulating facts, statistics, and gathering other kinds of information), (2) contextualizing a group's activities within the normative order (explaining what the consumer group, for example, _is_ and _does_, communicating differences, values, philosophies, positions, etc.), and (3) transmitting accumulated knowledge and experience (including meanings and values) from one "generation" (of disabled persons) to another. Thus, the documentary materials might be tentatively grouped into three types, as follows:

Type-1 [monitoring the environment]: In-house research studies and surveys of existing services, programs and other kinds of resources (municipal, regional, provincial) available for use by disabled citizens, e.g. travel and transportation, education, housing, accessible public buildings, home care, legislation, funding, progress and activity reports, quarterly reports.... Studies and surveys may be conducted and information gathered by such means as interviewing, observation, questionnaires, library research, media-watching, and scanning public documents. Personnel (authors) involved could include summer students, volunteer consumers, staff, the organization's research officer, board members, and hired outside researchers. Of course, as services, programs, and policies change (for better or for worse), the monitoring might either shift focus elsewhere, or continue to track the changes (given time, money and other available resources). Study and survey results are potentially useful for yielding trend data, though how the information is otained

> and compiled in the first place with respect to quality and consistency is important for the researcher to consider.
>
> Type-2 [contextualizing the group in the normative order]: Press releases, position papers, recommendations, background studies, briefs, pamphlets and brochures, special publications, and newsletters that are submitted or otherwise distributed (solicited as well as unsolicited) to service agencies, government commissions of inquiry, government departments, public officials, researchers and research organizations, private companies.... It is also not unusual to find position papers or even briefs to appear as rewritten and updated versions of older papers and presentations made in previous years. Authors of these documents are primarily staff and board members, or they may come out of conference or other kinds of workshop situations involving grassroots members.
>
> Type-3 [transmitting meaning and values to other disabled people]: Conference papers and reports, collected policy resolutions and positions, historical accounts and overviews, "backgrounders," brochures and pamphlets, operating manuals (e.g. board, committees, officers of the organization), recorded minutes of meetings, annual general meeting speeches, summaries, and reports.... These may be compiled by staff and board members, volunteer consumers, committees (workshops), and so forth. Some of these accounts and overviews also include within them assessments, evaluations, or other kinds of retrospective commentary on position papers, briefs, and statements that were presented, orally as well as in written form, in the past.

These types or categories are of course not mutually exclusive. Research studies and surveys conducted in-house, for example, quite often become the basis for briefs, position papers, and reports presented or sent elsewhere. Older material is sometimes reworked and integrated into newer text. As well, as services, programs, and policies change and as new legislation appears, new information is gathered to assess the impact, or lack of it, on the disabled community. These briefs, reports, presentations, and so forth in turn become part of the organization's historical record and archives that the grassroots (or anyone) can consult and read. The documents that I consulted for information and insights into the themes and issues that I identified at the outset of my field research fall into virtually all three types, though the ones I found more useful for my work came primarily from the second and third types.

I am aware, in reference to the first type of document, that the means by which the organization gathers information, what it decides to compile, and how it compiles it is biased towards what the group seeks to accomplish, to pursue as goals, what "reality" and meaning it wants to communicate, and what resources it has at its disposal to carry out the work in the first place. I am also fully aware of the fact that the content and style of communication as well as the use of language in all the material put together for public consumption, as in the second and third types, probably differs over time, across situations, and across target audiences according to the issues of the day and the pragmatic intentions and concerns of the organization and its members.* Some of the issues and goals

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* One example I can offer here with respect to language use and text relates, interestingly, to the name changes of the Alberta Committee itself. Prior to and in 1981, the Committee included in its name the phrase "Action Group." After 1982, it dropped that phrase and emphasized the words "Disabled Persons" and "Disabled Citizens." 1982, of course, was the year Canada patriated its constitution; the Charter of Rights that is part of the constitution finally gave legal protection to the mentally handicapped and the physically disabled. Presumably these name changes were made to reflect a more conciliatory and consultative stance, whereas the stand prior to 1982 was more militant. Changes in the group's name, if made for the reason that I assume (and I infer this partly from interview material), may have their parallel in the style and language of documents produced "before" and "after" 1982. Textual/content analysis might indeed reveal style, language, and content differences before and after 1982, at least as it pertained to what this particular group was trying to do in the province of Alberta. In a history of the Committee's consumer and IL philosophy,

themselves change and shift from year to year, while others retain a significant and fairly consistent profile.

The particular goals that remain significant for disabled consumers and for the independent living/disabled consumer movement over the years (i.e. the mid-1970s to today) have been social integration, deinstitutionalization, and independent living. These have been without question the key issues of consumerism and the independent living focus. The type-2 and type-3 documents I described above produced during this time period consistently addressed them. In explaining and thus contextualizing the group's activities within the normative order (type-2), and in transmitting the meanings and values of the movement to other disabled people, to public officials and to the public in general (type-3), emphasis would be put upon how the goals could be achieved.

Papers and briefs on transportation, education, housing, human rights, employment, and social services issues (remaining constant over almost two decades) presented "facts" to some extent (type-1 documents), but identified these as areas in social life in which could be found formidable obstacles to independent and integrated community living. These materials also contained recommendations and suggestions on how various obstacles could be overcome. With a Charter of Rights and other legal/constitutional means of achieving disabled consumer goals now available, many of the documents written since 1982 (all types) have included case law and cited legal precedent much more than before (the law cited often pertains to human rights commissions and tribunal decisions in the areas of religious, ethnic, and disability rights).

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propositions could probably be made of how text style and language over those years was shaped by the authors' intention to influence their audiences, by the consequences of their efforts, and by changing issues and events.

My choice of documents, then, was not arbitrary. Nor are the documents themselves capricious. As intentional and reflexive outcomes of collective effort, they are precisely those that attempt to contextualize the disabled consumer group's activities within the normative order and its challenges to it, and that articulate and try to communicate some of the fundamental values, knowledge, and the meaning of disabled consumer activism. The documents, in a sense, embody within them a social movement that is often inaccessible and unobservable.

In any event, short of a full-scale textual/content analysis of all these types of documents there is no other practical way of determining or identifying exactly what the differences in form, style, and content are over the years, how significant they are from the organization's perspective (could there even be consensus over this?), or whether these differences really "make a difference." What their over-all effect is and how well the documents "do the work" of the organization and the movement remains conjectural, but may be an interesting point of departure for future analyses. Other interpretations of the same documentary materials are always possible, of course, and I recognize that a pragmatic textual/content analysis is as good a starting point as any in trying to reveal the intentions, values, and meanings of disabled consumer activity and to reconstruct the inner logic of such activity.

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APPENDIX 2

Item 1. Disability Status by Province/Region by Sex and Age Group

Item 2. Disabled Persons by Nature of Disability by Sex and Age Group

Item 3. Disabled Persons by Degree of Disability by Sex and Age Group

Item 4. Disabled Persons by Degree of Dependence Performing Everyday Activities by Sex and Age Group

Item 5. Disabling Condition by Cause of Disability

Item 6. Disability Status by Labor Force Status by Sex and Age Group

Item 7. Disability Status by Age Group and Current Education Level

All Items taken from the Canadian Health and Disability Survey, October 1983/June 1984, Report (1986). Statistics Canada, Cat. No. 82-555E.

Canadian Health and Disability Survey, October 1983/June 1984

TABLE 1. Disability Status by Province/Region by Sex and Age Group

Persons Age 15 and Over

Province/region by sex and age group	Disability status			
	Total	Disabled		Not disabled
		Number	Per cent	
	thousands			
CANADA				
Both sexes				
All ages	19,136	2,448	12.8	16,688
15-24 years	4,335	165	3.8	4,170
25-34 "	4,335	230	5.3	4,105
35-54 "	5,840	581	9.9	5,258
55-64 "	2,270	561	24.7	1,709
65 years and over	2,356	910	38.6	1,446
Male				
All ages	9,357	1,108	11.8	8,249
15-24 years	2,190	78	3.6	2,112
25-34 "	2,146	108	5.0	2,038
35-54 "	2,917	269	9.2	2,649
55-64 "	1,086	268	24.7	819
65 years and over	1,017	385	37.9	632
Female				
All ages	9,779	1,339	13.7	8,439
15-24 years	2,145	87	4.1	2,058
25-34 "	2,189	122	5.6	2,067
35-54 "	2,922	312	10.7	2,610
55-64 "	1,183	293	24.8	890
65 years and over	1,339	525	39.2	814
Newfoundland				
Both sexes				
All ages	418	52	12.4	365
15-24 years	116	4	3.4	112
25-34 "	96	6	6.3	91
35-54 "	119	12	10.1	108
55-64 "	41	11	26.8	30
65 years and over	46	20	43.5	26
Male				
All ages	208	26	12.5	182
15-24 years	58	--	--	56
25-34 "	47	--	--	45
35-54 "	61	6	9.8	55
55-64 "	21	6	28.6	15
65 years and over	21	10	47.6	12
Female				
All ages	210	27	12.9	183
15-24 years	58	--	--	56
25-34 "	49	--	--	46
35-54 "	59	6	10.2	53
55-64 "	20	5	25.0	15
65 years and over	24	10	41.7	14
Prince Edward Island				
Both sexes				
All ages	92	11	12.0	82
15-24 years	22	--	--	22
25-34 "	19	--	--	18
35-54 "	26	--	--	24
55-64 "	10	--	--	8
65 years and over	15	6	40.0	9

Canadian Health and Disability Survey, October 1983/June 1984

TABLE 1. Disability Status by Province/Region by Sex and Age Group - Continued

Persons Age 15 and Over

Province/region by sex and age group	Total	Disability status		
		Disabled		Not disabled
		Number	Per cent	
	thousands			
Prince Edward Island - Continued				
Male				
All ages	45	5	11.1	40
15-24 years	11	--	--	11
25-34 "	9	--	--	9
35-54 "	13	--	--	12
55-64 "	5	--	--	4
65 years and over	7	--	--	4
Female				
All ages	47	6	12.8	41
15-24 years	11	--	--	11
25-34 "	10	--	--	9
35-54 "	13	--	--	12
55-64 "	5	--	--	4
65 years and over	8	--	--	5
Nova Scotia				
Both sexes				
All ages	652	97	14.9	555
15-24 years	154	6	3.9	147
25-34 "	139	7	5.0	132
35-54 "	189	24	12.7	166
55-64 "	76	21	27.6	55
65 years and over	94	39	41.5	55
Male				
All ages	314	45	14.3	269
15-24 years	77	--	--	74
25-34 "	67	--	--	64
35-54 "	93	11	11.8	81
55-64 "	36	10	27.8	26
65 years and over	41	17	41.5	24
Female				
All ages	338	52	15.4	286
15-24 years	77	--	--	74
25-34 "	72	4	5.6	68
35-54 "	97	13	13.4	84
55-64 "	40	11	27.5	29
65 years and over	53	22	41.5	31
New Brunswick				
Both sexes				
All ages	529	74	14.0	455
15-24 years	129	5	3.9	124
25-34 "	117	7	6.0	111
35-54 "	153	18	11.8	134
55-64 "	59	16	27.1	44
65 years and over	70	29	41.4	42
Male				
All ages	258	36	14.0	221
15-24 years	65	--	--	63
25-34 "	57	--	--	54
35-54 "	76	9	11.8	67
55-64 "	28	8	28.6	20
65 years and over	31	13	41.9	18

Canadian Health and Disability Survey, October 1983/June 1984

TABLE 1. Disability Status by Province/Region by Sex and Age Group – Continued

Persons Age 15 and Over

Province/region by sex and age group	Total	Disability status		
		Disabled		Not disabled
		Number	Per cent	
	thousands			
New Brunswick – Concluded				
Female				
All ages	271	38	14.0	233
15-24 years	64	--	--	62
25-34 "	60	--	--	57
35-54 "	77	9	11.7	68
55-64 "	31	7	22.6	24
65 years and over	39	15	38.5	24
Atlantic Region				
Both sexes				
All ages	1,691	234	13.8	1,457
15-24 years	421	16	3.8	405
25-34 "	371	20	5.4	351
35-54 "	487	55	11.3	432
55-64 "	187	50	26.7	137
65 years and over	224	93	41.5	132
Male				
All ages	824	112	13.6	713
15-24 years	212	8	3.8	203
25-34 "	180	9	5.0	172
35-54 "	242	27	11.2	215
55-64 "	90	25	27.8	65
65 years and over	100	42	42.0	58
Female				
All ages	866	122	14.1	744
15-24 years	210	8	3.8	202
25-34 "	191	11	5.8	180
35-54 "	245	28	11.4	217
55-64 "	97	25	25.8	72
65 years and over	124	50	40.3	74
Quebec				
Both sexes				
All ages	5,071	584	11.5	4,487
15-24 years	1,140	37	3.2	1,103
25-34 "	1,175	53	4.5	1,122
35-54 "	1,595	152	9.5	1,444
55-64 "	591	138	23.4	453
65 years and over	569	204	35.9	365
Male				
All ages	2,463	259	10.5	2,203
15-24 years	575	14•	2.4•	561
25-34 "	583	24	4.1	559
35-54 "	788	70	8.9	718
55-64 "	279	69	24.7	210
65 years and over	237	82	34.6	155
Female				
All ages	2,609	325	12.5	2,283
15-24 years	565	22•	3.9•	542
25-34 "	593	29	4.9	563
35-54 "	807	82	10.2	725
55-64 "	313	69	22.0	243
65 years and over	332	122	36.7	210

Canadian Health and Disability Survey, October 1983/June 1984

TABLE 1. Disability Status by Province/Region by Sex and Age Group – Continued

Persons Age 15 and Over

Province/region by sex and age group	Disability status			
	Total	Disabled		Not disabled
		Number	Per cent	
	thousands			
Ontario				
Both sexes				
All ages	6,913	937	13.6	5,976
15-24 years	1,538	62	4.0	1,476
25-34 "	1,489	92	6.2	1,397
35-54 "	2,153	231	10.7	1,922
55-64 "	867	219	25.3	647
65 years and over	867	333	38.4	534
Male				
All ages	3,360	416	12.4	2,944
15-24 years	777	31	4.0	747
25-34 "	727	43	5.9	684
35-54 "	1,073	104	9.7	969
55-64 "	415	103	24.8	312
65 years and over	368	135	36.7	233
Female				
All ages	3,553	522	14.7	3,032
15-24 years	761	31	4.1	730
25-34 "	762	49	6.4	713
35-54 "	1,080	128	11.9	953
55-64 "	451	116	25.7	335
65 years and over	499	198	39.7	301
Manitoba				
Both sexes				
All ages	783	109	13.9	674
15-24 years	175	8	4.6	168
25-34 "	168	10	6.0	158
35-54 "	222	21	9.5	201
55-64 "	98	21	21.4	77
65 years and over	119	50	42.0	70
Male				
All ages	380	46	12.1	334
15-24 years	88	--	--	85
25-34 "	83	4	4.8	79
35-54 "	110	9	8.2	101
55-64 "	46	9	19.6	37
65 years and over	52	21	40.4	31
Female				
All ages	403	63	15.6	340
15-24 years	87	5	5.7	83
25-34 "	85	6	7.1	80
35-54 "	112	12	10.7	100
55-64 "	52	12	23.1	40
65 years and over	67	29	43.3	38
Saskatchewan				
Both sexes				
All ages	732	116	15.8	616
15-24 years	171	7	4.1	163
25-34 "	160	9	5.6	150
35-54 "	196	21	10.7	175
55-64 "	90	23	25.6	67
65 years and over	115	54	47.0	61

Canadian Health and Disability Survey, October 1983/June 1984

TABLE 1. Disability Status by Province/Region by Sex and Age Group – Continued

Persons Age 15 and Over

Province/region by sex and age group	Total	Disability status		
		Disabled		Not disabled
		Number	Per cent	
		thousands		
Saskatchewan – Concluded				
Male				
All ages	363	55	15.2	308
15-24 years	86	--	--	83
25-34 "	80	5	6.2	75
35-54 "	99	10	10.1	89
55-64 "	44	12	27.3	33
65 years and over	53	25	47.2	28
Female				
All ages	369	61	16.5	308
15-24 years	84	4	4.8	80
25-34 "	79	4	5.1	75
35-54 "	98	11	11.2	87
55-64 "	46	12	26.1	34
65 years and over	62	29	46.8	33
Alberta				
Both sexes				
All ages	1,742	192	11.0	1,550
15-24 years	430	16	3.7	414
25-34 "	474	23	4.9	451
35-54 "	511	48	9.4	464
55-64 "	168	42	25.0	126
65 years and over	159	64	40.3	95
Male				
All ages	884	93	10.5	791
15-24 years	219	7*	3.2*	212
25-34 "	247	11	4.5	236
35-54 "	263	25	9.5	238
55-64 "	83	20	24.1	63
65 years and over	72	30	41.7	43
Female				
All ages	858	99	11.5	759
15-24 years	211	8*	3.8*	202
25-34 "	227	12	5.3	215
35-54 "	249	23	9.2	226
55-64 "	85	22	25.9	63
65 years and over	87	35	40.2	52
Prairie Region				
Both sexes				
All ages	3,257	417	12.8	2,840
15-24 years	776	31	4.0	745
25-34 "	802	42	5.2	760
35-54 "	929	90	9.7	840
55-64 "	356	86	24.2	270
65 years and over	394	168	42.6	226
Male				
All ages	1,627	194	11.9	1,432
15-24 years	394	14	3.6	380
25-34 "	410	20	4.9	390
35-54 "	471	44	9.3	427
55-64 "	173	40	23.1	133
65 years and over	178	76	42.7	102

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TABLE 1. Disability Status by Province/Region by Sex and Age Group – Concluded

Persons Age 15 and Over

Province/region by sex and age group	Total	Disability status		
		Disabled		Not disabled
		Number	Per cent	
	thousands			
Prairie Region – Concluded				
Female				
All ages	1,630	223	13.7	1,407
15-24 years	382	17	4.5	365
25-34 "	392	22	5.6	370
35-54 "	458	46	10.0	412
55-64 "	183	45	24.6	137
65 years and over	215	92	42.8	123
British Columbia				
Both sexes				
All ages	2,204	275	12.5	1,929
15-24 years	460	20	4.3	441
25-34 "	498	23	4.6	475
35-54 "	674	53	7.9	621
55-64 "	269	67	24.9	202
65 years and over	302	112	37.1	190
Male				
All ages	1,084	127	11.7	957
15-24 years	232	11*	4.7*	222
25-34 "	246	12*	4.9*	234
35-54 "	343	24	7.0	319
55-64 "	129	30	23.3	99
65 years and over	134	50	37.3	84
Female				
All ages	1,120	148	13.2	972
15-24 years	228	9*	3.9*	219
25-34 "	252	11*	4.4*	241
35-54 "	332	29	8.7	303
55-64 "	140	37	26.4	103
65 years and over	168	62	36.9	107

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TABLE 5. Disabled Persons by Nature of Disability by Sex and Age Group

Persons Age 15 and Over

Sex by age group	Nature of disability			
	Total disabled[1]	Mobility	Agility	Seeing
	thousands			
Both sexes				
All ages	2,448	1,596	1,334	331
15-34 years	395	189	156	37
35-54 "	581	352	300	53
55-64 "	561	396	331	48
65 years and over	910	662	544	193
Male				
All ages	1,108	646	576	134
15-34 years	186	77	77	18
35-54 "	269	144	132	26
55-64 "	268	175	158	20
65 years and over	385	249	209	70
Female				
All ages	1,339	953	768	197
15-34 years	209	112	81	20
35-54 "	312	207	169	27
55-64 "	293	220	173	27
65 years and over	525	413	335	123

	Hearing	Speaking	Mental handicap	Nature unknown
	thousands			
Both sexes				
All ages	634	116	83	197
15-34 years	67	42	41	61
35-54 "	112	23	19	68
55-64 "	133	13*	9*	41
65 years and over	322	37	14*	27
Male				
All ages	341	66	50	103
15-34 years	31	23	24	31
35-54 "	63	14*	15*	37
55-64 "	79	8*	--	22
65 years and over	168	21	7*	14*
Female				
All ages	293	50	33	94
15-34 years	36	19	17	30
35-54 "	49	9*	--	31
55-64 "	54	--	--	19
65 years and over	154	17	--	13*

[1] Shows the number of persons with a disability, and is not the total of the natures of disability.

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TABLE 6. Disabled Persons by Degree of Disability by Sex and Age Group

Persons Age 15 and Over

Sex by age group	Degree of disability				
	Total	Some disability	Moderate disability	Major disability	Degree unknown
	thousands				
Both sexes					
All ages	2,448	1,315	568	345	219
15-34 years	395	232	62	26	75
35-54 "	581	344	117	48	72
55-64 "	561	311	136	71	43
65 years and over	910	429	252	200	29
Male					
All ages	1,108	598	250	143	117
15-34 years	186	104	26	16	40
35-54 "	269	147	58	24	40
55-64 "	268	150	65	31	22
65 years and over	385	198	102	71	15*
Female					
All ages	1,339	717	318	202	102
15-34 years	209	129	36	10*	35
35-54 "	312	196	60	24	32
55-64 "	293	161	71	40	21
65 years and over	525	231	151	129	14*

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TABLE 7. Disabled Persons by Degree of Dependence Performing Everyday Activities by Sex and Age Group

Persons Age 15 and Over

Everyday activity by sex and age group	Degree of dependence					
	Total	Dependent	Partially dependent	Independent	Unable to assess	Not stated
	thousands					
Shop for groceries or other necessities						
Both sexes						
All ages	2,448	588	320	1,309	156	74
15-34 years	395	54	48	257	25	11*
35-54 "	581	107	75	344	40	14*
55-64 "	561	127	77	299	39	18
65 years and over	910	299	119	410	51	31
Male						
All ages	1,108	224	106	624	121	33
15-34 years	186	26	19	115	20	--
35-54 "	269	46	24	157	35	7*
55-64 "	268	51	26	149	33	8*
65 years and over	385	100	37	204	33	12*
Female						
All ages	1,339	364	214	685	35	42
15-34 years	209	28	29	142	--	--
35-54 "	312	61	51	187	--	8*
55-64 "	293	76	51	150	--	10*
65 years and over	525	198	83	206	18	19

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TABLE 7. Disabled Persons by Degree of Dependence Performing Everyday Activities by Sex and Age Group – Continued

Persons Age 15 and Over

Everyday activity by sex and age group	Degree of dependence					
	Total	Dependent	Partially dependent	Independent	Unable to assess	Not stated
	thousands					
Get around in own neighbourhood or own area						
Both sexes						
All ages	2,448	347	135	1,845	46	75
15-34 years	395	25	15*	336	9*	11*
35-54 "	581	44	32	482	8*	15*
55-64 "	561	62	35	437	9*	18
65 years and over	910	216	53	590	20	31
Male						
All ages	1,108	119	53	879	23	33
15-34 years	186	13*	7*	154	--	--
35-54 "	269	17	14*	227	--	7*
55-64 "	268	23	13*	219	--	8*
65 years and over	385	67	20	279	8*	11*
Female						
All ages	1,339	228	82	965	23	42
15-34 years	209	12*	8*	181	--	--
35-54 "	312	27	18	255	--	8*
55-64 "	293	40	22	218	--	10*
65 years and over	525	149	34	311	12*	19
Do heavy household chores, gardening or yardwork						
Both sexes						
All ages	2,448	980	350	819	222	77
15-34 years	395	95	67	199	24	11*
35-54 "	581	203	100	225	36	16
55-64 "	561	242	82	166	52	18
65 years and over	910	440	100	229	109	32
Male						
All ages	1,108	380	148	457	89	34
15-34 years	186	38	27	102	13*	--
35-54 "	269	86	37	125	13*	7*
55-64 "	268	103	38	96	23	8*
65 years and over	385	152	47	135	40	12*
Female						
All ages	1,339	599	201	362	133	43
15-34 years	209	56	40	97	11*	--
35-54 "	312	117	64	100	23	9*
55-64 "	293	139	44	70	30	10*
65 years and over	525	287	54	95	69	20
Do everyday work within home, including cooking						
Both sexes						
All ages	2,448	319	210	1,610	230	79
15-34 years	395	38	27	285	35	11*
35-54 "	581	61	53	401	50	16
55-64 "	561	62	50	366	64	19
65 years and over	910	158	80	557	82	33

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TABLE 7. Disabled Persons by Degree of Dependence Performing Everyday Activities by Sex and Age Group – Concluded

Persons Age 15 and Over

Everyday activity by sex and age group	Degree of dependence					
	Total	Dependent	Partially dependent	Independent	Unable to assess	Not stated
			thousands			
Do everyday work within home, including cooking – Concluded						
Male						
All ages	1,108	157	70	636	210	35
15-34 years	186	20	8•	122	30	--
35-54 "	269	31	18	164	47	8•
55-64 "	268	33	19	146	61	9•
65 years and over	385	73	25	204	72	13•
Female						
All ages	1,339	162	140	974	20	43
15-34 years	209	18	19	163	--	--
35-54 "	312	30	34	237	--	9•
55-64 "	293	29	31	220	--	10•
65 years and over	525	85	55	353	11•	20
Get around within own home						
Both sexes						
All ages	2,448	67	62	2,224	18	76
15-34 years	395	8•	--	367	--	11•
35-54 "	581	8•	11•	544	--	15•
55-64 "	561	12•	16	511	--	18
65 years and over	910	40	31	803	--	32
Male						
All ages	1,108	30	27	1,006	12•	33
15-34 years	186	--	--	169	--	--
35-54 "	269	--	--	252	--	7•
55-64 "	268	--	8•	243	--	8•
65 years and over	385	15•	14•	342	--	11•
Female						
All ages	1,339	37	35	1,218	7•	43
15-34 years	209	--	--	198	--	--
35-54 "	312	--	7•	292	--	8•
55-64 "	293	--	8•	268	--	10•
65 years and over	525	25	17	461	--	20
Take personal care of oneself						
Both sexes						
All ages	2,448	107	81	2,163	18	79
15-34 years	395	18	9•	352	--	11•
35-54 "	581	15•	15•	530	--	16
55-64 "	561	19	18	500	--	20
65 years and over	910	54	38	781	--	32
Male						
All ages	1,108	53	38	973	10•	34
15-34 years	186	11•	--	162	--	--
35-54 "	269	9•	7•	243	--	8•
55-64 "	268	9•	10•	239	--	9•
65 years and over	385	23	18	329	--	12•
Female						
All ages	1,339	54	43	1,190	8•	5
15-34 years	209	7•	--	190	--	--
35-54 "	312	--	9•	287	--	8•
55-64 "	293	10•	9•	261	--	11•
65 years and over	525	31	20	451	--	20

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TABLE 11. Disabling Condition by Cause of Disability

Persons Age 15 and Over

Disabling condition	Total	Congenital	Disease or illness/ stroke	After effect of disease, illness, or treatment	Accident	Aging	Other	Don't know
				thousands				
ALL DISABLING CONDITIONS	3,867	208	662	305	575	623	268	1,226
Mental disorders	83	23	--	--	--	--	--	58
Diseases of the nervous system and sense organs	811	66	89	82	61	219	88	207
Sight disorders	225	19	27	19	13*	74	10*	63
Hearing disorders	494	30	29	55	41	142	73	123
Other diseases of central nervous system	92	17	33	8*	7*	--	--	20
Diseases of the circulatory system	524	13*	197	45	11*	77	40	140
Ischaemic heart disease	117	--	56	9*	--	16	7*	27
Other heart	224	7*	78	23	--	29	18	67
Other circulatory	183	--	63	14*	8*	32	15*	47
Diseases of the respiratory system	173	17	55	23	--	12*	21	38
Emphysema and asthma	90	13*	36	8*	--	--	11*	19
Other respiratory	83	--	20	15	--	10*	11*	19
Diseases of the digestive system	48	--	11*	9*	--	--	--	15*
Diseases of the musculoskeletal system and connective tissue	1,441	47	201	86	459	216	77	356
Arthritis/rheumatism	573	--	144	23	62	155	25	157
Lower limbs	121	--	25	--	19	38	--	29
Upper limbs	83	--	20	--	8*	24	--	24
Back	62	--	18	--	11*	15*	--	12*
Other and site not specified	308	--	82	13*	26	78	13*	92
Other musculoskeletal problems	868	41	56	63	396	61	51	199
Lower limbs	242	15*	11*	29	112	18	11*	45
Upper limbs	95	--	--	--	53	--	--	21
Back	388	17	18	15*	186	26	31	95
Other and site not specified	142	--	23	13*	45	12*	--	38
Neoplasms	48	--	19	11*	--	--	--	15*
Endocrine, nutritional etc.	93	--	35	--	--	7*	14*	27
Other	387	34	51	43	30	89	21	118
Unknown	259	--	--	--	--	--	--	252

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TABLE 17. Disability Status by Labour Force Status by Sex and Age Group

Persons Age 15 and Over

Labour force status by sex and age group	Disability status			
	Total	Disabled		Not disabled
		Number	Per cent	
	thousands			
TOTAL – LABOUR FORCE STATUS				
Both sexes				
All ages	19,136	2,448	12.8	16,688
15-24 years	4,335	165	3.8	4,170
25-34 "	4,335	230	5.3	4,105
35-54 "	5,840	581	10.0	5,258
55-64 "	2,270	561	24.7	1,709
65 years and over	2,356	910	38.6	1,446
Male				
All ages	9,357	1,108	11.8	8,249
15-24 years	2,190	78	3.6	2,112
25-34 "	2,146	108	5.0	2,038
35-54 "	2,917	269	9.2	2,649
55-64 "	1,086	268	24.7	819
65 years and over	1,017	385	37.9	632
Female				
All ages	9,779	1,339	13.7	8,439
15-24 years	2,145	87	4.1	2,058
25-34 "	2,189	122	5.6	2,067
35-54 "	2,922	312	10.7	2,610
55-64 "	1,183	293	24.8	890
65 years and over	1,339	525	39.2	814
Employed				
Both sexes				
All ages	11,094	675	6.1	10,420
15-24 years	2,324	65	2.8	2,259
25-34 "	3,168	126	4.0	3,042
35-54 "	4,313	293	6.8	4,021
55-64 "	1,111	154	13.9	958
65 years and over	178	37	20.8	141
Male				
All ages	6,502	400	6.2	6,102
15-24 years	1,210	29	2.4	1,181
25-34 "	1,830	70	3.8	1,760
35-54 "	2,589	169	6.5	2,419
55-64 "	738	103	14.0	635
65 years and over	135	29	21.5	106
Female				
All ages	4,593	275	6.0	4,318
15-24 years	1,114	36	3.2	1,078
25-34 "	1,338	56	4.2	1,282
35-54 "	1,725	123	7.1	1,601
55-64 "	373	50	13.4	323
65 years and over	43	9*	20.9*	34

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TABLE 17. Disability Status by Labour Force Status by Sex and Age Group – Concluded

Persons Age 15 and Over

Labour force status by sex and age group	Total	Disability status		
		Disabled		Not disabled
		Number	Per cent	
	thousands			
Unemployed				
Both sexes				
All ages	1,233	98	7.9	1,135
15-24 years	491	23	4.7	468
25-34 "	345	20	5.8	325
35-54 "	315	38	12.1	277
55-64 "	80	17	21.3	63
65 years and over	--	--	--	--
Male				
All ages	688	57	8.3	631
15-24 years	275	15*	5.5*	260
25-34 "	196	13*	6.6*	183
35-54 "	165	19	11.5	146
55-64 "	51	10*	19.6*	41
65 years and over	--	--	--	--
Female				
All ages	545	41	7.5	504
15-24 years	216	9*	4.2*	208
25-34 "	149	7*	4.7*	142
35-54 "	150	19	12.7	131
55-64 "	29	7*	24.1*	22
65 years and over	--	--	--	--
Not in labour force				
All ages	6,809	1,675	24.6	5,134
15-24 years	1,521	77	5.1	1,444
25-34 "	822	85	10.3	737
35-54 "	1,212	251	20.7	961
55-64 "	1,078	390	36.2	688
65 years and over	2,176	872	40.1	1,304
Male				
All ages	2,167	651	30.0	1,516
15-24 years	705	34	4.8	671
25-34 "	120	26	21.7	94
35-54 "	164	80	48.8	84
55-64 "	297	154	51.9	143
65 years and over	881	357	40.5	524
Female				
All ages	4,641	1,024	22.1	3,618
15-24 years	815	43	5.3	773
25-34 "	702	59	8.4	643
35-54 "	1,048	171	16.3	877
55-64 "	781	236	30.2	545
65 years and over	1,295	516	39.8	779

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TABLE 25. Disability Status by Age Group and Current Education Level

Persons Age 15 and Over

Age group by current education level	Total	Disability status		
		Disabled		Not disabled
		Number	Per cent	
	thousands			
ALL AGES				
All education levels	19,136	2,448	12.8	16,688
0-8 years	3,934	1,066	27.1	2,868
High school	9,559	1,007	10.5	8,552
Some postsecondary education	1,622	111	6.8	1,511
Postsecondary certificate/diploma	2,162	168	7.8	1,994
University degree	1,858	95	5.1	1,763
15-24 years				
All education levels	4,335	165	3.8	4,170
0-8 years	281	28	10.0	253
High school	2,863	110	3.8	2,752
Some postsecondary education	644	16	2.5	628
Postsecondary certificate/diploma	395	9*	2.3 *	386
University degree	153	--	--	151
25-34 years				
All education levels	4,335	230	5.3	4,105
0-8 years	280	41	14.6	239
High school	2,200	122	5.5	2,077
Some postsecondary education	442	19	4.3	423
Postsecondary certificate/diploma	727	30	4.1	697
University degree	687	18	2.6	669
35-54 years				
All education levels	5,840	581	9.9	5,258
0-8 years	1,283	202	15.7	1,080
High school	2,702	262	9.7	2,439
Some postsecondary education	358	30	8.4	328
Postsecondary certificate/diploma	735	53	7.2	681
University degree	762	33	4.3	730
55-64 years				
All education levels	2,270	561	24.7	1,709
0-8 years	889	274	30.8	616
High school	968	221	22.8	747
Some postsecondary education	102	19	18.6	82
Postsecondary certificate/diploma	165	29	17.6	136
University degree	145	18	12.4	128
65 years and over				
All education levels	2,356	910	38.6	1,446
0-8 years	1,200	521	43.4	680
High school	828	291	35.1	536
Some postsecondary education	77	27	35.1	50
Postsecondary certificate/diploma	141	47	33.3	94
University degree	111	25	22.5	86

Note: The category "high school" includes persons who have either completed secondary education or at least had some secondary education but who have not had any postsecondary education.

APPENDIX 3

Item 1. Declaration on the Decade of Disabled Persons

Item 2. Canadian Charter of Rights and Freedoms

Item 3. U. N. Declaration on the Rights of Mentally Retarded Persons (Human Rights: A Compilation of International Instruments. United Nations, 1983)

Item 4. U. N. Declaration on the Rights of Disabled Persons (Human Rights: A Compilation of International Instruments. United Nations, 1983)

Item 5. Universal Declaration of Human Rights (Office of Public Information. United Nations, 1978)

Item 6. Bill C-62, The Employment Equity Act (Employment and Immigration Canada, 1986)

DECLARATION ON THE DECADE OF DISABLED PERSONS

THE GOVERNMENT OF CANADA

RECALLING *the resolutions of the United Nations' General Assembly 37/52 and 37/53 which adopted the World Programme of Action concerning Disabled Persons and called upon Member States, all relevant non-governmental organizations and organizations of disabled persons to ensure early implementation of the World Programme of Action concerning Disabled Persons and mindful that Member States of the United Nations are requested to develop plans related to the World Programme of Action,*

RECALLING ALSO *the Declaration of the United Nations on the Rights of Mentally Retarded Persons and the Rights of Disabled Persons,*

RECALLING FURTHER *the Canadian Charter of Rights and Freedoms (section 15) which prohibits discrimination on the basis of any mental or physical disability,*

EMPHASIZING *the objectives of the World Programme of Action which are the promotion of effective measures for prevention of disability and impairment for the rehabilitation and for the realization of the goals of "full participation" of disabled persons in social life and development, and of "equality;" meaning opportunities equal to those of the whole population and an equal share in the improvement in living conditions resulting from social and economic development,*

BEARING IN MIND *the distinction made between impairment (any loss or abnormality of psychological, physiological, or anatomical structure or function), disability (any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being), and handicap (a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is considered as normal, depending on age, sex, social and cultural factors, for that individual) and the resulting conclusion that a handicap is a function of the relationship between disabled persons and their environment,*

BEARING IN MIND ALSO *the definitions of the terms of action proposed in the World Programme as prevention (the measures aimed at preventing the onset of mental, physical and sensory impairments or at preventing impairment, when it has occurred, from having negative physical, psychological and social consequences), rehabilitation (a goal-oriented and time-limited process aimed at enabling an impaired person to reach an optimum mental, physical and/or social functional level, thus providing the person with tools to change his or her own life), equalization of opportunities (the process through which the general systems of society are made accessible to all),*

NOTING *the success of organizations of disabled persons and others in developing innovative and effective alternative means of enhancing the participation and integration of persons with disabilities in society,*

RECOGNIZING *the significant loss to the Canadian economy when the full potential and abilities of persons with disabilities are not utilized, and the real cost upon the economy due to segregation,*

NOTING IN PARTICULAR *the emergence of organizations of disabled persons and the need for participation and integration of persons with disabilities in society,*

PROCLAIMS 1983–1992 *the Decade of Disabled Persons during which the objectives of the World Programme of Action concerning Disabled Persons will be implemented in accordance with this Declaration of Principles which will direct and guide our governmental activities.*

PRINCIPLES

1. *The abilities, integrity, right of choice and dignity of individuals with disabilities shall be respected in all stages of their lives.*
2. *In the development and implementation of programmes and services every effort shall be made to avoid forcing individuals to leave their families and home communities with the goal of ensuring an early and lasting integration into society of individuals with disabilities.*
3. *Services and programmes shall be aimed at integrating disabled persons into existing social and economic structures rather than segregating such persons into parallel environments.*
4. *Persons with disabilities shall be ensured involvement in decision making which pertains to the design and organization of programmes and services considered necessary for the integration of disabled persons into all facets of society. In this respect there shall be a particular emphasis on rehabilitation.*
5. *Individuals with disabilities shall be assured access to fundamental elements of daily life that are generally available in the community. Whenever possible the effects of an impairment or disability on an individual's life shall not be determined by environmental factors.*
6. *Persons with disabilities shall be encouraged to engage in all aspects of society and to participate in social change to fulfill themselves and to meet their obligations as citizens.*
7. *The development of self-help organizations of persons with disabilities shall be encouraged so as to provide these citizens with a means of self-development and a voice of their own to articulate their needs, views and priorities.*
8. *A minimum standard in the provision of programmes and services to disabled persons shall be met across Canada; disparities shall be minimized despite rural isolation, poverty, indigenous status and regional economic conditions.*
9. *In the development of programmes aimed at the total population, attention shall be given to measures which could prevent or reduce the incidence of disability and impairment.*
10. *There shall be consultation among governments and all sectors of society to ensure that a coordinated effort is undertaken to allocate resources to the prevention of disability and to facilitate the rehabilitation and integration of persons with disabilities into all aspects of society.*
11. *There shall be action and public education to minimize environmental barriers, to remove systemic barriers and remedy social attitudes evolving from ignorance, indifference and fear, which impede the full participation of individuals with disabilities.*

Brian Mulroney

Prime Minister of Canada

CONSTITUTION ACT, 1981

PART I **SCHEDULE B**

CANADIAN CHARTER OF RIGHTS AND FREEDOMS

Whereas Canada is founded upon principles that recognize the supremacy of God and the rule of law:

Guarantee of Rights and Freedoms

Rights and freedoms in Canada

1. The *Canadian Charter of Rights and Freedoms* guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.

Fundamental Freedoms

Fundamental freedoms

2. Everyone has the following fundamental freedoms:
(*a*) freedom of conscience and religion;
(*b*) freedom of thought, belief, opinion and expression, including freedom of the press and other media of communication;
(*c*) freedom of peaceful assembly; and
(*d*) freedom of association.

Democratic Rights

Democratic rights of citizens

3. Every citizen of Canada has the right to vote in an election of members of the House of Commons or of a legislative assembly and to be qualified for membership therein.

Maximum duration of legislative bodies

4. (1) No House of Commons and no legislative assembly shall continue for longer than five years from the date fixed for the return of the writs at a general election of its members.

Continuation in special circumstances

(2) In time of real or apprehended war, invasion or insurrection, a House of Commons may be continued by Parliament and a legislative assembly may be continued by the legislature beyond five years if such continuation is not opposed by the votes of more than one-third of the members of the House of Commons or the legislative assembly, as the case may be.

Annual sitting of legislative bodies

5. There shall be a sitting of Parliament and of each legislature at least once every twelve months.

Mobility Rights

Mobility of citizens

6. (1) Every citizen of Canada has the right to enter, remain in and leave Canada.

Rights to move and gain livelihood

(2) Every citizen of Canada and every person who has the status of a permanent resident of Canada has the right

(*a*) to move to and take up residence in any province; and

(*b*) to pursue the gaining of a livelihood in any province.

Limitation

(3) The rights specified in subsection (2) are subject to

(*a*) any laws or practices of general application in force in a province other than those that discriminate among persons primarily on the basis of province of present or previous residence; and

(*b*) any laws providing for reasonable residency requirements as a qualification for the receipt of publicly provided social services.

Affirmative action programs

(4) Subsections (2) and (3) do not preclude any law, program or activity that has as its object the amelioration in a province of conditions of individuals in that province who are socially or economically disadvantaged if the rate of employment in that province is below the rate of employment in Canada.

Legal Rights

Life, liberty and security of person

7. Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.

Search or seizure

8. Everyone has the right to be secure against unreasonable search or seizure.

Detention or imprisonment

9. Everyone has the right not to be arbitrarily detained or imprisoned.

Arrest or detention

10. Everyone has the right on arrest or detention

(*a*) to be informed promptly of the reasons therefor;

(*b*) to retain and instruct counsel without delay and to be informed of that right; and

(*c*) to have the validity of the detention determined by way of *habeas corpus* and to be released if the detention is not lawful.

Proceedings in criminal and penal matters

11. Any person charged with an offence has the right

(*a*) to be informed without unreasonable delay of the specific offence;

(*b*) to be tried within a reasonable time;

(*c*) not to be compelled to be a witness in proceedings against that person in respect of the offence;

(*d*) to be presumed innocent until proven guilty according to law in a fair and public hearing by an independent and impartial tribunal;

(*e*) not to be denied reasonable bail without just cause;

(*f*) except in the case of an offence under military law tried before a military tribunal, to the benefit of trial by jury where the maximum punishment for the offence is imprisonment for five years or a more severe punishment;

(*g*) not to be found guilty on account of any act or omission unless, at the time of the act or omission, it constituted an offence under Canadian or international law or was criminal according to the general principles of law recognized by the community of nations;

(*h*) if finally acquitted of the offence, not to be tried for it again and, if finally found guilty and punished for the offence, not to be tried or punished for it again; and

(*i*) if found guilty of the offence and if the punishment for the offence has been varied between the time of commission and the time of sentencing, to the benefit of the lesser punishment.

Treatment or punishment

12. Everyone has the right not to be subjected to any cruel and unusual treatment or punishment.

Self-crimination

13. A witness who testifies in any proceedings has the right not to have any incriminating evidence so given used to incriminate that witness in any other proceedings, except in a prosecution for perjury or for the giving of contradictory evidence.

Interpreter

14. A party or witness in any proceedings who does not understand or speak the language in which the proceedings are conducted or who is deaf has the right to the assistance of an interpreter.

Equality Rights

Equality before and under law and equal protection and benefit of law

15. (1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

Affirmative action programs

(2) Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

Official Languages of Canada

Official languages of Canada

16. (1) English and French are the official languages of Canada and have equality of status and equal rights and privileges as to their use in all institutions of the Parliament and government of Canada.

Official languages of New Brunswick

(2) English and French are the official languages of New Brunswick and have equality of status and equal rights and privileges as to their use in all institutions of the legislature and government of New Brunswick.

Advancement of status and use

(3) Nothing in this Charter limits the authority of Parliament or a legislature to advance the equality of status or use of English and French.

Proceedings of Parliament

17. (1) Everyone has the right to use English or French in any debates and other proceedings of Parliament.

Proceedings of New Brunswick legislature

(2) Everyone has the right to use English or French in any debates and other proceedings of the legislature of New Brunswick.

Parliamentary statutes and records

18. (1) The statutes, records and journals of Parliament shall be printed and published in English and French and both language versions are equally authoritative.

New Brunswick statutes and records

(2) The statutes, records and journals of the legislature of New Brunswick shall be printed and published in English and French and both language versions are equally authoritative.

Proceedings in courts established by Parliament

19. (1) Either English or French may be used by any person in, or in any pleading in or process issuing from, any court established by Parliament.

Proceedings in New Brunswick courts

(2) Either English or French may be used by any person in, or in any pleading in or process issuing from, any court of New Brunswick.

Communications by public with federal institutions

20. (1) Any member of the public in Canada has the right to communicate with, and to receive available services from, any head or central office of an institution of the Parliament or government of Canada in English or French, and has the same right with respect to any other office of any such institution where

(*a*) there is a significant demand for communications with and services from that office in such language; or (*b*) due to the nature of the office, it is reasonable that communications with and services from that office be available in both English and French.

Communications by public with New Brunswick institutions

(2) Any member of the public in New Brunswick has the right to communicate with, and to receive available services from, any office of an institution of the legislature or government of New Brunswick in English or French.

Continuation of existing constitutional provisions

21. Nothing in sections 16 to 20 abrogates or derogates from any right, privilege or obligation with respect to the English and French languages, or either of them, that exists or is continued by virtue of any other provision of the Constitution of Canada.

Rights and privileges preserved

22. Nothing in sections 16 to 20 abrogates or derogates from any legal or customary right or privilege acquired or enjoyed either before or after the coming into force of this Charter with respect to any language that is not English or French.

Minority Language Educational Rights

Language of instruction

23. (1) Citizens of Canada

(*a*) whose first language learned and still understood is that of the English or French linguistic minority population of the province in which they reside, or

(*b*) who have received their primary school instruction in Canada in English or French and reside in a province where the language in which they received that instruction is the language of the English or French linguistic minority population of the province,

have the right to have their children receive primary and secondary school instruction in that language in that province.

Continuity of language instruction

(2) Citizens of Canada of whom any child has received or is receiving primary or secondary school instruction in English or French in Canada, have the right to have all their children receive primary and secondary school instruction in the same language.

Application where numbers warrant

(3) The right of citizens of Canada under subsections (1) and (2) to have their children receive primary and secondary school instruction in the language of the English or French linguistic minority population of a province

(*a*) applies wherever in the province the number of children of citizens who have such a right is sufficient to warrant the provision to them out of public funds of minority language instruction; and

(*b*) includes, where the number of those children so warrants, the right to have them receive that instruction in minority language educational facilities provided out of public funds.

Enforcement

Enforcement of guaranteed rights and freedoms

24. (1) Anyone whose rights or freedoms, as guaranteed by this Charter, have been infringed or denied may apply to a court of competent jurisdiction to obtain such remedy as the court considers appropriate and just in the circumstances.

Exclusion of evidence bringing administration of justice into disrepute

(2) Where, in proceedings under subsection (1), a court concludes that evidence was obtained in a manner that infringed or denied any rights or freedoms guaranteed by this Charter, the evidence shall be excluded if it is established that, having regard to all the circumstances, the admission of it in the proceedings would bring the administration of justice into disrepute.

General

Aboriginal rights and freedoms not affected by Charter

25. The guarantee in this Charter of certain rights and freedoms shall not be construed so as to abrogate or derogate from any aboriginal, treaty or other rights or freedoms that pertain to the aboriginal peoples of Canada including

(*a*) any rights or freedoms that have been recognized by the Royal Proclamation of October 7, 1763; and

(*b*) any rights or freedoms that may be acquired by the aboriginal peoples of Canada by way of land claims settlement.

Other rights and freedoms not affected by Charter

26. The guarantee in this Charter of certain rights and freedoms shall not be construed as denying the existence of any other rights or freedoms that exist in Canada.

Multicultural heritage

27. This Charter shall be interpreted in a manner consistent with the preservation and enhancement of the multicultural heritage of Canadians.

Rights guaranteed equally to both sexes

28. Notwithstanding anything in this Charter, the rights and freedoms referred to in it are guaranteed equally to male and female persons.

Rights respecting certain schools preserved

29. Nothing in this Charter abrogates or derogates from any rights or privileges guaranteed by or under the Constitution of Canada in respect of denominational, separate or dissentient schools.

Application to territories and territorial authorities

30. A reference in this Charter to a province or to the legislative assembly or legislature of a province shall be deemed to include a reference to the Yukon Territory and the Northwest Territories, or to the appropriate legislative authority thereof, as the case may be.

Legislative powers not extended

31. Nothing in this Charter extends the legislative powers of any body or authority.

Application of Charter

Application of Charter

32. (1) This Charter applies

(*a*) to the Parliament and government of Canada in respect of all matters within the authority of Parliament including all matters relating to the Yukon Territory and Northwest Territories; and

(*b*) to the legislature and government of each province in respect of all matters within the authority of the legislature of each province.

Exception

(2) Notwithstanding subsection (1), section 15 shall not have effect until three years after this section comes into force.

Exception where express declaration

33. (1) Parliament or the legislature of a province may expressly declare in an Act of Parliament or of the legislature, as the case may be, that the Act or a provision thereof shall operate notwithstanding a provision included in section 2 or sections 7 to 15 of this Charter.

Operation of exception

(2) An Act or a provision of an Act in respect of which a declaration made under this section is in effect shall have such operation as it would have but for the provision of this Charter referred to in the declaration.

Five year limitation

(3) A declaration made under subsection (1) shall cease to have effect five years after it comes into force or on such earlier date as may be specified in the declaration.

Re-enactment

(4) Parliament or a legislature of a province may re-enact a declaration made under subsection (1).

Five year limitation

(5) Subsection (3) applies in respect of a re-enactment made under subsection (4).

Citation

Citation

34. This Part may be cited as the *Canadian Charter of Rights and Freedoms.*

PART II

RIGHTS OF THE ABORIGINAL PEOPLES OF CANADA

Recognition of existing aboriginal and treaty rights

35. (1) The existing aboriginal and treaty rights of the aboriginal peoples of Canada are hereby recognized and affirmed.

Definition of "aboriginal peoples of Canada"

(2) In this Act, "aboriginal peoples of Canada" includes the Indian, Inuit and Métis peoples of Canada.

integrity of other States, interfering in their internal affairs, waging aggressive wars, suppressing national liberation movements or pursuing a policy of racial discrimination. Such acts are not only a flagrant violation of the Charter of the United Nations and principles of international law, but constitute an inadmissible distortion of the purposes that should guide scientific and technological developments for the benefit of mankind.

5. All States shall co-operate in the establishment, strengthening and development of the scientific and technological capacity of developing countries with a view to accelerating the realization of the social and economic rights of the peoples of those countries.

6. All States shall take measures to extend the benefits of science and technology to all strata of the population and to protect them, both socially and materially, from possible harmful effects of the misuse of scientific and technological developments, including their misuse to infringe upon the rights of the individual or of the group, particularly with regard to respect for privacy and the protection of the human personality and its physical and intellectual integrity.

7. All States shall take the necessary measures, including legislative measures, to ensure that the utilization of scientific and technological achievements promotes the fullest realization of human rights and fundamental freedoms without any discrimination whatsoever on grounds of race, sex, language or religious beliefs.

8. All States shall take effective measures, including legislative measures, to prevent and preclude the utilization of scientific and technological achievements to the detriment of human rights and fundamental freedoms and the dignity of the human person.

9. All States shall, whenever necessary, take action to ensure compliance with legislation guaranteeing human rights and freedoms in the conditions of scientific and technological developments.

55. Declaration on the Rights of Mentally Retarded Persons

Proclaimed by the General Assembly of the United Nations on 20 December 1971 (resolution 2856 (XXVI))

The General Assembly,

Mindful of the pledge of the States Members of the United Nations under the Charter to take joint and separate action in co-operation with the Organization to promote higher standards of living, full employment and conditions of economic and social progress and development,

Reaffirming faith in human rights and fundamental freedoms and in the principles of peace, of the dignity and worth of the human person and of social justice proclaimed in the Charter,

Recalling the principles of the Universal Declaration of Human Rights, the International Covenants on Human Rights, the Declaration of the Rights of the Child and the standards already set for social progress in the constitutions, conventions, recommendations and resolutions of the International Labour Organisation, the United Nations Educational, Scientific and Cultural Organization, the World Health Organization, the United Nations Children's Fund and other organizations concerned,

Emphasizing that the Declaration on Social Progress and Development has proclaimed the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged,

Bearing in mind the necessity of assisting mentally retarded persons to develop their abilities in various fields of activities and of promoting their integration as far as possible in normal life,

Aware that certain countries, at their present stage of development, can devote only limited efforts to this end,

Proclaims this Declaration on the Rights of Mentally Retarded Persons and calls for national and international action to ensure that it will be used as a common basis and frame of reference for the protection of these rights:

1. The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.

2. The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.

3. The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his capabilities.

4. Whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.

5. The mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interests.

6. The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If prosecuted for any offence, he shall have a right to due process of law with full recognition being given to his degree of mental responsibility.

7. Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.

56. Declaration on the Rights of Disabled Persons

Proclaimed by the General Assembly of the United Nations on 9 December 1975 (resolution 3447 (XXX))

The General Assembly,

Mindful of the pledge made by Member States, under the Charter of the United Nations; to take joint and separate action in co-operation with the Organization to promote higher standards of living, full employment and conditions of economic and social progress and development,

Reaffirming its faith in human rights and fundamental freedoms and in the principles of peace, of the dignity and worth of the human person and of social justice proclaimed in the Charter,

Recalling the principles of the Universal Declaration of Human Rights, the International Covenants on Human Rights, the Declaration of the Rights of the Child and the Declaration on the Rights of Mentally Retarded Persons, as well as the standards already set for social progress in the constitutions, conventions, recommendations and resolutions of the International Labour Organisation, the United Nations Educational, Scientific and Cultural Organization, the World Health Organization, the United Nations Children's Fund and other organizations concerned,

Recalling also Economic and Social Council resolution 1921 (LVIII) of 6 May 1975 on the prevention of disability and the rehabilitation of disabled persons,

Emphasizing that the Declaration on Social Progress and Development has proclaimed the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged,

Bearing in mind the necessity of preventing physical and mental disabilities and of assisting disabled persons to develop their abilities in the most varied fields of activities and of promoting their integration as far as possible in normal life,

Aware that certain countries, at their present stage of development, can devote only limited efforts to this end,

Proclaims this Declaration on the Rights of Disabled Persons and calls for national and international action to ensure that it will be used as a common basis and frame of reference for the protection of these rights:

1. The term "disabled person" means any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities.

2. Disabled persons shall enjoy all the rights set forth in this Declaration. These rights shall be granted to all disabled persons without any exception whatsoever and without distinction or discrimination on the basis of race, colour, sex, language, religion, political or other opinions, national or social origin, state of wealth, birth or any other situation applying either to the disabled person himself or herself or to his or her family.

3. Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible.

4. Disabled persons have the same civil and political rights as other human beings; paragraph 7 of the Declaration on the Rights of Mentally Retarded Persons applies to any possible limitation or suppression of those rights for mentally disabled persons.

5. Disabled persons are entitled to the measures designed to enable them to become as self-reliant as possible.

6. Disabled persons have the right to medical, psychological and functional treatment, including prosthetic and orthetic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the process of their social integration or reintegration.

7. Disabled persons have the right to economic and social security and to a decent level of living. They have the right, according to their capabilities, to secure and retain employment or to engage in a useful, productive and remunerative occupation and to join trade unions.

8. Disabled persons are entitled to have their special needs taken into consideration at all stages of economic and social planning.

9. Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities. No disabled person shall be subjected, as far as his or her residence is concerned, to differential treatment other than that required by his or her condition or by the improvement which he or she may derive therefrom. If the stay of a disabled person in a specialized establishment is indispensable, the environment and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age.

10. Disabled persons shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature.

11. Disabled persons shall be able to avail themselves of qualified legal aid when such aid proves indispensable for the protection of their persons and property. If judicial proceedings are instituted against them, the legal procedure applied shall take their physical and mental condition fully into account.

12. Organizations of disabled persons may be usefully consulted in all matters regarding the rights of disabled persons.

13. Disabled persons, their families and communities shall be fully informed, by all appropriate means, of the rights contained in this Declaration.

UNIVERSAL DECLARATION OF HUMAN RIGHTS

PREAMBLE

WHEREAS recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people,

Whereas it is essential, if man is not to be compelled to have recourse, as a last resort, to rebellion against tyranny and oppression, that human rights should be protected by the rule of law,

Whereas it is essential to promote the development of friendly relations between nations,

Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom,

Whereas Member States have pledged themselves to achieve, in co-operation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms,

Whereas a common understanding of these rights and freedoms is of the greatest importance for the full realization of this pledge,

Now, therefore, THE GENERAL ASSEMBLY *proclaims*

THIS Universal Declaration of Human Rights as a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance, both among the peoples of Member States themselves and among the peoples of territories under their jurisdiction.

Article 1

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

Article 2

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

Article 3

Everyone has the right to life, liberty and security of person.

Article 4

No one shall be held in slavery or servitude; slavery and the slave trade shall be prohibited in all their forms.

Article 5

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

Article 6

Everyone has the right to recognition everywhere as a person before the law.

Article 7

All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

Article 8

Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law.

Article 9

No one shall be subjected to arbitrary arrest, detention or exile.

Article 10

Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal, in the determination of his rights and obligations and of any criminal charge against him.

Article 11

1. Everyone charged with a penal offence has the right to be presumed innocent until proved guilty according to law in a public trial at which he has had all the guarantees necessary for his defence.
2. No one shall be held guilty of any penal offence on account of any act or omission which did not constitute a penal offence, under national or international law, at the time when it was committed. Nor shall a heavier penalty be imposed than the one that was applicable at the time the penal offence was committed.

Article 12

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.

Article 13

1. Everyone has the right to freedom of movement and residence within the borders of each state.
2. Everyone has the right to leave any country, including his own, and to return to his country.

Article 14

1. Everyone has the right to seek and to enjoy in other countries asylum from persecution.
2. This right may not be invoked in the case of prosecutions genuinely arising from non-political crimes or from acts contrary to the purposes and principles of the United Nations.

Article 15

1. Everyone has the right to a nationality.
2. No one shall be arbitrarily deprived of his nationality nor denied the right to change his nationality.

Article 16

1. Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.
2. Marriage shall be entered into only with the free and full consent of the intending spouses.
3. The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

Article 17

1. Everyone has the right to own property alone as well as in association with others.
2. No one shall be arbitrarily deprived of his property.

Article 18

Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief in teaching, practice, worship and observance.

Article 19

Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

Article 20

1. Everyone has the right to freedom of peaceful assembly and association.
2. No one may be compelled to belong to an association.

Article 21

1. Everyone has the right to take part in the government of his country, directly or through freely chosen representatives.
2. Everyone has the right of equal access to public service in his country.
3. The will of the people shall be the basis of the authority of government; this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures.

Article 22

Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international cooperation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

Article 23

1. Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.
2. Everyone, without any discrimination, has the right to equal pay for equal work.
3. Everyone who works has the right to just and favourable remuneration ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.
4. Everyone has the right to form and to join trade unions for the protection of his interests.

Article 24

Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.

Article 25

1. Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.
2. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

Article 26

1. Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.
2. Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the United Nations for the maintenance of peace.

3. Parents have a prior right to choose the kind of education that shall be given to their children.

Article 27

1. Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.
2. Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

Article 28

Everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized.

Article 29

1. Everyone has duties to the community in which alone the free and full development of his personality is possible.
2. In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society.
3. These rights and freedoms may in no case be exercised contrary to the purposes and principles of the United Nations.

Article 30

Nothing in this Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein.

C-62

First Session, Thirty-third Parliament,
33-34-35 Elizabeth II, 1984-85-86

THE HOUSE OF COMMONS OF CANADA

BILL C-62

An Act respecting employment equity

AS PASSED BY THE HOUSE OF COMMONS
APRIL 23, 1986

C-62

Première session, trente-troisième législature,
33-34-35 Elizabeth II, 1984-85-86

CHAMBRE DES COMMUNES DU CANADA

PROJET DE LOI C-62

Loi concernant l'équité en matière d'emploi

ADOPTÉ PAR LA CHAMBRE DES COMMUNES
LE 23 AVRIL 1986

1st Session, 33rd Parliament,
33-34-35 Elizabeth II, 1984-85-86

THE HOUSE OF COMMONS OF CANADA

BILL C-62

An Act respecting employment equity

Her Majesty, by and with the advice and consent of the Senate and House of Commons of Canada, enacts as follows:

SHORT TITLE

Short title

1. This Act may be cited as the *Employment Equity Act.*

PURPOSE

Purpose of Act

2. The purpose of this Act is to achieve equality in the work place so that no person shall be denied employment opportunities or benefits for reasons unrelated to ability and, in the fulfilment of that goal, to correct the conditions of disadvantage in employment experienced by women, aboriginal peoples, persons with disabilities and persons who are, because of their race or colour, in a visible minority in Canada by giving effect to the principle that employment equity means more than treating persons in the same way but also requires special measures and the accommodation of differences.

INTERPRETATION

Definitions

3. In this Act,

"designated groups" *«groupes...»*

"designated groups" means women, aboriginal peoples, persons with disabilities and persons who are, because of their race or colour, in a visible minority in Canada;

"employer" *«employeur»*

"employer" means any person who employs one hundred or more employees on or in

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1^re^ session, 33^e^ législature,
33-34-35 Elizabeth II, 1984-85-86

CHAMBRE DES COMMUNES DU CANADA

PROJET DE LOI C-62

Loi concernant l'équité en matière d'emploi

Sa Majesté, sur l'avis et avec le consentement du Sénat et de la Chambre des communes du Canada, décrète :

TITRE ABRÉGÉ

Titre abrégé

1. *Loi sur l'équité en matière d'emploi.*

OBJET

Objet

2. La présente loi a pour objet de réaliser l'égalité en milieu de travail de façon que nul ne se voie refuser d'avantages ou de chances en matière d'emploi pour des motifs étrangers à sa compétence et, à cette fin, de corriger les désavantages subis, dans le domaine de l'emploi, par les femmes, les autochtones, les personnes handicapées et les personnes que leur race ou leur couleur place parmi les minorités visibles du Canada, conformément au principe selon lequel l'équité en matière d'emploi requiert, outre un traitement identique des personnes, des mesures spéciales et des aménagements adaptés aux différences.

DÉFINITIONS

Définitions

3. Les définitions qui suivent s'appliquent à la présente loi.

«employeur» *"employer"*

«employeur» Quiconque emploie au moins cent salariés au sein ou dans le cadre d'une entreprise fédérale au sens de l'article 2 du *Code canadien du travail*, ainsi que toute personne morale employant au moins cent connection with a federal work, undertaking or business as defined in section 2 of the *Canada Labour Code* and includes any corporation established to perform any function or duty on behalf of the Government of Canada that employs one hundred or more employees, but does not include

(*a*) a person who employs employees on or in connection with a work, undertaking or business of a local or private nature in the Yukon Territory or the Northwest Territories, or

(*b*) a corporation that is a department as defined in the *Financial Administration Act*;

"Minister"
«ministre»

"Minister" means

(*a*) the Minister of Employment and Immigration, or

(*b*) such member of the Queen's Privy Council for Canada as is designated by the Governor in Council as the Minister for the purposes of this Act;

"prescribed"
Version anglaise seulement

"prescribed" means prescribed by regulations of the Governor in Council.

EMPLOYMENT EQUITY

Employer's duty

4. An employer shall, in consultation with such persons as have been designated by the employees to act as their representatives or, where a bargaining agent represents the employees, in consultation with the bargaining agent, implement employment equity by

(*a*) identifying and eliminating each of the employer's employment practices, not otherwise authorized by a law, that results in employment barriers against persons in designated groups; and

(*b*) instituting such positive policies and practices and making such reasonable accommodation as will ensure that persons in designated groups achieve a degree of representation in the various positions of employment with the employer that is at least proportionate to their representation

(i) in the work force, or

(ii) in those segments of the work force that are identifiable by qualification, eligibility or geography and from which

salariés et constituée pour l'accomplissement de fonctions au nom du gouvernement du Canada, à l'exclusion :

a) d'une personne qui emploie des salariés au sein ou dans le cadre d'une entreprise, d'une affaire ou d'un ouvrage de nature locale et privée dans le territoire du Yukon et les territoires du Nord-Ouest;

b) d'un établissement public assimilé à un ministère aux termes de la *Loi sur l'administration financière*.

«groupes concernés»
"designated..."

«groupes désignés» Les femmes, les autochtones, les personnes handicapées et les personnes que leur race ou leur couleur place parmi les minorités visibles du Canada.

«ministre»
"Minister"

«ministre» S'entend :

a) soit du ministre de l'Emploi et de l'Immigration;

b) soit du membre du Conseil privé de la Reine pour le Canada que le gouverneur en conseil désigne comme ministre responsable aux fins de la présente loi.

ÉQUITÉ EN MATIÈRE D'EMPLOI

Obligations de l'employeur

4. En consultation avec les personnes que les salariés ont désignées pour les représenter ou avec l'agent négociateur des salariés lorsque ces derniers sont représentés par un agent négociateur, l'employeur réalise l'équité en matière d'emploi par les actions suivantes :

a) détermination et suppression de ses règles et usages en matière d'emploi, non d'autre part autorisés par une règle de droit, dans les cas où ils font obstacle à la carrière de membres des groupes désignés;

b) instauration d'usages et de règles positifs et prise de mesures raisonnables d'adaptation pour que le nombre de membres de ces groupes dans ses différents postes soit au moins proportionnel à leur représentation :

(i) au sein de la population active,

(ii) dans les secteurs de la population active susceptibles d'être distingués en fonction de critères de compétence, the employer may reasonably be expected to draw or promote employees.

Plan of goals to be prepared

5. (1) An employer shall, in respect of each year, prepare a plan setting out

(*a*) the goals that the employer intends to achieve in implementing employment equity in the year or years to which the plan relates; and

(*b*) the timetable for the implementation of those goals.

Retention of plan

(2) A copy of a plan prepared under subsection (1) shall be retained by the employer at the employer's principal place of business in Canada for a period of at least three years after the last year in respect of which the plan is prepared.

REPORTS

Employer must file

6. (1) On or before June 1, 1988 and on or before June 1 of each year thereafter, every employer shall file with the Minister a report in respect of the immediately preceding calendar year containing information in accordance with prescribed instructions indicating, in the form and manner prescribed,

(*a*) the industrial sector in which employees of the employer are employed, the location of the employer and employees, the number of all employees of the employer and the number of persons in designated groups so employed;

(*b*) the occupational groups of the employer and the degree of representation of persons in designated groups in each occupational group;

(*c*) the salary ranges of employees and the degree of representation of persons in designated groups in each range and prescribed subdivision thereof; and

(*d*) the number of employees hired, promoted and terminated and the degree of representation in those numbers of persons in designated groups.

Certificate required on report

(2) A report under subsection (1) shall, in prescribed manner, be certified as to the accuracy of the information contained there-

d'admissibilité ou d'ordre géographique où il serait fondé à procéder à ses recrutements ou à l'avancement de ses salariés.

Plan de mise en œuvre et échéancier

5. (1) À chaque année, l'employeur élabore un plan énonçant :

a) les objectifs qu'il entend atteindre dans la réalisation de l'équité en matière d'emploi à l'égard de l'année ou des années auxquelles se rapporte le plan en question;

b) l'échéancier de mise en œuvre de ces objectifs.

Conservation du plan

(2) L'employeur doit, au moins durant les trois ans qui suivent la dernière année pour laquelle le plan visé au paragraphe (1) a été élaboré, garder une copie de ce plan à sa principale place d'affaires au Canada.

RAPPORTS

Rapport de l'employeur

6. (1) Au plus tard le 1er juin de chaque année à compter de 1988, l'employeur dépose auprès du ministre, pour la précédente année civile, un rapport, comportant les renseignements conformes aux instructions réglementaires et établi en la forme et selon les modalités réglementaires, qui donne les indications suivantes :

a) les branches d'activité de ses salariés, le lieu de son établissement et le lieu de travail de ses salariés, le nombre de ceux-ci et celui des membres des groupes désignés qui en font partie;

b) les catégories professionnelles qui composent son personnel et la représentation des membres de ces groupes dans chacune d'elles;

c) les échelles de rémunération de ses salariés et la représentation des membres de ces groupes figurant à chacune d'elles ou à chacune de leurs tranches réglementaires;

d) le nombre des recrutements, des avancements et des cessations de fonctions ainsi que, dans chaque cas, la représentation des membres des mêmes groupes.

Attestation d'exactitude

(2) L'exactitude des renseignements fournis dans le rapport visé au paragraphe (1) est attestée selon les modalités réglementaires.

in and the certificate shall be signed by the employer or, where the employer is a corporation, by a prescribed person on behalf of the corporation and under its seal.

Retention of records

(3) All records that are used in the compilation of the information included in a report made by an employer under subsection (1) shall be retained by the employer at the employer's principal place of business in Canada for a period of at least three years after the year in respect of which the report is made.

Offence

7. An employer who fails to comply with section 6 is guilty of an offence and liable on summary conviction to a fine not exceeding fifty thousand dollars.

Minister to send copy

8. The Minister shall, on the receipt of a report filed under section 6, send a copy thereof to the Canadian Human Rights Commission.

Consolidation of reports to be tabled in Parliament

9. The Minister shall in each year prepare a consolidation of the reports received in that year under section 6 and shall, as soon as possible thereafter but not later than the end of that year, cause the consolidation, together with an analysis thereof made by the Minister, to be laid before each House of Parliament.

Copies of reports available

10. Each report filed with the Minister under section 6 shall be available for public inspection at such places as may be designated by the Minister and any person may, on payment of a prescribed fee, not to exceed the costs of furnishing a copy, obtain from the Minister a copy of the report.

GENERAL

Regulations

11. The Governor in Council may make regulations

(*a*) defining, for the purposes of subsection 6(1), the expressions "salary", "hired", "promoted" and "terminated";

(*b*) describing persons who are considered to be members of any designated group;

(*c*) prescribing anything that is to be prescribed under this Act; and

L'attestation est signée par l'employeur ou, dans le cas d'une personne morale, par son représentant désigné par règlement et sous son sceau.

Conservation des documents

(3) L'employeur doit, au moins durant les trois années qui suivent celle à l'égard de laquelle il a fait un rapport en application du paragraphe (1), conserver à sa principale place d'affaires au Canada tous les documents qui ont été utilisés dans la compilation des renseignements que contient le rapport en question.

Infraction

7. L'employeur qui ne se conforme pas à l'article 6 commet une infraction et encourt, sur déclaration de culpabilité par procédure sommaire, une amende maximale de cinquante mille dollars.

Copie à la Commission canadienne des droits de la personne

8. Le ministre fait parvenir à la Commission canadienne des droits de la personne une copie du rapport déposé en application de l'article 6 dès qu'il reçoit ce rapport.

Regroupement des rapports à déposer devant le Parlement

9. Chaque année le ministre regroupe les rapports visés à l'article 6 en un ensemble qu'il assortit d'une analyse. Il fait déposer ces documents devant chaque chambre du Parlement dans les meilleurs délais mais au plus tard à la fin de l'année.

Accès du public aux rapports

10. Le public peut consulter les rapports visés à l'article 6 aux lieux désignés par le ministre et en obtenir copie auprès de celui-ci contre versement d'un droit réglementaire n'excédant pas le coût de la copie.

DISPOSITIONS GÉNÉRALES

Règlements

11. Le gouverneur en conseil peut, par règlement :

a) pour l'application du paragraphe 6(1), définir «rémunération», «recrutement», «avancement» et «cessation de fonctions»;

b) spécifier des personnes qui sont réputées faire partie d'un groupe désigné quelconque;

c) prendre toute mesure d'ordre réglementaire prévue par la présente loi;

(*d*) generally for carrying out the purposes and provisions of this Act.

Guidelines

12. In order to provide employers with information that the Minister deems would be of assistance to employers in implementing the requirements of sections 4 and 5, the Minister may issue guidelines directed to employers pertaining to any of the matters referred to in those sections.

Review of operation of Act

13. (1) Five years after the coming into force of this Act, and at the end of every three year period thereafter, a comprehensive review of the provisions and operation of this Act including the effect of such provisions shall be undertaken by such committee of the House of Commons as may be designated or established by the House for that purpose.

Report on review to be tabled

(2) Within six months after the completion of the review referred to in subsection (1), the committee so designated or established for that purpose shall submit a report on the review to Parliament including a statement of any changes the committee would recommend.

COMING INTO FORCE

Commencement

14. This Act shall come into force on a day to be fixed by proclamation.

d) prendre toute autre mesure d'application de la présente loi.

Directives

12. En toute matière visée aux articles 4 et 5, le ministre peut établir, à l'intention des employeurs, des directives susceptibles, selon lui, de les aider à se conformer aux dispositions de ces articles.

Examen de l'application de la loi

13. (1) Cinq ans après l'entrée en vigueur de la présente loi, et à la fin de chaque période ultérieure de trois ans, un comité de la Chambre des communes désigné ou établi par la Chambre à cette fin procède à un examen complet des dispositions et de l'application de la présente loi ainsi que de leur effet.

Rapport : examen

(2) Dans les six mois suivant la fin de l'examen visé au paragraphe (1), le comité désigné ou établi à cette fin présente au Parlement un rapport concernant l'examen et exposant tous les changements qu'il peut désirer recommander.

ENTRÉE EN VIGUEUR

Entrée en vigueur

14. La présente loi entre en vigueur à la date fixée par proclamation.

Published under authority of the Speaker of the House of Commons by the Queen's Printer for Canada

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APPENDIX 4

Item 1. Citizens Task Force for Physically Disabled Persons (from the Report submitted December 1987 to the City of Edmonton)

Appendix 4, Item 1

THE CITY OF Edmonton
CITIZENS TASK FORCE FOR
PHYSICALLY DISABLED PERSONS

5TH FLOOR CENTENNIAL LIBRARY
7 SIR WINSTON CHURCHILL SQUARE
EDMONTON ALBERTA
T5J 2V4

December 18, 1987

His Worship Mayor Laurence Decore
and Members of City Council
City Hall
1 Sir Winston Churchill Square
Edmonton, Alberta
T5J 2R7

Dear Mayor Decore and Members of City Council:

We are pleased to convey to you the final report of the City of Edmonton Citizens Task Force for Physically Disabled Persons.

Since its establishment over a year ago, the Task Force has met twice monthly, reviewed municipal services, solicited and received input from the disabled community, met with members of the Administration and carried out the Mission established for it by City Council.

After lengthly and involved discussions on problems faced by disabled people and strengths and weaknesses of the City's services we have produced 62 recommendatons for your consideration.

On behalf of members of the Citizens Task Force for Physically Disabled Persons, we would like to express our gratitude to all the associations, groups, individuals, and civic departments who provided advice and input to the Task Force. We would especially like to thank Edmonton City Council for the opportunity the Task Force has afforded the disabled community.

Sincerely,

Louise Miller
Louise Miller
Chairman

William Miller
Vice-Chairman

Citizens Task Force for Physically Disabled Persons

REPORT OF THE CITIZENS TASK FORCE ON PHYSICALLY DISABLED PERSONS

MISSION AND RECOMMENDATIONS

The Citizens Task Force for Physically Disabled Persons was established by Edmonton City Council on March 11, 1986, to advise the Mayor and Council on the needs of the physically disabled community in Edmonton and how City services could be improved to meet these needs.

Ten disabled citizens and representatives of the Custom Transportation Advisory Board and the Advisory Committee for the Message Relay Centre were appointed members. The Task Force met twice monthly and sub-committees met as required.

The Task Force received input from organizations, citizens and civic Departments to aid in its review and deliberations. Copies of the report were circulated to all City Departments for review and comment prior to finalizing the report.

Specifically, the Citizens Task Force was mandated to:

- recommend to Council a City of Edmonton policy statement with respect to municipal services for the disabled.
- recommend to Council on the appropriateness, terms of reference, and structure of a continuing Advisory Committee on the physically disabled;
- review existing municipal services for the disabled;
- advise Council as to which municipal services for the disabled require improvement and recommend means and priorities for addressing these needs;
- advise Council on directions for future planning for services for the disabled;
- recommend to Council ways to promote awareness of civic programs for the disabled; and
- advise on the establishment and content of an equal opportunities program regarding the disabled.

The Citizens Task Force was subsequently also requested by City Council to review the action required to provide authority for the City of Edmonton to enforce handicapped parking areas in major shopping centres (i.e. on private property).

The Citizens Task Force on Physically Disabled Persons makes the following recommendations to the City of Edmonton.

POLICY

1. THE CITY OF EDMONTON SHALL PROMOTE FULL INTEGRATION OF DISABLED CITIZENS INTO THE COMMUNITY THROUGH INFORMATION, EDUCATION AND PROVISION OF NECESSARY CITY SERVICES. THE CITY ALSO RECOGNIZES AND ACKNOWLEDGES THE BENEFIT OF INPUT FROM DISABLED CITIZENS IN ENSURING CIVIC SERVICES MEET THEIR NEEDS.

   IT IS THE POLICY OF THE CITY OF EDMONTON THAT DISABLED CITIZENS HAVE THE RIGHT TO ACCESS SERVICES PROVIDED BY THE CITY. THE CITY OF EDMONTON SHALL ENSURE ACCESS TO THESE SERVICES THROUGH SPECIAL PROVISIONS AND/OR SPECIAL SUBSIDIES AS REQUIRED BY DISABLED CITIZENS.

   THE CITY OF EDMONTON, AS AN EMPLOYER, SHALL ENSURE DISABLED CITIZENS HAVE ACCESS TO EMPLOYMENT OPPORTUNITIES WITH THE CITY CORPORATION. WHERE APPROPRIATE FOR EMPLOYEE AND EMPLOYER, THE CITY SHALL MODIFY FACILITIES AND/OR WORK SCHEDULES FOR QUALIFIED INDIVIDUALS. THE CITY OF EDMONTON SHALL ALSO ENSURE THAT THE ADMINISTRATION IS MADE AWARE OF THE POTENTIAL FOR EMPLOYMENT OPPORTUNITIES FOR DISABLED WORKERS.

ADVISORY COMMITTEE

2. THAT THE CITY OF EDMONTON ESTABLISH AN ADVISORY COMMITTEE FOR SERVICES FOR PHYSICALLY DISABLED PERSONS.

ACCESS

3. That the City of Edmonton review and monitor the accessibility of existing and proposed Municipal buildings and facilities.

4. That the Planning and Building Department, City of Edmonton, hire and train a physically disabled person to review plans for new and renovated buildings for accessibility.

5. That a single, separate, accessible large washroom where a disabled person be assisted by a caregiver of either sex be available and clearly identified in all buildings occupied by the City of Edmonton.

6. That the City of Edmonton encourage development of single, separate, accessible large washrooms in all new and renovated public buildings in the City of Edmonton, through the land use and/or development approval process.

7. That in the "Pararamp Program" of the Transportation Department, City of Edmonton (excluding the "Demand Program"), the highest priority be given to completing ramped curb access throughout Edmonton's central business districts.

8. That the City of Edmonton's Transportation Department establish a procedure for priorizing the locations of pararamp construction within the "Demand Program" in conjunction with representatives of the disabled community.

9. That consideration be given to increase the annual budget allocated for pararamp construction by the Transportation Department to meet the needs of Edmonton's disabled community.

10. That representatives of the physically disabled community liaise with the Transportation Department to review the applicability of the "Turtle Crossing" for expanded use in the City of Edmonton.

11. That the Planning and Building Department liaise with representatives of the physically disabled community to ensure Edmonton's pedway system is accessible for disabled persons.

12. That the City of Edmonton improve signage to buildings in the pedway network, including handicapped accessibility.

13. That the Planning and Building Department develop a map of the pedway network to assist potential users, including physically disabled persons, and that maps be located throughout the pedway network.

14. That facilities in all Edmonton Parks be made more accessible for physically disabled persons, specifically with regard to parking, large print signage for designated parking, access to grassy areas from parking areas, accessible washrooms, and contrasting colors on step-nose for steps.

15. That washroom facilities for physically disabled persons be included in all Parks and Recreation facilities.

16. That the Parks and Recreation Department expand staff training to increase the awareness level of Parks and Recreation Personnel working with disabled persons.

COMMUNICATION

17. That, to increase public awareness regarding the needs of physically disabled persons, the existing handicapped accessibility guide in the white pages of the telephone directory be replaced by a two-page guide listing and describing civic services for physically disabled persons.

18. That the guide proposed above (Recommendation #17) be designed for use by visually-impaired persons.

19. That representatives of the Physically Disabled Community work with the Alberta Committee of disabled persons (A.C.D.C.) and Edmonton Telephones to determine criteria for an accessibility guide which will meet the array of needs of disabled persons in the City of Edmonton.

20. That Edmonton Telephones develop an index of accessible business premises and also identify the degree of accessibility on yellow pages advertising.

21. That Corporate Communications produce a brochure which lists and describes the services provided by the City for the physically disabled community.

22. That the City of Edmonton, in cooperation with disabled citizens, develop an educational resource to inform City Departments about the abilities and needs of physically disabled persons.

23. That the Transportation Department undertake a feasibility study evaluating the visual identification and advertising revenue proposal submitted by the Task Force.

24. That Edmonton Telephones expand and upgrade the telephone message relay centre to ensure non-hearing persons have the same access to telephone services as hearing persons.

EMPLOYMENT

25. That the Personnel Department, City of Edmonton, establish a comprehensive employment program for disabled persons including:

    - The maintenance by the Personnel Department of records of the number of physically disabled persons who apply for and who are appointed to positions within the City;

    - The increase of proactive recruitment methods (including advertising of all job openings, other than those restricted to present employees or those on layoff, with employment agencies of and/or serving disabled persons) to ensure physically disabled persons are informed of job positions;

    - The employment of a Personnel Officer to recruit, market and place physically disabled persons within the City and to provide awareness of the abilities of physically disabled persons to all City Departments; the present equal opportunities officer should continue to work in policy development and other related areas; and

    - The development and implementation of a program of awarness seminars or workshops for employees, managers and senior representatives, emphasizing the skills and abilities of disabled persons as workers.

26. That qualifications for positions including level of education and conditions of employment be reviewed and evaluated to ensure there is no systematic discrimination.

27. That any written tests or examinations continue to be adapted for blind or visually-impaired persons.

28. That alternate methods of assessment (in addition to interviews) be considered when selecting candidates for positions.

29. That City Council establish a funding program to provide on the job training for disabled persons in order to increase the opportunities available to them.

30. That sources of funding from outside groups to assist on the job training of physically disabled persons continue to be researched.

31. That increased funding be made available to improve accessibility to the work place and to continue to provide for technical and other aids for physically disabled candidates, including sign language interpreters for interviews and training.

32 That opportunities for promotion for present disabled employees be expanded, and that progressive career paths be developed for interested disabled employees.

33. That City employees who become disabled continue to have the duties of their job redefined, if possible, be placed in another equal or similar position or be retrained for a similar position.

34. That the City of Edmonton include a long-term disability plan within the benefits provided for all permanent employees.

35. That every opportunity continue to be taken to advertise achievements of disabled persons.

36. That City Council adopt the principle that any private company awarded a contract for a city service should follow an employment program regarding disabled persons similar to the City of Edmonton.

FUNDING

37. That Edmonton City Council review the guidelines for policy C193, Grants-in-Aid to organizations and individuals, with the intention of amending to permit funding of health-related concerns for physically disabled persons; and that there be additional designated funds administered on the recommendation of a specially appointed committee comprised of representatives from the physically disabled community.

38. That the City of Edmonton establish a special fund to support innovative projects to assist the physically disabled community; and that a specially appointed committee comprised of representatives from the physically disabled community establish priorities and review applications for funding.

39. That members of the Advisory Committee for Services for Physically Disabled Persons be paid honoraria by the City.

HOME CARE

40. That the City of Edmonton request the Government of Alberta to broaden the eligibility criteria for the Home Care Program to permit physically disabled persons who live independently and require only support services to enter the program.

HOUSING OPTIONS

41. That City of Edmonton, in cooperation with groups of disabled citizens, request the Provincial Government to acquire, renovate, and manage additional housing units (covering a range of unit types) in the inner city for use by disabled citizens.

42. That Edmonton Housing Authority liaise with Edmonton Residential Aid Placement Service (R.A.P.S.) to facilitate the coordination of the two services.

43. That the City of Edmonton advise organizations of disabled people of the opportunities which exist under Council's policy on "lease or sale of city-owned land for Social Housing Development."

44. That the City of Edmonton encourage the private sector to incorporate units adapted for physically disabled persons into new housing developments through tax concessions.

45. That the City make available city-owned houses at nominal cost for renovation by service clubs or other non-profit organizations to meet the needs of physically disabled citizens.

46. That when the City of Edmonton makes tax concessions or when City-owned land is involved, concessions, lease or sale of land for development of housing for physically disabled people be conditional upon the involvement of disabled people in the design and planning of housing units.

47. That City Council recommend to the Province of Alberta the expansion of the senior citizens property tax rebate to apply to physically disabled persons of all ages owning and renting accommodation.

TRANSPORTATION

48. That the Transportation Department, City of Edmonton, investigate the feasibility of an integrated Transportation system.

49. That the Transportation Department ensure that all current and future L.R.T. Station construction incorporate design features to permit full accessibility by physically disabled persons.

50. That input from the disabled community in Edmonton be included in deliberations relating to the planning for the South Light Rail Transit (S.L.R.T.).

51. That the Transportation Department improve the electronic and mechanical signage on buses, in addition to the signage at transit zones.

52. That the Transportation Department consider establishing designated drop-of and pick-up spots for physically disabled persons, particularly at major downtown transit zones.

53. That drivers of regular Edmonton Transit System Buses (E.T.S.) be provided educational sessions regarding the transit needs of physically disabled persons.

54. That the identified concerns regarding the disabled Adult Transportation System (D.A.T.S.) be forwarded to the Custom Transportation Services Advisory Board and the Transportation Department for action.

55. That the Transportation Department ensure that any contract to deliver D.A.T.S. service include consistent and comprehensive training programs for drivers.

56. That the Transportation Department develop and adopt standards for designated parking spaces for disabled persons for city owned and/or managed facilities.

57. That the Planning and Building Department, in consultation with the Transportation Department, request Council to amend the land use bylaw to include the above standards for the number and dimensions of designated parking spaces for disabled persons in developments and major redevelopments having public parking.

58. That the City of Edmonton recognize the identification placards for disabled persons implemented by the Province of Alberta for parking privileges currently provided for in the parking meter exemption program.

59. That the City of Edmonton support amendments to the planning act in the spirit and intent of Bill 271 which was designed to provide municipalities with the means of requiring and enforcing the provision of parking for disabled people on private property.

OTHER RECOMMENDATIONS

60. That Bylaw No. 8000, "A Bylaw to Provide for Municipal Elections in the City of Edmonton," be amended to permit physically disabled persons who have previously registered for home-based voting in writing to register in subsequent years for this service by telephone.

61. That Edmonton Public Library budget $20,000 per annum for the acquisition of approximately 400 new talking book titles each year commencing in 1988.

62. That the suggestions for new services and additional improvements to existing services received during review of the final report be referred to the Advisory Committee for Services for Physically Disabled Persons (Recommendation #2) for consideration and recommendation to Council.

APPENDIX 5

Item 1. Premier's Council on the Status of Disabled Persons (1987-1988, Province of Alberta; News Release, Backgrounder)

Item 2. Premier's Council on the Status of Disabled Persons (Towards a New Vision of Abilities in Alberta. Draft, March 1989)

Appendix 5, Item 1

THE PREMIER OF ALBERTA
Legislature Building. Edmonton. Alberta. Canada T5K 2B7 / 403/427-2251

December 22, 1987

A MESSAGE FROM THE PREMIER

REGARDING THE STATUS OF PERSONS WITH DISABILITIES

Earlier this year, I met with Rick Hansen while he was in Edmonton as part of his Man-In-Motion World Tour. I was impressed by Rick's courage and determination, and the outstanding efforts he had made to make people aware of the potential of disabled people. My feeling of respect and admiration for Rick, and others with disabilities, was shared by all Albertans, and this was demonstrated by their very generous response to the Man-In-Motion Tour.

During my meeting with Rick, I made a commitment to establish a Premier's Council on the Status of Disabled Persons.

I asked Community and Occupational Health Minister, Jim Dinning, to prepare a report for the provincial Cabinet on the establishment of the Council and to make recommendations on the Council's mandate, terms of reference, and membership. To assist him in this work, Mr. Dinning appointed a Steering Committee and this Committee has now presented the government with a report entitled "A Proposal for the Premier's Council on the Status of Persons with Disabilities". The report is the result of extensive consultation with the disabled community and contains specific recommendations concerning the Council.

Before acting on the report, I would like to hear from the disabled community on the proposals contained in the report. A copy of the report is enclosed with this letter. I would be grateful if you and your organization would review the Steering Committee's proposals and let me have your comments by January 31, 1988. A short questionnaire and prepaid envelope are enclosed for your convenience. If you require further information, please feel free to contact the Steering Committee's office at 10030 - 107 Street, Edmonton; telephone 422-1095 or toll free at 1-800-272-8841.

. . . 2

Your participation in this important process will only help to make this Premier's Council a meaningful and effective organization.

Sincerely,

Don R. Getty

Don R. Getty

DRG/pdl

Enclosures

THE PREMIER OF ALBERTA

Legislature Building. Edmonton. Alberta. Canada T5K 2B7 / 403/427-2251

A MESSAGE FROM THE PREMIER REGARDING THE PREMIER'S COUNCIL ON THE STATUS OF PERSONS WITH DISABILITIES

The legislation establishing the Premier's Council on the Status of Persons with Disabilities has now been placed before the Legislature for consideration.

I had the honour to introduce the legislation as Bill No. 1 of the current Session. By making this Bill the first one introduced, the government has emphasized the commitment it has to ensuring that the potential of disabled people is fully realized. A copy of the Bill is enclosed for your information.

Gary McPherson has recently been appointed as the first Chairman of the Council. I have known Gary for a number of years and am confident that under his leadership the Council will play a major role in ensuring that persons with disabilities become full and equal participants in the life of Alberta.

A copy of the press release announcing Gary's appointment is attached.

I invite you to submit nominations to the Council and, for your use, nomination forms are enclosed. Further information can be obtained by contacting the Council's offices at Seventh Floor, Seventh Street Plaza, 10030 - 107 Street, Edmonton, Alberta T5J 3E4. Phone: 422-1095 or Toll Free 1-800-272-8841 (Voice or TDD).

Sincerely,

Don R Getty

Don R. Getty

March 29, 1988

RECEIVED APR 1 8 1988

Alberta **NEWS RELEASE**

GOVERNMENT OF ALBERTA

451

FOR IMMEDIATE RELEASE

Edmonton, April 15, 1988...Alberta Premier Don Getty today announced that Gary McPherson, a life-long advocate of the disabled will be the first Chairman of the Premier's Council on the Status of Persons with Disabilities.

"The Council reflects a commitment I made to Rick Hansen, on behalf of all Albertans, during his incredible Man in Motion Tour last March. At that time, I said the awareness he created, and our support for disabled persons would carry-on long after his campaign was over. I'm especially pleased to see Gary McPherson head-up the Council because as Chairman of Rick Hansen's Alberta Man in Motion Committee, he displayed the understanding, and the enthusiasm that will help ensure the Council will make a difference in the lives of disabled Albertans, " said Premier Getty.

"McPherson's personal commitment and strong record of service to the disabled make him well suited to lead the Council in its goal that Albertans with disabilities should be full and equal participants in the life of our province."

"The legislation to create the council was introduced in this Session as Bill One which in a meaningful and symbolic way reflects the importance Albertans and my government place on issues involving the disabled."

"I strongly support the goal of the Premier's Council to help all disabled persons lead independent, healthy lives and achieve their full potential in their community", said Jim Dinning, Minister of Community and Occupational Health and Minister responsible for the Council.

The Council will have legislated power to review, recommend and influence government policies regarding the disabled. It will promote a greater awareness and understanding of the disabled and work to remove the barriers that often stand in their way.

Nominations to the Council, which will have up to 15 members, are now being accepted. The deadline for receipt of nominations (which should include a resume) is May 13, 1988. Nomination forms and more information are available, from the Premier's Council on the Status of Persons with Disabilities, 7th Floor, Seventh Street Plaza, South Tower, 10030 - 107 Street, Edmonton, Alberta T5J 3E4 or telephone (403) 422-1095. Voice or T.D.D. call toll-free 1-800-272-8841.

Other members of the Council will be announced in early July and it is expected that the Council will be fully operational by Fall, 1988.

Mr. McPherson is appointed to a three-year term.

-30-

Contact:

Geoff Davey
Press Secretary
Office of the Premier
(403) 427-2251

Mark Gregory
Communications Advisor
Community and Occupational Health
(403) 427-6466

Alberta

BACKGROUNDER

GOVERNMENT OF ALBERTA

Premier's Council on the Status of Persons with Disabilities

COUNCIL GOALS:

In realizing its mandate, the Council will work towards the following goals:

- The attainment of equality by each and every person with a disability.
- The independence, self-responsibility, self-determination and realization of maximum potential for all persons with disabilities, in all facets of life, including:
    - education
    - family
    - health
    - recreation
    - residential
    - employment
    - transportation
    - legal
- The opportunity for each and every person with a disability to exercise his/her choice in all facets of life.
- The provision, by the generic service system, if the individual wishes, of individualized services on an equitable basis to each person with a disability.
- A positive perception by society of persons with disabilities.
- Change which will positively influence the status of persons with disabilities.

COUNCIL OBJECTIVES:

- To investigate, develop, promote and assist in the understanding of a definition of *disability*.
- To investigate, develop, promote and assist in an understanding of the factors that affect the *status* of persons with disabilities.
- To enable all members of society to recognize each person with a disability as an individual functioning as a complete person in his/her own right.
- To work towards the achievement of service equity utilizing (at the consumer's choice) generic, community-based services.
- To research, develop, promote and provide a greater understanding of the full range of services required by, and available to persons with disabilities.
- To promote ways in which current resources can be reallocated to increase the supply of services in the community.
- To promote a public dialogue about the status of disabled persons.
- To maintain credibility in all aspects of the Council's affairs.
- To facilitate and to become a catalyst for change, where such change will positively influence the status of persons with disabilities.

COUNCIL ACTIVITIES:

The Council will encourage public discussion through public consultation on all matters relating to the status of persons with disabilities. It will also prepare communication packages containing information that will:

- promote public awareness about the wellness of persons with disabilities
- promote professional awareness about persons with disabilities
- provide information of an educational nature about disabling conditions to public and professional audiences.

Other Council activities will include:

- Review of current and future policies affecting and concerning the status of persons with disabilities, and recommend improvements to government.
- Review of the barriers, gaps and overlaps in the provision of funding, services and programs to persons with disabilities, and recommend to government ways in which funding, services, and programs may improve.
- Identification of current and emerging issues that affect the status of persons with disabilities, and present them to respective government departments and consumers, and present periodic information that will illustrate improvements in the status of persons with disabilities in Alberta.
- Investigation of issues that influence the status of persons with disabilities.

MEMBERSHIP:

The Council will consist of up to a maximum of 15 people, including the Chairman.

Membership will include representation from the public at large.

It will comprise persons whose combined knowledge and understanding will include not only matters of *disability*, but also rural, urban and native issues. Membership will, therefore, include individuals from those different sectors of the Alberta community.

A substantial number of Council members will be persons with disabilities, and/or parents or guardians of such persons.

Each member of Council, although possibly known and recognized for his/her activities within another organization, must function and speak as an independent representative to the Council.

Members of the public service whose work is related to policy development and/or service delivery may work with the Council in a consultative role at the request of Council, but may not hold membership on the Council by virtue of their position.

The term of office for membership on the Council, including the Chairman, will be up to three years. Terms will be staggered to ensure continuity in the Council affairs. Council members may be reappointed.

REFERENCE:

Patrick Delaney
Premier's Council on the
Status of Persons with Disabilities
422-1095

Mark Gregory
Communications Advisor
Community and Occupational Health
427-6466

THE PREMIER'S COUNCIL
ON THE STATUS OF PERSONS WITH DISABILITIES

TOWARDS A NEW VISION OF ABILITIES IN ALBERTA

DRAFT

MARCH 1989

A NEW ERA APPROACHES FOR ALBERTANS WITH DISABILITIES

Public Policy has Reflected Paternalistic Assumptions

Historically across North America, the definition of disability has been heavily influenced by medical etiology. Disabilities have been viewed through the perspective of discrete diagnostic categories; the symptoms and consequence of the diagnosis were naturally the associated mental and physical limitations. This focus on illness traditionally has served to cultivate the belief that persons with disabilities are not "normal", not "able", and not "well". Solving the problem of disability meant "fixing" the person with disability. Those individuals who could not be "fixed" were assumed to be incapable. This assumption essentially applied, regardless of the nature of the disability

Public (government) policy has traditionally reflected the limiting assumptions of this medical definition of disability. As a result, public policy has been paternalistic in its approach to persons with disability. Emphasis was placed on "curing" the person with disability but, in the absence of a cure, the alternative was protecting and caring for persons with disabilities. As a consequence, they were removed from their families and home communities and placed in institutions. Across North America, such segregation became the policy norm.

Public Policy has Historically Perpetuated Negative Values and Attitudes

This policy approach by government has served to reinforce negative values and attitudes towards persons with disabilities. Albertans with disabilities from across the Province have been congregated in institutions such as Alberta Hospital Ponoka, Alberta Hospital Edmonton, Michener Centre, Alberta School for the Deaf, and Aberhart Centre.

Consequently, most "normal" Albertans have lived their lives experiencing minimal contact with persons with disabilities. This public policy stance has served to reinforce the belief that all persons with disabilities belong in institutions. Moreover, such segregation has served to perpetuate the fear that not only must persons with disabilities be protected from society, society must also be protected from persons with disabilities.

The responses of private citizens to disability have mirrored such assumptions based on limitations and incapability. Fund raisers have mounted financially successful campaigns which portray persons with disabilities as objects of pity and charity and these images have reinforced beliefs in the helpless "plight" of persons with disabilities.

Our language has also reflected our mental images of charity and pity. Words and phrases such as "suffering from a handicap", "afflicted", "crippled", and "deformed" illustrate the illness assumptions in our descriptions of persons with disabilities. Language and humour also have represented negative attitudes toward persons with disabilities. Labels such as "spastic", "retard", "freak", and the "village idiot" have been used to depersonalize and devalue persons with disabilities. More recently, persons with disabilities pursuing independence and achievement have been described as "courageous", "heroic", and an "inspiration". Although these terms are more positive in tone, they again do not promote assumptions that persons with disabilities undertake "normal" activities. Segregation from society, congregation in institutions and language associated with disability have all served to perpetuate ignorance and fear in members of society as to the actual needs, desires, and capabilities of persons with disabilities.

Public Policy and Public Attitudes are now Reflecting Positive Changes

Public policy and public attitudes have become more enlightened in the last two decades. The American civil rights movements of the 1960's served to raise the consciousness of all North Americans about the human rights of all citizens. New philosophies of treatment have demonstrated that community integration can be an effective alternative to institutionalization. Public officials, professionals, and service agencies are increasingly recognizing the importance of community support systems to promote healthy families and healthy communities.

The Charter of Rights has lead to increasing recognition of citizenship for all Canadians. This has been demonstrated by the recent Federal Court decision giving the right to vote to persons residing in institutional settings. As well, employment equity programs represent the growing public and private awareness of the right, the ability, and the desire of persons with disabilities to make a contribution to society. And, public figures such as Rick Hansen and his "Man-In-Motion Tour" have also educated the public to see the ability as opposed to the limitations in all persons with disabilities.

Complex Challenges Still Remain

As we approach the 1990's, however, many challenges remain. Progress has undoubtedly been made in questioning our limiting assumptions about persons with disabilities, and public attitudes have become more enlightened. However, such progress has been somewhat uneven. Misunderstanding, fear, and negative judgments still exist regarding persons with disabilities.

Progress in the past has often been slowed by ideological conflicts. This has served to divide advocacy and consumer groups, with such groups often postulating opposing visions of lifestyle and service delivery. Such conflicts have contributed to pendulum-like swings in approaches to service delivery. These swings were often implemented in the absence of appropriate planning, funding and infrastructure. This is perhaps best illustrated by the reality faced by individuals who have been discharged from institutions and placed in urban independent living situations without appropriate community support services.

Public policy has been fragmented in its approach to persons with disabilities. Government agencies have often developed policy for specific segments of the population of persons with disabilities. For example, the Workers' Compensation Board addresses policy for the worker with a work related disability, while vocational rehabilitation addresses the needs of those whose disability has other origins. This lack of integration has resulted in the promotion of a variety of approaches. Given such a fragmented approach to policy, policy gaps or duplications exist for those persons who do not clearly fall into definite jurisdictional boundaries, e.g. people with brain injuries.

Community integration has also proven to be a complex issue because this lifestyle approach may not be appropriate or be preferred by all persons with disabilities. Individual choice and corresponding options are increasingly being desired by consumers.

The product of a fragmented approach to public policy development has been a confusing, fragmented service system. Many programs work at cross purposes to each other. For example, Alberta Career Development and Employment's programs promote the integration of persons with disabilities into the workforce, yet this is hampered by the funding policies and guidelines surrounding the Alberta Assured Income for the Severely Handicapped program. No financial alternative exists to cover the cost of services provided under AISH and persons with disabilities obtaining entry level positions cannot afford to pay for the services they require. Consequently, persons who wish to work are reluctant to enter the workforce because the subsequent loss of AISH benefits results in a financial hardship.

For those Albertans with disabilities who have the potential, the opportunity to make an economic contribution is central to realization of positive social roles, yet persons with disabilities represent a largely untapped labour pool. For any number of reasons, employment opportunities for persons with disabilities are limited, e.g., the cost of technical aids, inaccessible work sites, job design, and/or the limited understanding of employers.

Finally, issues surrounding disability can only become more complex. For example, medical technology has led to the survival of many persons who may be left with severe impairments that are not well understood or accommodated by the existing service system. It is projected that the costs related to these often preventable disabilities will escalate dramatically in subsequent decades. Alberta's changing demographics will also be an influential factor. Our aging population can be expected to contribute to an increasing number of persons with disabilities. This trend will also have significant economic and social implications.

We Stand on the Threshold of a New Era

While the 1990's are expected to bring new challenges, they also hold new promise. As is recognized in "Caring and Responsibility: A Statement of Social Policy for Alberta", social policy and economic policy can no longer be developed in isolation. It states:

> "The future economic growth of the Province depends on the development of capable and productive individuals. Indeed, social policy must lead if Albertans are to fulfill their expectations. . .it must form the supporting factor in the development of a strong economic environment."

Such a perspective is positive for all Albertans who have a disability. This philosophy provides a framework in which all individuals can exercise their right, responsibility, and capability to be financially contributing citizens. Such a framework also encourages the exploration of lifestyle and service delivery alternatives for persons with disabilities given the Alberta Government's commitment:

> "to foster individual self-reliance and provide positive opportunities for individuals to achieve their personal goals, to take responsibility for their actions, and to be contributing and caring members of Alberta society."

The challenge for future economic growth in Alberta also necessitates more effective integration of policy in the public and private sectors. For example, as traditional entry-level labour pools continue to decline in numbers, Alberta employers are becoming increasingly open to exploring under-utilized labour pools. Coordinated public and private policy could effectively assist persons with disabilities in acquiring appropriate training, transportation and access to employment as well as necessary technical aids, benefits, and family/community support services.

Albertans with disabilities themselves continue to be effective public educators. Public attitudes are changing as Albertans increasingly gain opportunities for interaction with persons with disabilities. **As neighbours and co-workers come to know and work with individuals with disabilities, the focus of awareness will continue to shift to the person from the limitation, and to the ability from the disability.**

POLICY IN THE NEW ERA MUST BE INTEGRATED, ENABLING, AND PREVENTION FOCUSED

Public Policy towards Persons with Disabilities needs Transformation

Various policy fields such as Health, Social Services, Education, Employment, and Housing have historically been recognized as affecting persons with disabilities. However, limited coordination between these policy fields has contributed to today's collage of philosophy, policy and direction that has frustrated persons with disabilities.

A critical precursor to current and future public (government) policy revision is the definition of a policy field of disability. Such a policy field must be based on the premise that all policy with potential to affect persons with disabilities must contribute to and reinforce a consistent, comprehensive, and positive vision of persons with disabilities.

Policy affecting persons with disabilities must encompass three facets: social, economic and citizenship. Social policy requires commitment to a dignified and humane society ensuring quality of life for all Albertans. Within economic policy there needs to be recognition of the abilities and potential of disabled persons to make an economic contribution, and citizenship policy means making a commitment to full and equitable participation within the community life of the province.

Government and private sector policy must also be integrated if this positive vision for persons with disabilities is to be achieved. Recruitment practices, job design, and disability benefits, are only a few examples of private sector policy decisions which need to be compatible with public policy if persons with disabilities or employees who become disabled are to be enabled for employment.

A final component of the transformation of both public and private sector policy must be the replacement of the concept of cost with the concept of investment. Given our historical paternalistic assumptions, we have seen service delivery for persons with disabilities as necessitating ever-escalating financial expenditures. If policies and programs are designed to facilitate independence, refinement of ability, and self-reliance in individuals and families, then financial outlays can often be short-term in nature. And for those programs that are clearly long-term, expenditures can be minimized, becoming periodic in application as opposed to ongoing.

Public Values and Attitudes need Transformation

Transformation of public values and attitudes with regard to persons with disabilities is a mammoth and complex task. Yet it is only through the awareness and re-education of all Albertans regarding existing limiting assumptions, values and beliefs that Albertans with disabilities can become full and equitable participants in Alberta society. Thus, there is a need for complementary initiatives by government, the private and not-for-profit sectors, communities, and individuals to mobilize attitudinal change.

Fundamental to such educational initiatives must be a focus on ability and potential. The outcome of our policy history has been the education of a generation of Albertans who perceive the "lack of ability" in persons with disabilities. We as Albertans must come to understand that persons with disabilities are not handicapped by their disability; rather, they are limited by inflexible social and physical environments which place the responsibility of adaptation on persons culturally defined as not "normal".

Many aspects of Alberta society are fundamentally shaped by government policy. As a result, it is critical that all government policy reflects positive, enabling values and attitudes towards persons with disabilities. There is need for a common set of policy principles to act as a foundation or framework for any public policy impacting Albertans with disabilities; compatibility with this framework would ensure the consistent promotion of positive values and attitudes.

Disability Policy must Include a Focus on Prevention

In addition to defining a policy field of disability and the promotion of positive values and attitudes, public policy makers must recognize the interrelationship of lifestyle and the development of certain disabilities. This reality has been recognized in some cases; for example, education campaigns have been mounted to educate expectant mothers as to the detrimental affects of smoking and alcohol consumption on the development of the fetus. Much is left to be done, however. The occurrence of one of the most rapidly growing disabilities, i.e. brain injury, can be closely related to lifestyle choices of the high risk population of young adult males.

Thus, public policy must reflect an emphasis on the promotion of healthy individuals, healthy families, and healthy communities. The Premier's Commission on Future Health Care for Albertans has undertaken a commitment to develop policy that focuses on "innovation, promotion, and prevention". However, the responsibility for this promotion does not rest with public policy alone. The private sector, not-for-profit sector, communities, families, and individual Albertans all have critical roles to play if a shift from a "sickness" to a "wellness" perspective is to be achieved.

THE COUNCIL'S PRINCIPLES

To focus pursuit of the mission, five principles have been proposed. These principles form the belief system that will guide Council's input into the two key areas of policy review and public education. These principles are interrelated and each must be viewed in the context of the others.

INDIVIDUAL RESPONSIBILITY AND PERSONAL CONTROL

- A system is needed that ensures individuals have the opportunity to make decisions and choices about issues affecting their lives.
- Mechanisms to support and assist individuals to make decisions must exist and should be provided in a way that will maximize freedom of individual choice, without denying the necessity to intervene where those decisions would clearly result in purposeful self-destruction or harm to others.
- Personal and financial supports must be in place for those who need them so that genuine options exist from which to choose.
- Freedom of choice must encompass the concept of "dignity of risk", meaning that people should also have the opportunity to risk making their own mistakes.

OPPORTUNITY FOR FULL PARTICIPATION IN COMMUNITY LIFE

- Individuals with disabilities must have a range of options for living and working in the community that provides opportunities to maximize participation in the life of the community of his or her choice.
- Support systems must be in place to facilitate and promote full participation in society.

PERSONAL CONTRIBUTION AND INHERENT WORTH

- Persons with disabilities must be recognized for their abilities and expenditure on training and support should be viewed as an investment in people.
- The concept of return on the investment must be expanded to include not only the economic contribution persons with disabilities will make in terms of taxes

and dollars reinvested in the community, but also contributions in the areas of community service and societal enrichment.

- Public education and policy must address the interrelationships of social, economic, and citizenship issues.

EQUITY OF OPPORTUNITY

- Barriers to participation in society that are purely a function of disability must be removed in order to create an "equal playing field". Among the barriers are lack of public awareness, lack of flexible and available support services, and financial costs directly related to a disability.
- The basic costs incurred directly as a result of a disability must be substantially reduced or eliminated on a universal basis, without the use of a means or asset test to determine eligibility.

CONSUMERS AS CONSULTANTS

- Consumers and their families must have input into policies that have potential to impact on the status of disabled persons.
- Consultation with consumers must occur as a matter of course whenever changes are being considered, thereby acknowledging the value of that input and the right of individuals to influence their government.

APPENDIX 6

Item 1. The Employment Equity Workforce: Persons with Disabilities

Taken from Employment and Immigration Canada, Employment Equity Act, Annual Report to Parlaiment 1988. Pps. 49-58. Cat. No. MP 1-4-/1988.

Persons with Disabilities

Persons with disabilities are people who, because of any persistent physical, mental, psychiatric, sensory or learning impairment, believe that they are potentially disadvantaged in employment, and who so identify themselves to an employer, or agree to be so identified by an employer, for the purposes of the Employment Equity Act.

Geographic Location

In Canada, the representation of persons with disabilities ranges from less than 9% of the population in the Yukon and Northwest Territories, to a high of 16.9% in Nova Scotia.

Age Distribution

Statistics show that in 1986, 9% of people with disabilities were under 15 years of age, while 21.5% of all Canadians were under the age of 15. Over one third of persons with disabilities were over 65 as compared to one tenth of the Canadian population.

Part I: Profile of Persons with Disabilities in the Canadian Labour Force

The following information is based on the statistics drawn from the Health and Activity Limitation Survey.[1] Between 1984 and 1986, the number of employed persons with disabilities increased by 11.2%. By 1986, the labour force participation rate of persons with disabilities between the ages of 15 and 64 was 49%, compared with 47.8% in 1984. Since not all disabilities affect work activities, the participation rates have been divided into two categories: people who are limited by their disability and those who are not. The participation rate for people who were limited by their disability was 37.7%, a much lower rate than that of persons with disabilities who indicated that they were not limited at work. In the age group of 15 to 64, those people who reported limitations at work had an unemployment rate of 20% compared to 9% for those without limitations.

There were substantial differences in the occupational profile of persons with disabilities with limitations at work in comparison to other persons with disabilities whose statistics were closer to those of the total population. Less than 5% of persons with disabilities with limitations at work were Upper-level or Middle and Other Managers in comparison to 8.4% of the total population; persons with disabilities without limitations at work had just under 6% representation.

Over 18% of the total population of persons with disabilities were employed in Other Manual Workers occupations; this rose to 20% for those people who were limited at work by their disability. Less than [illegible] of persons with disabilities with limitations at work were in the Professionals group, as compared to 12% of the total Canadian population in these occupations.

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[1] Unpublished data, Statistics Canada.

Part II: Analysis of Persons with Disabilities in the Workforce Covered Under the Employment Equity Act

Representation in the Employment Equity Workforce

The data reported in the employers' 1987 employment equity reports indicated an under-representation of persons with disabilities in the workforce covered by the Employment Equity Act. Employers reported a total of 9352 persons with disabilities out of a total population of 586,861 employees under the Act. Persons with disabilities represented 1.6% of the workforce covered by the Act, which is about one third of their overall representation in the Canadian labour force.[2]

Women with disabilities comprised 34.9% of the group of employees with disabilities. The representation of women in the group of persons with disabilities was about 6% lower than the representation of all women in the workforce covered by the Act.

Representation by Employment Status

The distribution of persons with disabilities by employment status was very similar to the distribution of the workforce. As indicated in Table 1, 8650 persons with disabilities (92.5%) were in permanent full-time employment, 671 (7.2%) were in permanent part-time employment, and 31 (0.3%) were in temporary employment.

The distribution of men and women with disabilities across employment status indicated that 96.9% of men with disabilities were employed in permanent full-time employment, compared to 84.2% of women with disabilities. Less than 3% of men with disabilities worked in permanent part-time positions compared to 15.7% of women with disabilities.

Representation by Industrial Sector

The representation of persons with disabilities was low in all industrial sectors. The Transportation and Communications sectors showed the lowest representation (1.4% in each sector); the Banking sector had a representation of 1.8% of employees with disabilities; and the Others sector reported the highest representation at 2.4%. The representation of women with disabilities was consistently lower across industrial sectors than the representation of all women in the workforce.

Graph 1 presents the sectoral distribution of persons with disabilities and compares it with that of the workforce under the Act. The group shows higher proportions in the Banking and Others sectors, and lower in Transportation and Communications.

The majority of women in this group worked in the Banking sector, while the largest proportion of men worked in the Transportation sector.

Geographic Representation

The data reported by employers on the representation of employees by province or territory and designated Census Metropolitan Area (CMA) showed that 51.9% of persons with disabilities in the workforce were employed in the CMAs. Overall, 58.4% of all employees in the workforce were employed in the CMAs.

As was the case for the entire workforce, 42.8% of all persons with disabilities worked in Ontario. In comparison with the entire workforce covered under the Act, proportionately fewer persons with disabilities were employed in Quebec, and proportionately more were employed in the Atlantic and Prairie provinces.

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[2] Depending on the method of calculation used for the definition of availability data of the persons with disabilities, this figue could vary between 4% and 5.4%. In the first case, the number includes those that worked in 1985 or 1986 (Census base), while the second one includes those who worked at any point between 1981 and 1986 (Health and Activity Base).

Table 1:
Distribution of Persons with Disabilities by Employment Status, by Sex and by Industrial Sector, Compared to the Employment Equity Workforce

	Persons with Disabilities		Workforce			
Employment Status	Banking	Transportation	Communications	Others	All Sectors	
Full-time	2,675	2,735	2,268	972	8,650	523,917
Men	928	2,459	1,647	859	5,893	326,257
Women	1,747	276	620	101	2,744	197,656
Women %	65.3%	10.1%	27.3%	10.4%	31.7%	37.7%
Part-time	362	110	190	9	671	55,706
Men	27	55	72	6	160	14,149
Women	335	55	118	3	511	41,557
Women %	92.5%	50.0%	62.1%	33.3%	76.2%	74.6%
Temporary	2	16	7	6	31	7,238
Men	0	15	6	5	26	4,914
Women	2	1	1	1	5	2,324
Women %	100.0%	6.3%	14.3%	16.7%	16.1%	32.1%
All	3,039	2,861	2,465	987	9,352	586,861
Men	955	2,529	1,725	870	6,079	345,320
Women	2,084	332	739	105	3,260	241,537
Women %	68.6%	11.6%	30.0%	10.6%	34.9%	41.2%

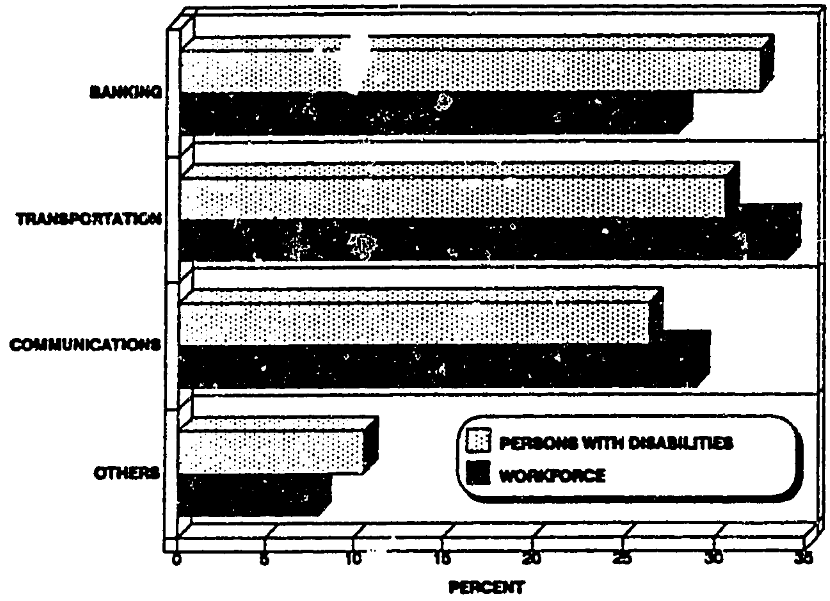
Average Salaries in the Employment Equity Workforce

Table 2 presents information on the estimated average salaries for persons with disabilities. The overall average salary for the group was $29,468, compared to $29,274 for the workforce covered under the Act. It is important to note that men made up a larger proportion of this group than did men in the workforce. The estimated average salary paid to men with disabilities in permanent full-time employment was $34,061, which was marginally lower than the estimated average salary of $34,920 for men working full-time in the workforce. Women with disabilities employed in permanent full-time positions had an estimated average salary of $23,356, which was about 5.4% lower than the estimated average salary ($24,675) of women in full-time employment in the workforce.

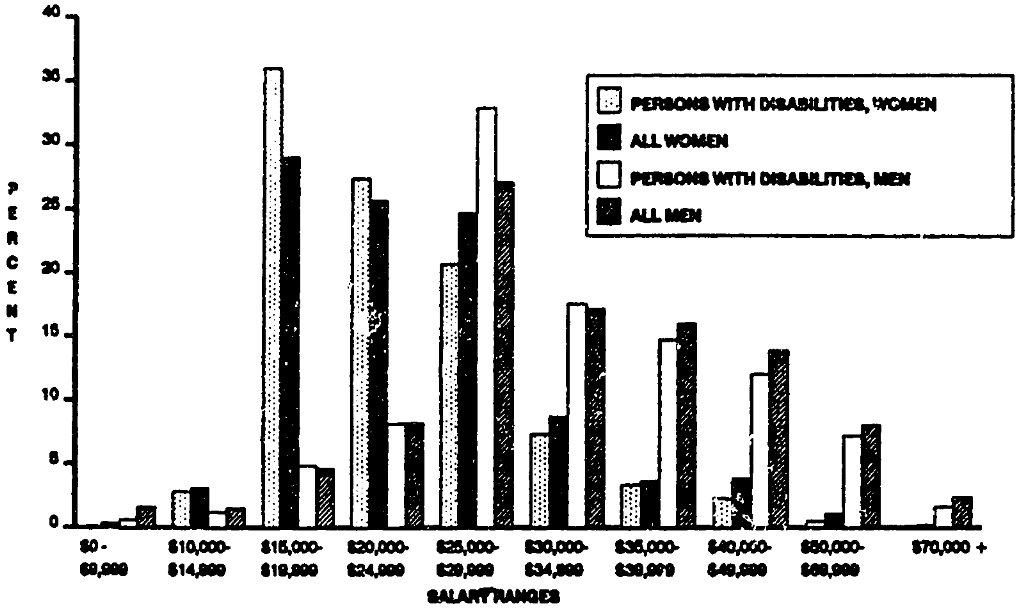
A wage gap was also evident between the salaries paid to men and women within the group of persons with disabilities. Women with disabilities who were employed in permanent full-time employment were paid 68.6% of the salaries paid to men with disabilities employed in the same employment status category. This wage gap was similar (2% lower) to that which existed between the salaries paid to men and women in the workforce.

Graph 2 further illustrates the differences in salaries paid to men and women with disabilities who were

GRAPH 1: DISTRIBUTION OF PERSONS WITH DISABILITIES BY INDUSTRIAL SECTOR



GRAPH 2: FULL-TIME SALARY DISTRIBUTIONS OF PERSONS WITH DISABILITIES AND THE WORKFORCE



employed in permanent full-time positions. Women with disabilities were concentrated in the lower salary ranges. Employers reported that 66.1% of women with disabilities were paid less than $25,000, compared to 14.6% of men with disabilities. Conversely, 2.7% of women with disabilities were paid $40,000 or more, as opposed to almost 20.6% of men with disabilities.

Salaries by Industrial Sector

Both men and women with disabilities were consistently paid lower average salaries in all industrial sectors compared to the average salaries paid to men and women in the workforce. Despite the lower average salaries for men and women with disabilities, the average salary for the group of persons with disabilities was above the average salary for all employees in the Banking and Transportation sectors (full-time employment). As noted, the proportion of men with disabilities in the group was higher than the proportion of men in the workforce; this may explain in part the higher average salary for the group of persons with disabilities in these sectors.

The wage gap between men and women with disabilities working full-time was largest in the Banking sector, where women with disabilities were paid 55.9% of what men with disabilities were paid. The wage difference was the smallest in the Communications sector, where women were paid 81.4% of what men were paid.

The differences in the average salaries paid to women with disabilities in permanent full-time employment and those paid to women in the workforce covered under the Act varied from sector to sector. Women with disabilities employed in the Transportation sector were paid 99.3% of what women in the workforce were paid, and women with disabilities were paid 94.2% of what women in the workforce in the Others sector were paid.

Occupational Distribution

Although the representation of persons with disabilities employed in the workforce was low overall, the occupational distribution of those employees was similar to the occupational distribution of all employees in the workforce. The occupational group with the highest proportion of persons with disabilities was the Clerical Workers group (28.3%). This is similar to the proportion (27.5%) of the workforce in the Clerical category.

Clerical Workers, Semi-skilled Manual Workers and Middle and Other Managers occupational groups accounted for the greatest proportions of persons with disabilities (total of 59.9% of all permanent full-time employees with disabilities). These three occupational groups also accounted for the greatest proportions of all employees in the workforce (a total of 60.1% of all permanent full-time employees).

The greatest difference between the distribution of persons with disabilities and the workforce occurred in the Middle and Other Managers occupational group, where 11.9% of persons with disabilities were employed full-time compared to 13.2% of all full-time employees.

Table 3 shows the occupational distribution of men and of women with disabilities. Over two thirds (67.6%) of all women with disabilities were employed in the Clerical Workers group. This was a higher proportion than that of women in general under the Act (61.5% of all women employed full-time). Less than 8% of women with disabilities were Middle and Other Managers compared to 13.8% of men with disabilities and 10.7% of women in the workforce.

The distribution of men with disabilities and that of men in the workforce indicated that a higher proportion of the former were in the Clerical Workers group compared to the proportion of all men in the workforce (10% and 6.9% respectively for permanent full-time employees).

The occupational groups in which there were the highest proportions of men with disabilities employed included Semi-skilled Manual Workers (25.6%), Skilled Crafts and Trades Workers (17.3%), and Middle and Other Managers (13.8%). Together, these three categories accounted for 56.7% of all men with disabilities reported under the Act. The same three occupational categories had the greatest proportions of all men within the workforce, and accounted for 59.2% of all men reported.

Table 2:
Estimated Average Salaries for Persons with Disabilities by Industrial Sector, by Sex and by Employment Status, Compared to the Employment Equity Workforce

	Persons with Disabilities			Workforce		
Industrial Sector	Full-time	Part-time	All Emp.** Status	Full-time	Part-time	All Emp.* Status
Banking	$27,451	$10,116	$25,302	$27,210	$10,833	$24,517
Men	$38,603	$10,574	$37,524	$39,984	$10,116	$38,835
Women	$21,586	$10,066	$19,706	$22,368	$10,876	$20,018
Women/Men *	55.9%	95.2%	52.5%	55.9%	107.5%	51.5%
Transportation	$32,191	$10,491	$31,653	$31,939	$10,654	$30,568
Men	$32,981	$9,628	$32,526	$33,183	$11,035	$32,045
Women	$25,173	$12,171	$24,271	$25,345	$10,134	$23,376
Women/Men *	76.3%	126.4%	74.6%	76.4%	91.8%	72.9%
Communications	$31,809	$23,521	$31,104	$32,668	$21,224	$31,487
Men	$33,514	$23,016	$32,987	$35,306	$18,827	$34,345
Women	$27,297	$23,852	$26,727	$28,186	$22,433	$27,209
Women/Men *	81.4%	103.6%	81.0%	79.8%	119.2%	79.2%
Others	$32,396	$14,722	$32,133	$34,200	$12,665	$33,105
Men	$33,291	$16,458	$33,073	$36,222	$12,539	$35,248
Women	$24,877	$11,250	$24,434	$26,417	$12,792	$25,221
Women/Men *	74.7%	68.4%	73.9%	72.9%	102.0%	71.6%
All Sectors	$30,640	$14,418	$29,468	$31,047	$14,030	$29,274
Men	$34,061	$16,797	$33,529	$34,920	$14,279	$33,842
Women	$23,356	$13,631	$21,889	$24,675	$13,947	$22,767
Women/Men *	68.6%	81.2%	65.3%	70.7%	97.7%	67.3%

* Women's salaries as a proportion of men's.
** All Employment Status.

Table 3:
Occupational Distribution of Persons with Disabilities by Industrial Sector and by Sex, Compared to the Employment Equity Workforce

Occupational Group	Banking		Transportation		Communications		Others		All Sectors		Workforce	
	Men	Women	Men	Women	Men	Women	Men	Women	Men	Women	Men	Women
Upper level Managers	2.6%	0.0%	0.8%	0.7%	0.9%	0.2%	1.0%	0.0%	1.1%	0.1%	1.3%	0.1%
Middle and Other Managers	48.7%	8.8%	4.6%	4.3%	10.1%	6.6%	9.7%	10.9%	13.8%	7.9%	14.8%	10.7%
Professionals	16.8%	7.0%	2.2%	1.4%	4.0%	1.6%	6.2%	3.0%	5.6%	5.1%	5.6%	5.7%
Semi-Professionals and Technicians	1.8%	0.8%	5.3%	2.5%	10.2%	2.6%	7.5%	4.0%	6.4%	1.5%	7.3%	2.7%
Supervisors	3.3%	8.2%	2.0%	2.9%	1.5%	1.6%	2.6%	6.9%	2.1%	6.2%	2.2%	5.3%
Foremen/Women	0.3%	0.0%	7.1%	0.0%	5.7%	1.6%	6.1%	0.0%	5.5%	0.4%	4.8%	0.3%
Clerical Workers	22.0%	74.6%	9.7%	66.3%	5.8%	48.4%	6.1%	68.3%	10.0%	67.6%	6.9%	61.5%
Sales Workers	0.6%	0.2%	1.9%	3.3%	3.0%	5.2%	0.7%	0.0%	1.8%	1.6%	2.3%	2.7%
Service Workers	1.7%	0.2%	2.4%	13.0%	0.1%	0.5%	1.3%	2.0%	1.5%	1.6%	1.7%	3.0%
Skilled Crafts and Trades Workers	0.9%	0.1%	23.0%	0.4%	17.9%	1.3%	17.3%	1.0%	17.3%	0.4%	17.4%	0.4%
Semi-skilled Manual Workers	0.2%	0.0%	29.3%	4.3%	37.3%	29.7%	19.8%	1.0%	25.6%	7.2%	27.0%	7.0%
Other Manual Workers	1.0%	0.0%	11.8%	0.7%	3.5%	0.8%	21.9%	3.0%	9.2%	0.4%	8.7%	0.6%
Total	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%

Occupational Distribution by Industrial Sector

The occupational distribution of persons with disabilities was relatively similar across all industrial sectors when compared to the occupational distribution of the entire workforce covered by the Act.

Banking

Within the Banking sector, the majority of persons with disabilities were employed in the Clerical Workers group (56.4%), a slightly higher proportion than that of all Banking employees reported in this occupational group (54.7%). Nearly three quarters of the women with disabilities (74.6%) in this sector were employed in Clerical work, compared to 22% of the men with disabilities.

About one quarter (24.2%) of all employees in the Banking sector were reported in the Middle and Other Managers occupational group. Persons with disabilities had a slightly lower proportion of employees reported within this occupational group (22.6%).

Almost 9% of women with disabilities were employed in the Middle and Other Managers category.

Transportation and Communications

Within both the Transportation and Communications sectors, the largest proportions of persons with disabilities were in the Semi-skilled Manual Workers occupational group, 26.8 and 35.2% respectively. In the Communications sector the proportion of persons with disabilities employed as Semi-skilled Manual Workers was much higher than for all employees (28.5%).

The largest difference in the proportion of persons with disabilities compared to all employees within the Transportation sector occurred in the Skilled Crafts and Trades Workers group, where 20.7% of persons with disabilities were reported compared to 17.1% of the workforce in this sector.

Others

The greatest proportion of persons with disabilities employed in this sector worked in the Other Manual Workers category (20.3%). As well, persons with disabilities were considerably more concentrated in the Other Manual Workers and the Skilled Crafts and Trades occupational groups than were all employees within this sector, 20.3% compared to 15.3%, and 15.4% compared to 10.5% respectively.

Hirings and Terminations

In 1987, the total number of hirings in full-time employment for persons with disabilities was 323, and the total number of terminations of full-time employment was 655. Of all employees reported as hired within the workforce under the Act, 0.7% of these employees were persons with disabilities. Of all employees reported whose employment was terminated, 1.2% of these employees were persons with disabilities.

The data on hirings and terminations for persons with disabilities show that there was a net decrease of 304 positions for persons with disabilities (including the three employment status categories). This compares to a net increase of 2297 positions for the workforce. For the full-time employment status category, the data indicated that there was a net decrease of 332 jobs for persons with disabilities and a total net decrease of 5928 positions within the entire workforce.

Men with disabilities had a greater net decrease in employment than did women with disabilities. Men accounted for 51.7% of hirings and 68.2% of terminations of employment for a net decrease of 280 positions. The net decrease of positions for women with disabilities was 52.

There was a net decrease in full-time employment for persons with disabilities in every occupational group except for the Other Manual Workers category. The Professionals occupational category was also relatively stable. The two occupational groups which experienced the greatest decrease in employment for persons with disabilities were the Semi-skilled Manual Workers and Skilled Crafts and Trades Workers groups. There was a net increase of 39 jobs for women with disabilities in the Other Manual Workers group while men with disabilities experienced a net decrease of 39 positions in this category.

Promotions

Persons with disabilities received 963 promotions, 94.5% of which occurred within the permanent full-time employment status category. Persons with disabilities as a group received 1.4% of all full-time promotions reported by employers.

Women received 43.5% of all promotions of persons with disabilities in full-time employment.

In permanent full-time employment, a larger proportion of persons with disabilities were promoted within the Middle and Other Managers occupational group (27.1%) compared to the proportion of all employees in the workforce (24.7%). As well, a higher proportion of persons with disabilities were promoted within the Professionals category (11.8%) compared to the proportion of all employees within the workforce covered by the Act (10.1%).

Promotions by Industrial Sector

Table 5 shows the distribution of persons with disabilities who were promoted in full-time employment. Note that 82.3% of all women with disabilities promoted in full-time employment were reported in the Banking sector. More than one half of these women with disabilities were promoted within the Clerical Workers occupational group.

Table 4:

Hirings, Terminations and Net Effect in Full-time Employment for Persons with Disabilities by Industrial Sector and by Sex, Compared to the Employment Equity Workforce

Industrial Sector	Persons with Disabilities			Workforce		
	Hirings	Terminations	Net effect	Hirings	Terminations	Net effect
Banking	95	251	(156)	12,979	15,187	(2,208)
Men	39	93	(54)	4,225	4,327	(102)
Women	56	158	(102)	8,754	10,860	(2,106)
Transportation	141	231	(90)	24,921	26,826	(1,905)
Men	81	212	(131)	20,040	22,319	(2,279)
Women	60	19	41	4,883	4,508	375
Communications	55	99	(44)	8,496	9,560	(1,064)
Men	28	72	(44)	4,621	5,850	(1,229)
Women	27	27	0	3,875	3,710	165
Others	32	74	(42)	3,249	4,000	(751)
Men	19	70	(51)	2,154	2,870	(716)
Women	13	4	9	1,095	1,130	(35)
All Sectors	323	655	(332)	49,645	55,573	(5,928)
Men	167	447	(280)	31,040	35,366	(4,326)
Women	156	208	(52)	18,607	20,208	(1,601)

Note: Negative numbers are between parentheses.

Table 5:
Promotions in Full-time Employment for Persons with Disabilities, by Industrial Sector and by Sex, Compared to the Employment Equity Workforce

Industrial Sector	Persons with Disabilities			Workforce		
	Men	Women	Total	Men	Women	Total
Banking	242	326	568	11,719	25,195	36,909
Transportation	172	26	198	11,868	2,581	14,449
Communications	62	36	98	5,549	4,362	9,911
Others	38	8	46	1,886	823	2,709
All Sectors	514	396	910	31,022	32,961	63,978

APPENDIX 7

Item 1. Number of Accepted Time-Loss Injuries, by Nature of Injury and Province, 1985-1987

Taken from Statistics Canada, Work Injuries 1985-1987, December 1988. Cat. No. 72-208.

TABLE 3. Number of Accepted Time-Loss Injuries, by Nature of Injury and Province, 1985-1987

Code	Nature of Injury		Total	Newfoundland Terre-Neuve	Prince Edward Island Île-du-Prince-Édouard	Nova Scotia Nouvelle-Écosse	New Brunswick Nouveau-Brunswick	Québec	Ontario
100	Amputation or enucleation	1985	1,533	16	xx	80	42	243	601
		1986	1,403	19	xxx	75	58	..	686
		1987	1,291	22	xxx	55	59	..	619
110	Asphyxia, strangulation, drowning	1985	63	14	-	x	x	22	xxx
		1986	45	x	-	x	x	..	xx
		1987	60	xxx	-	-	-	..	xx
120	Burn or scald (heat)	1985	12,854	152	52	296	253	3,895	4,375
		1986	9,089	126	63	260	316	..	4,413
		1987	9,236	203	49	236	316	..	4,608
140	Concussion	1985	1,955	xxx	x	15	16	1,280	340
		1986	793	xxx	x	20	19	..	357
		1987	1,062	11	x	36	22	..	341
160	Contusion, crushing, bruise	1985	95,671	1,725	383	1,648	1,654	29,774	40,145
		1986	65,316	1,793	258	1,735	1,983	..	39,603
		1987	67,739	1,771	306	1,765	2,161	..	41,398
1	Cut, laceration, puncture	1985	62,545	1,443	183	1,525	1,285	15,683	23,495
		1986	48,563	1,606	212	1,468	1,396	..	24,808
		1987	50,204	1,593	262	1,471	1,398	..	25,714
172	Dislocation	1985	1,736	18	xxx	60	28	288	629
		1986	1,527	30	xx	62	23	..	672
		1987	1,614	65	12	37	xxx	..	667
175	Electric shock, electrocution	1985	607	xx	x	x	x	336	201
		1986	337	xx	x	x	10	..	240
		1987	345	xx	-	x	xx	..	269
178	Fracture	1985	26,296	283	49	893	658	6,963	8,408
		1986	19,728	289	86	867	681	..	8,967
		1987	18,902	300	69	674	637	..	8,438
182	Hernia	1985	4,244	10	10	166	75	1,343	1,657
		1986	2,916	13	17	156	74	..	1,631
		1987	2,733	xxx	16	131	55	..	1,620
185	Scratches, abrasion	1985	32,842	403	95	243	308	19,316	6,139
		1986	13,450	331	114	254	331	..	6,289
		1987	13,456	377	79	239	406	..	6,235
188	Sprains and strains	1985	216,579	3,476	852	6,470	3,763	45,244	90,804
		1986	179,106	3,880	980	6,585	4,089	..	95,776
		1987	186,492	4,254	1,047	6,160	4,680	..	101,489
195	Multiple injuries	1985	9,208	291	28	725	103	620	1,344
		1986	8,877	318	31	684	96	..	1,034
		1987	6,893	169	46	546	65	..	952
199	Occupational injury, NEC	1985	20,222	x	33	x	81	16,767	2,187
		1986	5,140	xx	16	x	18	..	4,439
		1987	6,435	18	21	27	19	..	5,368
203	Burn (chemical)	1985	3,514	13	13	76	47	1,018	1,301
		1986	2,530	14	18	63	67	..	1,375
		1987	2,485	15	19	-	46	..	1,427

TABLEAU 3. **Nombre d'accidents acceptés avec perte de temps, selon la nature de la lésion et la province, 1985-1987**

Manitoba	Saskatchewan	Alberta	British Columbia Colombie-Britannique	Northwest Territories Territoires du Nord-Ouest	Total		Nature de la lésion	Code
126	95	28	275	21	1,533	1985	Amputation ou énucléation	100
138	92	26	290	12	1,403	1986		
118	76	18	310	xx	1,291	1987		
-	x	x	11	x	63	1985	Asphyxie, strangulation, noyade	110
xx	15	xx	13	-	45	1986		
x	17	xx	20	xx	60	1987		
517	658	1,125	1,515	16	12,854	1985	Brûlures ou échaudures (chaleur)	120
583	586	1,077	1,649	16	9,089	1986		
585	634	990	1,599	16	9,236	1987		
56	-	84	145	xxx	1,955	1985	Commotions cérébrales	140
76	61	65	177	xxx	793	1986		
53	54	65	476	x	1,062	1987		
2,887	2,419	4,907	9,886	243	95,671	1985	Contusions, écrasements, meurtrissures	160
3,186	2,277	4,524	9,781	176	65,316	1986		
3,197	2,339	4,258	10,366	178	67,739	1987		
3,035	1,751	5,434	8,559	152	62,545	1985	Coupures, déchirures, perforations	170
3,095	1,666	5,066	9,156	90	48,563	1986		
3,183	1,590	4,759	10,110	124	50,204	1987		
73	128	237	256	12	1,736	1985	Luxation	172
70	124	248	280	13	1,527	1986		
87	122	255	354	xx	1,614	1987		
13	-	22	24	-	607	1985	Chocs électriques, électrocutions	175
24	-	26	29	-	337	1986		
13	-	21	28	x	345	1987		
1,135	1,154	2,966	3,644	143	26,296	1985	Fracture	178
1,262	1,082	2,685	3,737	72	19,728	1986		
1,159	983	2,397	4,163	82	18,902	1987		
196	95	351	330	11	4,244	1985	Hernie	182
217	133	378	293	xx	2,916	1986		
172	123	300	298	xxx	2,733	1987		
1,154	881	1,728	2,523	52	32,842	1985	Égratignures, éraflures	185
1,128	926	1,549	2,483	45	13,450	1986		
1,030	905	1,522	2,582	81	13,456	1987		
11,422	7,289	18,102	28,738	419	216,579	1985	Entorses et foulures	188
11,581	7,478	19,046	29,265	426	179,106	1986		
11,118	7,227	18,614	31,444	459	186,492	1987		
298	48	3,113	2,582	56	9,208	1985	Blessures multiples	195
405	41	4,199	2,029	40	8,877	1986		
339	37	4,661	34	44	6,893	1987		
xxx	891	238	14	x	20,222	1985	Blessures professionnelles, n.c.a.	199
xxx	132	481	38	-	5,140	1986		
20	216	643	102	x	6,435	1987		
189	-	437	413	xxx	3,514	1985	Brûlures (substances chimiques)	203
193	-	365	430	xx	2,530	1986		
156	-	369	448	xx	2,485	1987		

TABLE 3. Number of Accepted Time-loss Injuries, by Nature of Injury and Province, 1985-1987 – Concluded

Code	Nature of Injury		Total	Newfoundland Terre-Neuve	Prince Edward Island Île-du-Prince-Édouard	Nova Scotia Nouvelle-Écosse	New Brunswick Nouveau-Brunswick	Québec	Ontario
205	Contagious or infectious disease	1985	768	xx	x	xx	xx	210	339
		1986	476	23	14	x	x	..	284
		1987	549	x	xx	x	–	..	309
215	Dermatitis	1985	2,559	25	21	41	25	1,360	658
		1986	1,258	36	14	37	38		628
		1987	1,397	34	17	29	33	.	782
220	Freezing, frostbite	1985	248	xx	–	xx	x	37	61
		1986	148	12	xx	xx	xxx	..	44
		1987	94	x	x	–	xxx	..	28
230	Hearing loss or impairment	1985	1,445	x	x	84	10	612	463
		1986	915	–	x	68	32	.	527
		1987	1,165	x	–	63	31	..	656
240	Heat stroke, sunstroke, heat cramps, heat exhaustion	1985	50	–	–	–	–	xx	xxx
		1986	33	x	–	x	–	..	11
		1987	66	–	–	–	–	.	41
260	Inflammation or irritation	1985	13,791	40	29	64	189	8,060	1,530
		1986	6,360	59	10	71	154		2,112
		1987	8,073	93	83	10	165	..	2,153
270	Poisoning, systemic	1985	1,968	32	x	x	26	468	877
		1986	1,523	13	–	12	47	..	915
		1987	1,586	59	14	10	70	..	929
281	Silicosis	1985	77	–	–	51	–	xxx	14
		1986	46	–	x	34	–	.	xxx
		1987	16	x	–	xxx	x	.	x
284	Pneumoconiosis, NEC	1985	193	–	–	104	x	16	37
		1986	165	x	–	93	x		27
		1987	151	x	–	59	x		48
290	Radiation effect	1985	2,600	xxx	xxx	16	19	1,028	867
		1986	1,516	12	14	16	27	.	883
		1987	1,637	14	xx	12	35	.	978
299	Occupational illnesses, NEC	1985	687	–	–	–	–	43	123
		1986	591	x	x	–	x	.	140
		1987	743	x	–	117	x		124
405	Non-personal damage only	1985	166	xx	–	xx	11	57	37
		1986	156	11	x	xxx	19	..	63
		1987	148	xxx	–	x	22	..	60
999	Unclassified or unidentified disorders	1985	41,572	762	12	39	381	39,684	x
		1986	1,345	15	62	38	419	..	–
		1987	1,235	xxx	xxx	39	670	..	–
	Not coded by the Board	1985	...	...	...	...	...	...	
		1986	213,366	...	...	...	...	213,366	.
		1987	216,724	...	...	...	...	216,724	
	TOTAL	1985	555,991	8,743	1,787	12,624	8,986	194,377	186,648
		1986	586,718	8,624	1,935	12,620	9,909	213,366	195,937
		1987	602,531	9,047	2,068	11,732	10,918	216,724	205,259

TABLEAU 3. Nombre d'accidents acceptés avec perte de temps, selon la nature de la lésion et la province, 1985-1987 - fin

Manitoba	Saskatchewan	Alberta	British Columbia Colombie-Britannique	Northwest Territories Territoires du Nord-Ouest	Total		Nature de la lésion	Code
11	40	34	114	x	768	1985	Maladies contagieuses ou infectueuses	205
11	19	35	86	-	476	1986		
12	109	38	73	-	549	1987		
88	26	112	199	xx	2,559	1985	Dermatite	215
120	40	116	228	x	1,256	1986		
120	52	110	200	20	1,397	1987		
20	-	73	42	xx	248	1985	Congélations, gelures	220
xx	xxx	28	33	-	148	1986		
xxx	xx	xx	35	x	94	1987		
96	-	62	115	-	1,445	1985	Surdité ou troubles auditifs	230
107	-	95	83	x	915	1986		
150	-	93	147	24	1,165	1987		
x	19	x	15	-	50	1985	Coups de chaleur, insolations, crampes dues à la chaleur, épuisement	240
xx	xx	xxx	xx	-	33	1986		
x	xx	xx	14	-	66	1987		
584	828	1,332	1,119	16	13,791	1985	Inflammation ou irritation	260
564	888	1,390	1,094	18	6,360	1986		
439	918	1,505	2,688	19	8,073	1987		
143	63	248	103	xx	1,966	1985	Empoisonnement général	270
125	45	233	116	17	1,523	1986		
144	37	187	131	xx	1,586	1987		
x	-	-	x	-	77	1985	Silicose	281
-	-	x	x	-	46	1986		
-	-	x	-	x	16	1987		
21	-	xx	xxx	-	193	1985	Pneumoconiose, n.c.a.	284
29	x	x	xxx	-	165	1986		
12	xx	xxx	13	x	151	1987		
110	-	285	253	xx	2,600	1985	Effets de radiation	290
130	-	203	225	xx	1,516	1986		
89	-	180	325	-	1,637	1987		
33	241	xxx	238	x	687	1985	Maladies professionnelles, n.c.a.	299
52	226	xxx	159	x	591	1986		
49	197	xxx	215	27	743	1987		
18	-	31	-	x	166	1985	Dommages non corporels seulement	405
15	xxx	29	-	x	158	1986		
19	10	23	x	x	148	1987		
203	39	410	23	17	41,572	1985	Troubles non classés ou non identifiés	999
363	60	363	22	x	1,345	1986		
231	55	197	22	xx	1,235	1987		
...	...	...	...	...	...	1985	Non codé par la Commission	
...	...	..	...	...	213,366	1986		
...	...	...	...	...	216,724	1987		
22,440	16,666	41,376	61,146	1,198	555,991	1985	TOTAL	
23,495	15,916	42,249	61,711	956	583,718	1986		
22,510	15,715	41,236	66,200	1,122	602,531	1987		