

THE CULTURAL PRODUCTION OF THE DISABLED ROLE IDENTITY
IN CONTEMPORARY CANADIAN SOCIETY

by

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BScN University of British Columbia, 1979

THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF ARTS (COMMUNICATION)
in the Department
of
Communication

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SIMON FRASER UNIVERSITY

November 1987

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Abstract

In most countries in the world today, one person out of ten is disabled by sensory, mental or physical impairment. The presence of disability has some untoward effect on at least one quarter of the population of any country. Yet societies are so constructed that the disabled are barred from full and equal participation.

The report of the World Programme of Action concerning Disabled Persons [1983] cites the need to undertake studies focussing on the socio-cultural aspects of disability, in order to gain a more perceptive understanding of the relationship between the non-disabled and the disabled in different cultures. This thesis examines the process of the cultural production of the disabled role identity in contemporary Canadian society.

While this thesis draws from sociological, psychosocial and sociopolitical theory, it offers a synthesis that is intended to provide a communication perspective on the problem. The experiential meaning of disability is compared with the meaning conveyed by prevailing social values.

Evidence is provided of those forms and practises by which the contemporary disabled consumer group actively proceeds to establish its identity. The thesis argues that the appeals of the disabled for self-determinism and independence are more acceptable, and likely to succeed when they do not interfere with, and even serve to enhance, the cultural reproduction of existing social institutions.

The thesis argues that while there is an atmosphere of acceptance towards the disabled in contemporary culture, there is no actual evidence that basic attitudes toward disability have altered. A review of our cultural forms of expression is provided as evidence of the metaphoric role of disability in deeply ingrained social values. The potential for the utilization of the mass media to produce a gradual change in public perceptions of the disabled is posited.

The thesis concludes that the contemporary disabled consumer group defines and shapes itself from a sociocultural and sociopolitical perspective. The group's primary function is to produce a knowledgeable consumer who knows how to use the system to have his or her needs met. Integral to this goal is an awareness of the importance and use of mediated communication in the production of the group identity.

Acknowledgements

I extend thanks to the members of my thesis committee, Professor Martin Laba, Simon Fraser University, supervisor, for his guidance in helping me to establish and maintain a focus; Professor Charles Laszlo, University of British Columbia, for his insistence on excellence; and Professor Barry Truax, Simon Fraser University, for reading the material with a fresh perspective.

My appreciation is expressed also to the Board of Directors of the Canadian Hard of Hearing Association for their participation and patience, and to those many individuals, both hard of hearing and otherwise, in Canada and internationally, who answered my questions and provided bits of information and leads to other sources of information.

I must acknowledge also the contribution of my own personal enjoyment and enthusiasm for the discovery of information, the process of deductive reasoning, and the compilation of a thesis. There is a tremendous satisfaction attendant upon both acquiring knowledge and then finding that knowledge to be of immediate practical use.

Marilyn Dahl

Port Coquitlam

November, 1987

Table of Contents

Approval	ii
Abstract.....	iii
Acknowledgements.....	v
I Introduction	1
Method of Approach	3
II Literature Review	6
Sociological theory.....	6
Social psychology.....	19
Socio-political category.....	23
Cultural/communications perspective.....	28
Summary	31
III The Influence of The Disabled on the Cultural Production of Disabled Role Identity.....	33
Labelling, and choice of a self-label.....	34
Labelling, and choice of a reference group.....	41
The individual within the reference group.....	42
The reference group as a political communicator.....	44
The authority of the reference group; its effectiveness.....	45
The theory and ethic which informs the group.....	46
Summary	50
IV The Influence of Social Institutions on the Cultural Production of The Disabled Role Identity.....	52
Modern technology.....	52
Public institutions.....	58

	a] health care professionals and other service providers...	58
	b] government.....	64
	c] the mass media.....	66
	Summary.....	74
V	The Role of Symbols in the Cultural Production of the The Disabled Identity.....	77
	Terminology.....	79
	Characteristics of Effective Signs.....	81
	The Wheelchair Sign and its Symbolic Role.....	82
	The Cultural Production of a Sign for Hearing Disability.....	83
	Summary.....	90
VI	Summary and Conclusions.....	92
	Bibliography.....	97
	Appendix A	
	History of the "International Symbol of Access for the Hearing Impaired".....	104
	Appendix B	
	The Research Sample.....	109
	Summary of Results.....	110
	Table 1.....	111
	Questionnaire.....	113

CHAPTER I
INTRODUCTION

This thesis addresses the question of how the individual assumes the disabled role identity in contemporary Canadian culture. Diverse explanatory theories exist in sociological and social psychological literature. However, this thesis addresses the topic from a communications perspective. Viewed from a communications perspective, it is not sufficient to consider role identity only on the basis of social practises and social beliefs but also from the viewpoint of the human experience of disability, and the meaning which is consequent upon that experience. Some insight can then be obtained into those forms and practices which currently affect cultural reproduction of the disabled role in society.

This thesis provides a synthesis of thought drawn from sociological, psychosocial and sociopolitical fields. This synthesis of thought is analysed from a communications perspective to arrive at a conclusion of how meaning is attached by the self and by others to the disability, what this meaning has come to be, how this is communicated, and how this influences the individuals perception of self in the disabled role.

The Report published by the World Programme of Action Concerning Disabled Persons [U.N.N.Y.1983] cited research needs including the "need to undertake studies focusing on the socio-cultural aspects of disability". The purpose of such research would be to gain a "more perceptive understanding of the relationship between non-disabled and disabled persons in different

cultures "in order to develop responses which address the reality of the human environment." [ibid, section D.184, p.45]. The World Health Organization [Geneva, 1980] set a distinction, in the context of the health experience, between impairment, disability, and handicap. This distinction is profoundly influencing both the meaning which is communicated by disability, and the societal responses evinced by both the able and the disabled.

The W.H.O. definition states:

"Impairment: Any loss or abnormality of psychological, physiological, or anatomical structure or function.
 Disability: any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
 Handicap: A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors, for that individual." [ibid,ICIDH, WHO, GENEVA, 1980].

Impairment therefore is a neutral, objective specific description of an interference with a functional capacity. Disability is the impact of that impairment upon the activities of daily living, objectified as activity restriction. Handicap is the impairment socialized as disadvantage. Bury [1979, p.36] describes handicap as an evaluatory concept in which the interaction of impairment and disability with an individual's psychological makeup, the resources available, and social attitudes affects adversely the performance of ordinary roles.

Handicap is a value judgement applied by others or by oneself on the basis of a perception of failure to perform customary social roles. To move from impairment to handicap is to move from objectivity to subjectivity, from symptoms to social role.

Sociological and social psychology theory in part complement and in part overlap one another. In reviewing the literature there is often a blurring of the separate positions in the varied theoretical approaches. Furthermore, there has developed what must be called a sociopolitical disabled role theory in which one encounters social rehabilitation specialists presenting a political advocacy school of thought and action specific to the disabled. While there is an overlap, these three schools of thought represent distinct levels of theoretical analysis. In Chapter II these three schools of thought shall be separated in the literature review in order to arrive at a more systematic analysis.

Method of Approach

Disability will be viewed as a social phenomenon in terms of the dynamics of society as characterized by a disruption in social relations. Chapter II will review a selection of thought by sociologists as it applies to role theory, and the application of role theory and related concepts of disability by those sociologists and social psychologists who specialize in the area of disability. As well it will provide an introduction to the sociopolitical direction which the disabled community has adopted as a response to its perception of the significance of the disabled role identity.

Finally, from a communications perspective, literature is reviewed which describes the ongoing dynamic struggle for self definition in society. That is, the means by which the disabled individual and the group is able to construct, and communicate and affirm a certain reality within an existing

culture. The evidence is then that the disabled group in contemporary Canadian culture attempts to understand and use existing systems in an effective way. The goal is to produce societal acceptance of the disabled identity as competent decision-makers and consumers.

Chapter III examines how the disabled individual chooses a self-label and a reference group in contemporary society. This analysis of the process and significance of labelling and choice of reference group is then applied to the hearing disabled population in regard to the attempt to construct a separate identity for the hard of hearing. A discussion is also presented of the theory and ethic which informs the contemporary disabled consumer group. It is noted that the contemporary disabled consumer group functions from an informed philosophical and political stance. Pre-existing medical and charitable ethics are discarded in favour of a consumer ethic which emphasizes self-determinism and social activism.

Chapter IV integrates with Chapter III through analysis and discussion of the manner in which existing public social institutions receive and perceive the messages which the disabled are conveying about themselves in Canadian society. Evidence is presented of the ways in which technology has contributed to the shaping of the disabled identity. The dynamics and tensions of interdependence evident between health care professionals and service providers on the one hand and the disabled population on the other hand are cited as influencing the cultural production of disabled role identity. The role of government in using the resources of power to effect social change is discussed. An analysis is included of the major role of the

media in presenting images of disability which are eventually perceived as typifications of everyday experience. The evidence in this Chapter produces the conclusion that the struggle to produce a particular group identity is most successful when it does not interfere with, and indeed even enhances, the cultural reproduction of existing institutions.

The use of signs and symbols in the cultural production of a group identity is now a common societal norm. Chapter V focuses on the use of a symbol in contemporary society as a graphic indicator of access for the disabled. A case study is presented which explores the interpretive meanings that a selected population attaches to a specific sign. In this particular study a parallel is noted between the endeavours to establish a disabled group identity and the significance of who chooses the sign which symbolizes that identity.

Chapter VI concludes with a brief presentation of three main conclusions of the thesis which identify the definition and direction taken by the contemporary disabled consumer group in the cultural production of disabled role identity. Basic to the group success is the attempt to understand and use effective methods of communication to share the meaning of the disabled experience, both within the group and within the larger society.

CHAPTER II
LITERATURE REVIEW

This Chapter will review a selection of thought from sociological, psychosocial and sociopolitical fields. Role theory and its application as well as related concepts of disability will be discussed. An introduction will be provided to the sociopolitical direction which the disabled community has adopted in contemporary society. The selected communications literature will provide a synthesis of thought to illustrate how the group attempts to construct and communicate a meaningful identity within the existing social structure.

Sociological Theory

The concept of role and role identity from a sociological perspective includes not only the system of value expectations which touch upon the behaviours of any social actor, but also the long standing systems of power and status which control the social order. Such systems of power and status influence the perception of who the individual is, what one may do and what one may expect of life, and place constraints upon any deviation from that role. Such systems of power, status and values are most meaningfully communicated, not by specific stated rules of behaviour, but by all that is implied and indicated by [among other things] actions, looks, dress, abilities and achievements.

Maintaining the existing system provides the individual with security as to his or her own role identity. Attempts to change the definition of individual or group roles creates insecurity and anxiety for all those persons who are involved, in that all must reexamine their own role functions and renegotiate their relationship to everyone else within the social structure. Since the World Health Organization has redefined disability within a sociocultural perspective rather than a medico-legal definition there has been considerable evidence of legislated changes which result in increased access for the disabled to a more expanded role in society. It is necessary to have an understanding of disabled role theory in order to infer how these role relationships can be successfully renegotiated in relation to the existing social system.

Parsons [1951] uses the concept of role to describe the system of expectations which influence the behaviours of any social actor. The individual moves within the restrictions of carefully defined and long standing systems of power and status which control our social order. Such social forces represent a set of common value orientations, expressed in terms of role expectations. These values define what is possible and what is normal in the light of the particular society's values and social structure. It is desirable therefore to successfully enact those roles which conform to societal value expectations. Since many people master a large number of conformist roles, it would appear that in order to be "successful" the disabled person is "expected" to behave like a disabled person. The model for this disabled person role is created by the non-disabled in society.

Parsons believes that role theory provides an ideal model for evaluating the reciprocal interaction of disabled and non-disabled persons in terms of role expectations. Parsons also indicates the fact that one cannot declare oneself as sick and be legitimately so accepted, only certain designated persons may confer this status. Since such a person acts on behalf of society in conferring this designation, the "sick role" is a socially constructed one. However, Parsons' concept of the sick role as a sanction of impaired role performance has its limitations. Such sanctioning is only one aspect of society's reaction to the sick role. Moreover, society's reaction to short term illness is different from that to long term disability. Temporary confinement in a wheelchair evokes quite different responses from permanent relegation to it. Such types of reaction patterns are well established and documented [D.Thomas:1982].

While there are different reactions to temporary or long term illness and disability, those reactions are based on well established role behaviours. Social responses can be quite unthinking since it is acceptable to do and say what has "always been done". Berger [1963] points out that the social forces of custom, convention and habit, and even the inertia of doing what has always been done, are strong resistors of change and revolution. It can therefore be concluded that it will be very difficult to effect a change in society's perception of the "disabled role", or even the disabled person's perception of oneself.

There are two other concepts which are important to consider within the context of disabled role identity. One is Sarbin's construct of role

reciprocity: every role is closely interwoven with one or more others [Sarbin,1954]. Although this author does not apply his theories to the disabled role, an application can be drawn, and that application is that the disabled person usually has to interweave with more persons in more varied roles than does the able person: care givers, service providers, prosthetic maintainers, to name a few. The disabled person can also be said to fill more roles in that whatever else ones roles may be, the disabled role is added to and superimposed upon them.

I will also posit from the viewpoint of communications theory that these other persons, who are made significant through the process of care-giving interactions, are continually communicating to the disabled person that he or she is in a sick role [either temporary or chronic] as a receiver of care. They are also communicating just what being in that role implies. Inferences attendant on this role are that of passivity, dependency and inferiority. The meaning attached to the role comes not only through what the care-givers signify but also through what the individual perceives the implications to be.

The other construct is that of roles and statuses as interdependent. The rights and duties attributed to statuses are generally well understood, while role expectations are not as well understood. There are many more roles than statuses to learn, and people are exposed to differential socialization experiences for role learning. We can apply this in the context of the conflict between the inferior statuses and roles attributed to minorities including the disabled versus the higher status and role which the disabled person may hold due to other positions in the social hierarchy, for example

career roles. Newcomb [1950] however makes the point that each individual fills many different roles which are non-conflicting. It is surprising how many different roles the individual can fill with a minimum of conflict among them. We can therefore conclude that a great deal of meaningful communication is transpiring at all levels of interaction between social actors, in order to successfully negotiate the relationships between these various roles.

Gleidman & Roth [1980, p.28-29] provide illustrations of how the impact of success alters the way in which almost any disability is perceived and remembered: Franklin Roosevelt is remembered as a great President who happened to be crippled, not as a crippled President and John F. Kennedy as a President cut down before he could complete his work, not as a person disabled by Addison's Disease. The effect of these individual successes however does not alter social perceptions of the disabled group. Rather it sets apart the individual as different from his or her group. If the disabled person is successful, society tends to assume that he or she is able-bodied. Society therefore arbitrarily confers the status of inferiority on the disabled person and releases him or her from that status only through the act of conspicuous achievement: a behaviour which has a high social value.

One must also consider the powerful role of the media in shaping society's perceptions of the successful individual. What is communicated about the successful individual focuses on the achievement. If the disability is referred to, it is in terms of "rising above it", functioning like a normal.

Status also relates to power and control. Gleidman and Roth provide an analysis of social control from the perspective of the power of the establishment professionals versus the dependency of the parents of disabled children. They suggest that since power and influence are unlikely to accrue to individual sets of parents, they should form a group which, given sufficient power and influence could affect the professionals future. Strong [Strong, 1979 p.174] cites the uneven balance of power and concludes there are, "..... asymmetries of power, prestige and influence in which parents are guided towards a predetermined view of their child".

Sussman [1966] also considers dependency and control to be the major elements which influence the dynamics between major and minor groups. He defines the disabled and poor as dependent sub-groups in society and cites impairment, disability and handicap as distinct conditions of social as well as physical inadequacy. He applies the concepts of deviancy, minority status and marginality, and discusses the dynamics of dependency as related to control. Keeping sub-groups dependent maintains order and status quo and performs useful stabilizing functions in society. "The disabled social deviant role is constructed, interpreted and manifested as a result of the perceptions and attitudes of normals and disabled." [Sussman, 1966 p.249]

In contemplating the contemporary social attitude toward disability however, Sussmans position of the need to maintain power and control through subservience seems somewhat extreme. Rather, what may be operative is the assumption that someone who is disabled or deviant is defective in other ways also and therefore not competent to hold power or control. This is what

is being subtly communicated to the minority. This is the problem which the disabled must address: an able person cannot conceive of having a disabled person in a superior status role.

Sussman tempers his argument of the social construction of the disabled role by including a discussion on the mechanisms employed by the disabled person in attempting to handle the ambiguity of his or her marginal role. He or she may challenge the system through individual or organized collective action in an attempt to bring about some changes in his or her personal situation. Or he or she may outwardly accept and acknowledge the existing power and authority while carrying out subversive actions to undermine that power and consequently gain a perception of self as having some control over what is happening to him or her. Such an argument implies that the disabled person is making some attempt to influence perceptions of himself or herself and his or her role, even though he or she can only do so within the existing social structure. He describes the disabled person as being in an unresolvable conflict situation. He or she can neither absent himself or herself from society nor can he or she take part fully. Simultaneously he or she is a person of two worlds, the dominant majority world and the sub-universe of the minority.

D.Thomas [1982] also argues that the disabled must fit into an existing normative framework. He declares that to become disabled is to be given a new identity, separate from that which is normal. One who is born disabled has this separate, abnormal identity given at the moment the disability is identified. In both instances it involves a social learning process, a

gradual discovery that roles, norms and rules are all altered; different expectations and behaviours exist for the disabled actors within the social system. He cites the most firmly entrenched view of the disabled role as that of the "passive recipient of care", and "a problem".

Further, he writes, the meaning of the disabled identity changes with the perceptions of the public, the professionals, and the disabled themselves. For example, charitable fund-raisers present the disabled person as dependent, needy, and worthy of the act of charity. To the professionals he or she is the client who should be the grateful and cooperative recipient of professional decisions.

The disabled person's perception of self evolves gradually through a social learning process in which the nuances and meanings of the identity are assimilated. D.Thomas' position is that the disabled role identity is formed entirely as a result of the attitude and perceptions of society and the meaning which society communicates to the disabled individual. The disabled person then internalizes these meanings and fits himself or herself into the expected niche.

E.J.Thomas [Glaser and Glaser, 1970 p.269-271] also speaks from the position of the powerful effect of social perception and social response in shaping disabled role identity. He identifies several roles with accompanying expectations from society which include, "giving up of status and prestige", "a redefinition of oneself as altered", the expectation to "get well again", and "role optionality": society and culture expect a

reshaping towards normalization, although the person will never be able to again be normal.

Other sociologists define specific problems in the social structure which handicap the disabled individual. Stubbins [1970] relates the problems of disabled persons to some structural dimension of society and postulates prejudice as a function of conformity. His argument is that there is a strain towards conformity in every society and each has its myths and other devices to obscure all but official versions of social reality. "It may be said that there is a surplus of conformity that spreads over into manners, customs and modes of behaviour that is beyond a need for social cohesion...and visibly disabled persons are victimized by this surplus conformity." He states that while professionals still view disability primarily as an individual problem to be overcome by the attitude and motivation of the individual, disabled persons usually view their condition in terms of prejudice, a social problem.

Finkelstein [1980] agrees that the handicapping of the disabled is a social problem. That problem, he argues, is a hostile environment. Since advanced technology has led to greater personal independence for the disabled there has been a consequent shift on the part of the disabled, from an attitude of oppression and dominance to a stance that questions the nature of a society which "disables" impaired people. By "... attacking the environmental forces that turn the medical condition of disability into psycho-social conditions of handicap, radical changes in the situation of the disabled will result " [Finkelstein, 1980 p.24]. He maintains that studies in attitudes of the

disabled have not paid enough attention to the way that the environment symbolizes an oppressive relationship between impaired people and the larger communities.

From the perspective of the disabled person, it is not that the disabled person has withdrawn from his or her cultural environment but rather that the social environment excludes him or her by virtue of the physical and attitudinal barriers it erects and maintains. Such barriers are no less oppressive because their construction is an unthinking one. This social constructionist model however gives scant attention to the role which the disabled actor himself or herself plays in attempting to frame his or her identity. No role is entirely static, although there may be a general societal image of a particular category, each individual is in a state of dynamic interaction with others in any given situation. Each person is reacting in some manner calculated to influence the perceptions held of himself or herself by the other. F.J.Davis suggests that analysis of the ways in which the normal person conveys his or her perception of the disabled person, should include whether and to what extent the deviator himself or herself is engaged in trying to sustain a normal definition of his or her person.

Attention must also be given to labelling theory. West [1985] offers the opinion that the labelling perspective offers a "fruitful orientation" to understanding the social construction of the disabled identity, since the disabled identity is "ascribed following the act of recognition and

categorization" by others. The question then is, who confers the label? Is it the physician who diagnoses and defines the attributes or is it some lay framework of knowledge which both confers meaning on the attribute and shapes categorization of and reaction to the disabled person? Such a question should also explore the part which the disabled person has in shaping the perception of this label, whether or not he or she has any influence on it, and if so, how much influence.

In presenting a comparative analysis of the traditions of symbolic interactionism and of phenomenology, West arrives at a conclusion which more accurately represents a communications theory of labelling. That is the idea that labelling is a process which constantly interrelates the reactions of others with the labelled person's identity. "With the application of the label, meaning is constructed which has implications both for the individual's self-concept and for the way others respond." However, he then suggests that the cumulative effects of societal responses result in a self-fulfilling prophecy and the labelled identity comes to correspond with the general public image of that social category [Gerhardt and Wadsworth, 1985 p.106].

Glaser [1971] states that it is important for the deviant person to choose the appropriate self-label, and thereby the reference group as well. A choice of self-label is a statement of recognition of who one is and where one belongs, a claim to identity. The preferred self-label is more important in rehabilitation than the label which has been applied by society. From West's

point of view, the disabled person acquiesces to a particular label under societal influences, though he or she may believe that it is his or her own choice.

The process however is not that simple. The person who has chosen a self-label under whatever conditions may then choose to view the situation from his or her own perspective from within the group. That is, he or she may be engaged in constructing his or her own version of reality. What is most likely, given the interactional dynamics of relationships, is that one version of reality is constantly intermeshing with another. This must be more thoroughly examined from within the framework of reference group theory, which originates in the social psychology viewpoint.

While labelling theory situates the person in a particular niche, there is also the situation of the person who refuses the "deviance label" and attempts to "pass" as a normal person in society, and as a result has a marginal status. Although Berger and Luckman [1971] use a constructionist model, they conceptualize marginality in a manner which implies that the individual does attempt to influence the location and perception of his or her position in society. They view marginality as the idea of a person whose social identity as a normal is fragile and who therefore occupies an uncertain, ambiguous and not fully institutionalized position. Such a person is situated at a distance from what most people regard as the core institutions and values of society. Marginality will be discussed further within the framework of reference group theory.

From a symbolic interactionist framework, Goffman's research conclusions bridge theories from social psychology and sociology. Goffman [1969] analysed individual interactional processes in great detail. He introduced the well known concepts of stigma and spoiled identity [1963]. The person who is stigmatized is seen by others as not quite human or normal. While his concepts are highly applicable to the disabled, the theoretical work is flawed by a lack of first-hand data about the disabled and contains very scant discussion of reactions to invisible disabilities. It must be agreed however that the perception of being stigmatized by society has a powerful influence in shaping the individual's perception of self. The individual behaves accordingly in a manner reflecting his or her perception of having a stigma, which reinforces the societal perception of his or her deviance.

Goffman [1967] also explores the process of devaluation which results from perceiving oneself as being devalued by others. He provides an exhaustive analysis of interactive social situations which, while focussing mainly on interactions between normal persons, illustrates the lower status role of the disabled person and the tactics necessary to save face or to restore social equilibrium between a normal and a disabled person. He concludes that "the disabled person is in an inimical role in almost every social encounter outside his disability reference group." He remarks also that the onus is on the disabled person to perform the integrations needed to ease the tension when slips have occurred in polite social interactions. Contemporary society still attaches taboos to disability. It also attaches a taboo to overt rejection of the disabled. It is socially impolite to comment or to react in

an overtly negative way to disability. The able person is therefore placed in an ambiguous situation and is usually not schooled in the type of response to make unless it is communicated to him or her by the disabled person. Correct reaction patterns are socially learned through modelling situations as well as directly from the actors.

Social constructionists present a picture of a society which functions along formalized institutionalized lines in response to learned patterns of behaviour. In considering the social psychology approach to identity choice, we deal with the same bundle of data but choose to look at it from the perspective of how the individual reacts to the social situation, how he or she acts and reacts to influence his or her place within the social structure.

Social psychology

Literature pertaining to discussions of the stigma phenomenon provides an excellent illustration of how theories of social constructionists and social psychologists overlap. Wright [1960] adds to stigma the concept of "spread" and "spread phenomena": the tendency of persons perceiving one characteristic of another person [such as lameness] to develop other perceptions about that person which tend to be positive or negative according to the attitude generated by the first impression. A common behavioural illustration of this is the habit of the waitress or waiter to ask the normal person what the disabled person wants to order, inferring that since the person is visibly crippled he or she is also mentally crippled [Stubbins,1977].

This is popularly known as the "does he take sugar?" syndrome.

While Wright relates spread phenomena mainly to visible physical attributes, they are also commonly apparent in response to invisible disabilities. For example since hearing impaired persons often exhibit communication difficulties, such individuals are also assumed to be either lacking in intelligence, or unable to speak, or both.

Birenbaum [1970] extends the construct of spread to apply to the "contamination" effect of the disability on those close to the disabled person, terming it a "courtesy stigma." This is particularly evident he says, in the public response to parents of a disabled child, especially when the child is present. The invisible handicap of deafness has an advantage in that the child looks normal but a disadvantage in that the child's behaviour is thought to be due to inadequate parental control. Public response then has impact upon the parental definition of the child. Parents experience ambiguity in deciding which ways will most effectively present their child in a positive manner to others. Other responsibilities are added to the parental role, and status may be subtly altered.

The constructs of stigma, spread and courtesy stigma place further parameters on the shaping of the disabled role identity. The afflicted person is exposed to the realization that he or she has had a negative effect upon the status and social acceptability of those near to him or her. Moreover, the significant others who are recipients of a courtesy stigma can be expected to

harbour a certain degree of mixed feelings of resentment or enlarged sympathy towards the person responsible for this altered social perception.

The disabled person is also dealing with pervasive social attitudes which are difficult to counter because they are underlying and covert rather than overtly expressed. Roessler and Bolton [1978] cite research findings that while public, verbalized attitudes to the disabled are on the average mildly favourable, indirect evidence suggests that deeper un verbalized attitudes are more frequently hostile. That is, attitudes toward disabled persons are typically unfavourable, despite what most people say when asked.

It is quite plausible that individuals are not at all aware of the discrepancy between what they say and what they subconsciously think. A communicator may modify his or her image of a topic so as to reduce any perceived incongruence between it and his or her social values.

These writers all present the stigmatized persons as reacting in ways which indicate that they are aware of the stigmatization such that the label of deviant identity is reinforced. However, to determine the manner by which the individual influences his or her own choice of self label it is helpful to view his or her actions from the perspective of reference group theory.

While there are several different concepts of reference group theory I shall limit the focus here to the concept as discussed by both Sherif [Hyman and Singer, 1968] and Shibutani [Hyman and Singer, 1968]. They conceptualize

a reference group as that group whose outlook is used by the actor as the frame of reference in the organization of his or her perceptual field. This group therefore may not be the one to which the individual aspires to belong. It may not even be a group he or she chooses, but it is the group through whose frame of reference he or she sees the world. Such an example is minority group membership. Since each person belongs to numerous reference groups in society, whether by virtue of birth, career, social affiliation or status, or some minority attribute, he or she can be expected to experience conflicts and tensions as he or she fills varying roles and responds to varying expectations and events within each reference group.

Sherif discusses the uncertainty, inner conflict and insecurity experienced by the person who does not have a stable anchorage in a primary reference group. Such person is in a state of marginality and tends to feel insecure in reference group affiliation. Such a situation is much more likely during adolescence. Sherif also says that when individuals cannot relate themselves to the values of a particular group they tend to gravitate toward one another and to form an informal reference group, at least for the time being.

One could say that these persons are developing their own self-label, creating a peer group to which they can relate their aspirations, values, identity, and in which they can evaluate themselves favourably in comparison with others. Festinger [Hyman and Singer, 1968] posits that it is this drive for self-evaluation and favourable comparison with others which drives people into groups where they can feel that their opinions are correct and their

abilities adequate in relation to those of the others within the group.

Katz [Stubbins, 1977 p. 183] lists the personal choice of a self-label and reference group as of great value because "...to be part of a group may apply a sense of connection, a source from which the vital elements of identity and self-respect can be drawn." Part of the "becoming" of the existentialists is the coming to full awareness of who one is and with whom one identifies. This social psychological approach allows for a greater degree of self-determination on the part of the individual in both defining his or her own identity and in taking an active part in the creation of what he or she wishes this identity to be, and to be perceived to be by others. It also gives room for a recognition of the importance of group interaction in affecting attitude change and attitude formation.

Riley and Riley [Hyman and Singer, 1968] discuss the tendencies of groups to arrive at a concensus of opinion that is influenced by the opinions of members in the group. The individual's perceptions and responses form part of a pattern of the interactions among all the members of the group. Such an integrated response gives the individual a sense of security as to who he or she is, where he or she is located in society, and the perception that his or her personal opinion carries some weight with someone. A personal perception that one's own opinion is of value and has some influence in forming a group opinion is bound to enhance a sense of self worth and of "being someone", with a specific role identity.

Sociopolitical theory

While social psychologists focus on the establishing of a role identity and an arrival at self-worth within the concept of the reference group, there is evidence that the minority reference group also provides a locus for action in effecting constructive social change. The indications are that disabled groups develop along lines similar to that of other minority groups in society. Typically, the individual joins in search of acceptance and identity within the reference group, binds to the group, and melds with a collective attitude. The group eventually functions as a microcosm in society in which some members remain passive while others become politicized for social action.

This category of literature represents what I will term a sociopolitical thrust of disabled consumer theory, and the writers reviewed here represent the disciplines of social psychology, social economics, and the specialty of social rehabilitation. All argue for a position that can be summarized as that of shaping the disabled group towards an active political advocacy power role.

Tajfel [1978] argues that the consciousness raising of a minority group is the first consideration in developing a collective awareness and forming a solidarity. He cites the central factor in minority group membership as a common element of "awareness", and of "belonging", of sharing a collective awareness of the stereotypes held about group members by society. The group

members are sensitized to the socially relevant group attribute which separates them from the majority and is the characteristic which binds their reference group. The progression is towards an emergence of group feeling, solidarity and awareness, a collective awareness. The progression towards the politicization of the individual and the group is a more recent phenomenon than what Tajfel has discussed.

Merton [1957] touches on the role of the organized pressure group in informing authorities about the ostensible state of public opinion. There is recent evidence that this type of contemporary disabled consumer group educates its constituency to have a political "presence". Merton states that such a group, to function effectively, must maintain a substantial measure of social control within the group. This includes a stable authority system which knows the actual norms and role-performance of its members. Such a system affects and mediates the responses of its members, shaping towards a conformity of the reference group opinion.

The social structure provides for those in authority to become informed about the state of public opinion. Merton indicates that public opinion, to the extent that it is not only observable but also conspicuous, is significant in affecting the actual course of affairs and providing a frame of reference for the decision making of authoritative persons.

Dluhy [1981] more directly states the need for more knowledgeable political advocates and a proactive stance, with the manipulation of values as

expressed in language and symbols. "Words and symbols evoke passion and move people to action." Dluhy posits that right value appeal, proper policy design and stable political organization as well as the identification and understanding of the key decision makers are ingredients for successful advocacy. While Dluhy's discussion is directed primarily at those service personnel who advocate for the disabled, it also presents a blueprint for the consumer group itself.

Further practical direction is provided by Topliss [1982] who cautions the need for correct value appeal. She argues that the value appeal must be that of economic rationality which is the dominant value in all highly industrialized societies.

"Where government intervention is expected to result not only in enhancing the well-being of the immediate beneficiaries of the welfare measure but also in conferring a net benefit on society as a whole, such action is accepted as economically rational and can command the commitment of collective resources.... However compassionate the social response to handicap may be, the fact that it is informed by considerations of economic rationality means that the social values which esteem competent independence have never been seriously challenged, so that disability continues to carry a social stigma." [ibid,p.133]

This latter statement by Topliss is a significant point and agrees with the positions of Parsons, Berger, Roessler and Bolton discussed earlier. The perceptions and attitudes of the disabled themselves can be changed through a consciousness raising process, but it is much more difficult to change the well entrenched attitude of society towards the disabled and to reconstitute established social norms.

It is surprising to realize that even as recently as the late 1970's and early 1980's authors such as D.Thomas and Katz ignored the emergence of the politicization of the disabled consumer group. D.Thomas in 1980 writes only fleetingly of the recent emergence of a group "feeling", in a social sense. Katz [Stubbins:1977 p. 183] cites the development of disabled groups as of value for support and self-help. There is evidence however that since the early 1980's there is an organized and politicized disabled consumer movement both in Canada and in the United States which is seriously challenging entrenched social values. A few examples of the growing success of this movement in Canada are evidenced by the Federal Government's response to numerous representations, for example, the followup to the Obstacles Report, 1985; Bill C-62 concerning Employment equity, and the growing number of publications from the Department of The Secretary of State relating to disabled persons. As Sussman comments: "I have not heard disabled persons calling for more researchers, psychologists, and social workers but they are participating more in legal and political processes as remedies" [Sussman,1966,p.8].

There are also research publications and papers from the disabled consumer groups themselves. Simpson [1981] and Derksen [1981] provide an overview of the disabled consumer group movement which gives insight into the politicization of the group and the development of a power structure to effect social change. Implied in all of this is an acceptance of the fact that the basic social attitude toward disability cannot be changed. They focus instead upon the utilization of the consumer ethic. The phenomenon of consumer ethic influence is a central and significant trend which is gaining momentum in Canada.

Their analysis explains that existing social ethics have perpetuated a biased view. The volunteer charitable ethic defines the disabled person as the "poor deserving cripple"; the medical ethic defines him or her as the "patient"; the professional ethic defines him or her as the "client". Only under the new and correct definition of the consumer ethic does the disabled person define himself or herself within an ethic which influences policy.

By labelling himself or herself in an active decision-making role on a par with the normal consumers in society, which includes his or her service personnel, the disabled person presents a perception of self as not dependent, as sharing power, and as competent. The shift in meaning of the disabled role communicated through the acquisition of some power and control over decision-making also implies the acceptance of consumer accountability and responsibility. These are behaviours which are in the realm of the normal and the able and could lead toward the gradual perception of the individual as capable and able though different. The individual is still in the disabled role but the disabled role both of the individual and the group, can gradually come to have a different meaning to society.

Cultural/communications perspective

In viewing disability as a social phenomenon I have described a constructionist view which presents disability as mediated and restricted by prevailing social values. I have also shown a social psychological view which presents the disabled individual as to some extent influencing his or her position and perception of reality through the frame of reference of the group, yet still restricted by established social values.

From a cultural communications perspective I will adopt a practical and theoretical view which recognizes the ongoing social process of a culture in which a group is able to construct, articulate, affirm and communicate a certain reality. Such a view is based upon the belief that human experience is meant to be meaningful, and that much experience is constructed as a message to convey some idea in society. This social experience is an ongoing dynamic process, not a static state, a gradual building and evolution in which prevailing values and belief systems are open to evaluation and challenge. Alain Touraine [1977] described it as "the self-production of society", a system of social relations in which different actors continually struggle for control over society's basic orientations.

Turow [Communications, 1985] terms it a struggle for self-definition: the definition of society's cultural model, its model of knowledge, method of accumulating resources, and manner of implementing these elements into the forms and structures of daily life. The actors who have political and economic power dominate both the process of self-definition and its implementation within societal practice. Both Turow and Touraine touch on the role of the mass media as an agency of collective self-definition. Modern communications systems, particularly the mass media, are the medium which organizes and articulates what has already been implicit in the cultural milieu. The media present cultural models, depict preferred conduct by individuals and organizations, convey principles of institutional order.

Touraine also points to the media's role as a provoker of change. The media can present particular impressions or the needs of particular groups, direct

public attention toward certain issues and concerns, and turn them away from others. The function of such presentations of opinion is similar to that of the individual within his or her reference group, mainly to influence the arriving at a consensus of opinion over a period of time. In this manner, the media can be instrumental in bringing about a slow process of attitude change and of consciousness-raising within the community. Therefore, disabled groups must recognize the need to present information in a manner which will engage the audience and challenge them to respond.

In discussing the role of communication in social change, McQuail [1984] mentions the complex process of inter-communication needed to develop a common class awareness and the identity of a separate class as differentiated from other classes. Following this it is a matter of applied communication to mobilise support and produce the concerted effort to secure political advantage. While these processes apply to the use of mass communication to influence public opinion, they also relate to the very nature of the language which is used and the symbolisation which is employed to convey the message.

The disabled consumer group adopts the role of a pressure group and adopts those communication strategies which will enable it to effectively impart its ideas and make itself understood by those in authoritative positions. The consumer group presents a body of public opinion to the decision makers, the collective action of a social group. Such communication tends to have effect only over a period of time and when the audience is in a state of mind to receive such information. To say that the audience is in a state of mind

to receive such information means that the audience is receptive to what is being communicated. They have been placed in a state of receptivity by previous communications which have guided them towards particular impressions of what is right and acceptable. Bauer [1968] suggests that one "look at a high proportion of communications not as changing behaviour but as triggering the organism to do what it was very likely to do in any event."

In 1980, the World Health Organization issued its pronouncements designed to influence attitude change. The Federal government of Canada has responded to what it perceives as public opinion and social need by legislating social change and, in effect, legislating attitude change. However, in line with Bauer's suggestion that the "organism...was very likely to do this in any event", and that the audience was already in a state of mind to receive such information, it is noted that as early as 1974 authoritative position statements were being issued to suggest a readiness for change. To use only one example, in 1974, the Minister of Health and Welfare stated that the disabled wanted "out" from underneath paternalistic systems of care [LaLonde,1974],

Summary

In summary, a review of contemporary literature indicates that while traditional sociocultural values and constructs influence the disabled role identity, the interpretation and application of these values are dynamic and not static. There is no evidence of any change in individual attitudes toward disability. There is no evidence of a change in traditional basic

sociocultural values either. The evidence rather is that the disabled groups are attempting to use existing systems in an effective way. The attempt to acquire power and status, to influence legislation and social improvement, to have importance within one's own reference group and in the eyes of others are important to both the able and the disabled. This is the sort of approach which society understands. There is evidence of a change in social receptivity as a result of well communicated information.

At this point what is being communicated is the perception of the right to access to social functioning and the implausibility of denying such access to a significant segment of the population. There is an attempt to establish the commonality of disability. There is a decided thrust to increase visibility of the disabled, and to establish a high-profile group identity for various disabled groups in response to government initiatives. The most notable of these incentives is provided by the Disabled Persons Participation Programme [DPPP] within the Department of the Secretary of State.

Therefore, in assuming an identity in today's society, the disabled person is provided with a range of resources and role models within an apparent environment of increased social receptivity. Whether this receptivity increases or whether it experiences a conservative backlash due to economic constraints remains to be seen.

CHAPTER III

THE INFLUENCE OF THE DISABLED ON

THE CULTURAL PRODUCTION OF DISABLED ROLE IDENTITY

The review of literature in Chapter II indicates several existing perspectives on cultural production of the disabled role identity in contemporary society. From a social-constructionist stance, the individual fits into an existing, socially defined role. From a social psychological viewpoint the individual has some influence in selecting what his or her label is to be, through personal actions and choice of reference group. From a communications perspective the individual is continuously involved in an attempt to share and interpret the meaning of the human experience in the context of claiming or modifying a particular role.

This Chapter will examine how the disabled individual chooses a self-label and a reference group in contemporary society. It will explore what the choice of label signifies to the disabled person and will attempt to decipher the interpretations which disabled individuals place upon their experience. It will also examine the social purposes inherent in choosing and constructing the reference group, and the functions which the group fulfills in attempting to interpret and articulate the meaning of their particular experience in the public world. This examination of label and reference group will be applied most particularly to the hearing impaired, and specifically to that segment of the hearing impaired population which labels itself "hard of hearing".

Labelling and choice of a self-label

West [1985, p.104ff] has suggested that the labelling perspective is most useful in researching the social construction of the disabled identity. He cites choice of label and who chooses the label to be of particular significance. However, before one examines the choice of label, and who chooses the label, we should look at who creates the label and what words are used in this label.

While contemporary society speaks a common language [e.g. English or French], the various disciplines and professions have their own specific vocabulary with certain institutionalized meanings and usages to words. Thus, the physician confers a diagnostic label based on codified medical objective terms which describe a disability. The term itself may not be understood by the patient but nonetheless it may carry many shades of meaning including that of the authority of the giver and a certain helplessness on the part of the recipient. It is clinical and specific, and places the recipient in a separate category from the one who confers the label. As Parsons indicates, a medically conferred label also gives the recipient permission to be in the sick role [Parsons, 1951].

On the other hand, the social sciences have developed a social label to describe the same condition. A terminology has been adopted which attempts to describe the person's condition in social terms which in a more generalized fashion indicate that the person labelled is different from the social norm. The result is an entire vocabulary of euphemisms which supposedly remove the

stigma of specific diagnostic terms. One is no longer crippled, one is disabled. The word "retarded" is replaced by "mentally handicapped" and such children become "exceptional children". This term is also applied to children with multiple handicaps. The blind become "visually impaired", and a person with any degree of hearing loss becomes "hearing impaired". Such terms represent an attempt to describe disabling conditions in everyday language.

Kelly [1981] describes everyday language as concerned with immediate practicality, with a vocabulary limited to what is sufficient. "Everyday language is used to cope with socially given and accepted typifications and recipes in a way that is appropriate here and now" [ibid,p.89]. It is the language of immediacy. It is also the language of the common vernacular, developed by average people to deal with the communications needed to carry out their daily lives. The terminology used by the social services is not a part of the common vernacular developed by the "man on the street"; therefore this terminology also represents a form of label bestowed by a group of professionals upon the disabled. The social service terms are however a more generalized set of words, familiar to the general public, that have the potential with repeated usage to become a part of everyday language.

The other signifying function of this social label is that of removing the disabled person from the sick role to the disabled role. The social label indicates that the person's condition relates to the way in which that person functions in society. The label attempts to influence the way in which the disabled person is perceived by society. It also influences the

self-perception of the disabled individual. Consider the word "disabled". In itself, it is automatically associated in the public mind with visible crippling conditions involving mobility impairment. However, the redefinition of disability by the World Health Organization has influenced the hearing impaired to define and perceive themselves as disabled.

Labels also become symbols, and symbols have a power which is variable and dependent upon subjective factors [McQuail, 1984]. Numerous writers have repeatedly averred that words become invested with a signifying range of meaning and a symbolic potency far beyond what can be fully grasped by the actors involved in the communication. A pertinent example is found in the labels and definitions used to signify hearing loss. The physician will use a specific diagnostic term based upon type of pathology and degree of measurable audiological impairment. It may include words such as "severe" or "profound" or "legally deaf". The social services label is "hearing impaired" which covers the entire spectrum from mild loss to total deafness.

Hearing loss, however, is an extremely complex issue both because of its physiology and because it interferes with our primary method of communication, namely that of hearing and responding to the spoken word. There are also many cultural and practical factors related to assessing degree of hearing disability. The most important are time of onset of the impairment, degree and nature of physiological damage and the individual's ability to cope.

There is an entire framework of meaning built into the choice of different

labels and definitions by the different groups of hearing impaired people, which point toward differing values and social purposes. To the deaf, who have a particular subculture built around their sign language, the term "hearing impaired" represents a denial of their unique subculture and a lack of acceptance of the legitimacy of their language. To the hard of hearing, use of the term "hearing impaired" suggests that the user may be relegating them to a category that is a part of the deaf subculture, which action denies their intent to remain as a part of normal society, however marginal that participation may be. The hard of hearing person refuses to accept the label of "deaf" fearing it may also imply "unable to speak" and result in an attitudinal social barrier of "deaf and dumb".

The hard of hearing have therefore formed an organization for their particular category of hearing loss and developed their own definition based upon how they choose to function in society. This thesis will use the sociocultural definition employed by the hard of hearing themselves: "A hard of hearing person is a person with any level of hearing loss whose primary means of communication is by speech" [Anon.1983]. In contrast, a deaf person is a person with a profound hearing loss whose primary means of communication is by sign language. The development of a definition from a sociocultural standpoint, based upon a self-perception of functioning in society, shapes the way in which the individual intends to be perceived by society.

During the 1970's and 1980's a third category of label has been created by the professionals responsible for the habilitation of hearing impaired

children. This generation of hearing impaired children have been educated since early childhood in a total communications philosophy which maintains, in essence, that one should employ whatever method works to facilitate the child's communication needs, including sign language, speech, or a combination of both. The first products of this program have now reached young adulthood and call themselves "Total Communicators", which tends to signify that they can both speak and sign, though they may not be able to hear. They also prefer to be called "hearing impaired" rather than deaf or hard of hearing. These young adults take the position that there is no need to separate the hearing impaired into deaf and hard of hearing populations. There is of course considerably more meaning attached to this position than that of championing a particular communications and education philosophy. There are elements of youthful rebellion against existing values and reference groups as well as attempts to establish personal identity and place in society and quite possibly, a refusal to be relegated to the deaf sub-culture in society. There is also a need to find another reference group since the young deaf, who are better educated than the majority of people in the existing deaf subculture, tend to be rejected by the deaf reference group on the grounds that the youth are attempting to act like hearing people. There is also an unwillingness to be labelled hard of hearing as the term is associated with a stereotype of aging.

As Whiting [1976, p.199] comments, there is an ubiquitous "strain toward meaning" in human response to experience, an intent to construct a message which conveys a particular idea. Thus the youth, who normally experiment with the creation of new reference groups and with a search for unique identity,

have in this case had a separate identity created for them by educators of the hearing impaired. They struggle to locate themselves in relation to the hearing world and to the existing hearing impaired groups. Another complex layer of meaning is added to the experience which they attempt to convey.

Carey [1975,p.187] refers to human actions as a text, a sequence of symbols, speech, writing and gesture, that contain interpretations which must be read to grasp the significance of what is being communicated. He describes such human actions in a society as a "multiplicity of complex conceptual structures, many of them superimposed upon or knotted into one another, which are at once strange, irregular and inexplicit...". The reading of this text requires a peeling away of layers, a patient unravelling of the interconnectedness of acts and of meanings. Actions which are taken for granted within a social group as a typification of behaviour contain nuances and shades of meaning which are difficult to articulate to an outsider. To the deaf, acceptance of their name signifies not only a recognition of their language and their subculture but also a validation of the worth and rightness of a hard-fought battle to have their language of signs accepted as a valid communication system for people who cannot communicate by oral/aural methods. In essence, they claim a right to be recognized and to exist as they are within contemporary society. There is a long established history to their label, aside from that of being recognized as a very disabling condition with a markedly isolating effect in normal society.

The hard of hearing label does not connote the same degree of disability or of separation from society as does the term "deaf". Because the disability is

less dramatic and more hidden, there has been considerably less interest and fewer research studies produced to induce both professional and public understanding. The common public stereotype has been that of the elderly person with an ear trumpet, and it is one of the few, perhaps the only, one of the disabling conditions about which it is socially acceptable to make jokes.

The person who chooses the hard of hearing label is, like the deaf, claiming a right to be recognized and exist as one is within normal society. Yet, the existence the hard of hearing person is choosing is that of marginality.

Because of the effects of partial hearing loss, tensions are imposed upon interpersonal communication and rifts occur between the hearing disabled individual and his or her human environment. "Nothing of the auditory turmoil he is experiencing shows in his behaviour; and since these experiences generally make for strain and tension in interpersonal relations, the usual consensus is "best leave him alone". [Levine, 1960 p.65]. The isolation which the individual experiences in the withdrawal of the sound environment is therefore also compounded by the indications of withdrawal by the human environment. Before the 1980's there was not an identified population or a supportive community for this label, aside from a few small groups of hard of hearing seniors scattered across Canada. The label therefore was associated with a common stereotype of aging, and not with a condition which is increasingly common at any age and which is markedly disabling. The hard of hearing community consequently has the task of creating a meaningful public identity of their chosen label.

While choice of the self-label has meaning to the person who selects it, that meaning is not fully established until the communication is completed.

Communication is sharing meaning [Kelly,1983]. Sharing such meaning is a difficult task, for the able and the disabled persons speak from different provinces of meaning, from a different interiority of experience.

Meaning is constructed through the careful sharing of experience. We accept what is a part of our socially and culturally constructed sphere of reference and tend to ignore and avoid that which is strange and unconventional behaviour. We want what goes on around us in daily life to be that which is a part of the average experience, that which is typical. In choosing and establishing the self-label the disabled person needs two types of experience. One is that of sharing experience with other persons so labelled, to establish the commonality of experience, the other is the construction of a public typification of the label, so that it is recognized in the world of everyday life. Establishing a public typification of a disability does not mean that interior meanings have been shared. It is within the disability reference group that the person can expect to share and make public the meaning of the private experience.

Labelling and choice of a reference group

Another important function of the label is to assist the disabled person in choosing the appropriate reference group. Glaser [1971] indicates that the choice of self-label and choice of reference group is a statement of recognition of who one is and where one belongs, a claim to identity.

Out of all the varied definitions of reference groups given by social scientists I selected the following: a reference group is "that group whose presumed perspective is used by an individual as the frame of reference in the organization of his perceptual field" [Shibutani, 1962 p.41-42].

The reference group serves numerous functions. It is used as a standard for self-evaluation and personal goals, and as an attempt to satisfy certain individual needs and wants. It is within the reference group that the person can hope to share the interiority of the personal experience of disability. It is here that one can expect that their personal apprehension and interpretation can be successfully communicated, that their meaning can be grasped by another. Within the group, the disabled person is normal, not deviant. Since roles and statuses exist within each group, the person may have opportunity to satisfy leadership or other roles which have been unattainable in the public world.

The individual within the reference group

The person who joins the group is satisfying personal needs. He or she is also contributing to the shaping and functioning of the group, and also, is being influenced and shaped by the group. Numerous studies done by psychologists and sociologists have shown that the major determinants of individual attitudes are the values and norms of the individual's primary reference group [Merton, 1957]. Relationships within groups and sub-groups are of major importance in the construction of knowledge systems and

communication. Such relationships have a large influence in determining regulatory factors in cultures and subcultures.

The disabled person who joins a disability reference group is making a statement of acceptance of his condition and identifying with the disabled role as it is constructed and interpreted by the reference group. The reference group, through a process of communicating and consensus-building fashions and supports a group ideology. Members conform to certain ideas, values and norms which result in a certain perception of reality as it is seen from within the group. Sherif [1968] maintains that group interaction is a major determinant in attitude formation and attitude change. By intergroup communication a specific knowledge system, a group ideology, is constructed. This becomes the typification of their particular experience, the expression of their identity which they wish to convey to, and to have accepted by the rest of society. While the group may be ready to communicate its reality to society, there is no reason to expect that society will be avidly waiting to hear and to understand these revelations.

Benge [1972], in discussing modes of knowing, posits that our minds become programmed in such a manner that only certain approaches to reality remain possible. He also indicates that not only are there those who think in certain patterns and are slow to change attitudes, but there are also those who make no real effort, or have no desire, to understand what some minority group wishes to convey. They are the people who "do not want to know". The other related problem he notes is that where an effort is made to construct a

conceptual picture or a classification for a neat categorization of a condition. Reality is thereby reduced to an abstraction, and instances of human experience which do not fit into pre-conceived patterns tend to be discarded or ignored. The point is not that certain types of thinking and perception are invalid but that they are incomplete by themselves.

For the hard of hearing, there is no accumulated documentation of the personal experience, nor a documentation of research data from a behavioural or communications perspective. There is therefore no ready acknowledgement of the differing concepts which apply to the hard of hearing compared to that of the deaf. There is no ready recognition of the differing ways in which the two organize their perception of reality, and all which this implies. Nor is there an understanding of their unique problems and needs. Such knowledge has to be gradually assembled and constructed.

The reference group as a political communicator

Another function of the group is to be the official spokesperson, the "voice" of the reference group. For the disabled groups in contemporary society this has meant an increasing political and advocacy role. A review of research literature pertaining to the disabled consumer movement indicates careful planning of organization and strategy based upon theoretical social and political models [Bowe et al, 1975; Simpson, 1980]. Some groups with disabilities in Canada are organized under the [national] umbrella of the Council of Provincial Organizations of the Handicapped [COPOH]. The

organizational structure of the groups parallels that of the political parties and governmental structure in Canada and utilizes a participatory democracy model. The hearing disabled groups have the potential to develop a similar coalition under the national umbrella of the Canadian Coordinating Council on Deafness [CCCD] which up until now has advocated only for the needs of the deaf who need signed communication, although its self-assumed mandate purports to extend to the entire hearing impaired population. The CCCD as it is presently organized however is not an acceptable coalition model for consumer groups in that service providers and care givers fill decision-making positions and hold the balance of power in the organization.

In considering a coalition of hearing impaired organizations, the problem for the hard of hearing is that, having as yet no firmly established visibility as a unique disability group within the public mind, and having no professional group which actively advocates on their behalf, they may once again vanish from the public mind when coalesced with the deaf under the CCCD umbrella. Groenings and Leiserman [1975] indicate that various disability groups maintain their own separate voice and connection with government bodies and unite in coalitions when they have a common concern for a specific issue. They also solicit support from other disability groups to create a show of strength and solidarity in support of common causes.

The authority of the reference group and its effectiveness

Recognition by social, professional and legislative bodies provides the

group with more credibility and status. The group becomes legitimized. It then provides a recognizable and authoritative source to approach when a governmental figure wants consumer response or participation on a particular issue. It becomes a source for the media to approach and quote on a specific related issue. Such interactions provide the group with opportunities to convey and articulate the meaning of their experience in varied communication modalities and provinces of meaning. Layers of misunderstanding which shroud the condition are gradually stripped away to reveal something nearer to the core of the experience. The contributions of individuals shape what the group spokesperson conveys and inform the construction of the public typification of the disability. The group acts to communicate a coordinated management of the meaning of their human condition. Communication is the link between the particular social reality the group inhabits and the "human condition of being invariably enmeshed in multiple systems, each with its own logic of meaning and order" [Pearce & Cronen, 1980].

The theory and ethic which informs the group

Consideration must now be given to delineating what precisely is the perception of disability which the disabled groups wish to instill in the public mind. In communicating its position to the public, the contemporary disabled group functions from an informed philosophical and political stance. There is an awareness that social attitudes toward disability cannot be changed. Rather the focus is upon the importance of right value appeal, the manipulation of values as expressed in word and symbol. Topliss argues effectively that the right value appeal is that of economic rationality; the

measures requested must be seen to have a net benefit for society as a whole. Curbs lowered to accommodate wheelchairs are helpful to the shopping cart pusher and the baby stroller as well as to the walking infirm. Amplified telephone handsets are helpful to the public in noisy settings, captioned videos help the foreign language immigrant to learn English. For an appeal to be effective with the decision-makers it must rely not so much on a compassionate social response to handicap as on the indicators that a significant segment of the population is in some way affected and society as a whole will be helped by a solution [Topliss, 1982].

The politicized contemporary disabled group discards the medical [sick role] ethic and the charity ethic which presents the disabled as dependent and worthy of being helped. Both of these roles are accepted values in society. Instead the group adopts the consumer ethic which presents the condition of equal status in the decision-making process, demanding capability and independence [Simpson, 1980].

The group does incorporate a compassionate social response value in the appeal of being disadvantaged in society, and in presenting the position that it is society which has disabled impaired people through the creation of an environment which does not permit them free access. The indication is that the rest of society is able to move freely through all the social roles to which they have access because of the environmental structure of society. Society then has created the barriers which move the impaired person from impairment to disability and thus to the value-judgement of handicap, through being unable to perform the customary social roles.

However, in presenting a compassionate appeal, the disabled consumer group attempts to move away from the charity ethic type of compassionate plea which relies on the entreaty to help the helpless by featuring "cute kids", innocent and in distress, usually with very visible neural or muscular disabilities [Derksen,1980]. More recently this type of appeal has been altered by the actions of mobility-disabled young adults individually inserting themselves into the public attention through heroic marathons. The successful events always seem to feature an attractive, personable young adult presenting the noble goal of drawing attention to the disability, raising money for research, and proving the capability of the disabled to achieve. In light of disabled role theory, however, it must be said that this does not necessarily represent a healthy adjustment to the disabled role, but rather an overachievement in one area to compensate for deficiencies in another particular area. The older or less physically attractive adults who are involved in this type of marathon do not generate the same amount of media attention or public response. This type of marathon is generated by the individual, not by the media. The response of the media and their role in shaping public perception of the disabled identity will be addressed in Chapter IV.

The disabled consumer group does not itself initiate this type of activity, nor does it announce public support for it. The individual negotiates support from research agencies or other public institutions, as well as the general public. The high profile generated by the disabled hero focuses upon an individual overcoming a handicap, the implication being that it is up to other disabled individuals to attempt to overachieve in order to surmount a

handicap, not that it is up to society to remove environmental barriers so that the average disabled person can function in an average way. This is at variance with the disabled consumer group philosophy and policy which wants to present the disabled as the same as others, yet needing modifications to the environment for special needs, not as superheroes driven to overcompensation.

Elements of the compassionate appeal are also incorporated into the statistics provided in any appeal for funds, support or privileges. The fact that a significant proportion of the population is affected by the particular condition is important; or conversely, the fact that very few are affected may be used to elicit an emotional response to their great need. The appeal is to the basic human rights of all in society. Statistics, however, are most effectively used from the standpoint of an appeal to economic rationality values. Providing opportunity for a significant proportion of society to function independently and be self-supporting is a cost effective measure in the long run. Architectural modifications and communication devices will be more usable by all of society, not just to provide better access for the disabled. Consumer monitoring and research efforts benefit the entire community. Such rationale has "right value" appeal.

The consumer ethic approach springs from an analysis of existing beliefs and attitudes, an understanding of social reality as it is interpreted in the public mind and a consequent methodology which acts to use this knowledge to convey the desired perception of disability. Sometimes this is done in covert ways, acted out or implied. In one instance a woman with normal

hearing went to attend a meeting with three deaf men. She came away remarking that the communication had been quite difficult since they had not supplied an interpreter. The message they were slyly conveying was that within this setting, they three were in the majority and did not need an interpreter, she did, so she should have brought her own.

Summary

For the contemporary disabled group then, there is an attitude shift from oppression and helplessness to development of tactics to bring about social change. A strong element of self-determinism is evident, and there are indications that since the disabled are a part of the problem they intend also to be a part of the solution. There is an evident intention to shape events and people in order to communicate a certain public typification of disability. The disabled reference group is utilized as the primary tool for change. Since any group is a social unit, there are various roles and statuses within the group. There are leaders who organize, direct and politicize the group and move it along towards the development of a power structure to social action. The group becomes a tool for change, with leaders who present themselves in an active, decision-making role on a par with normal consumers in society.

While the various disability groups share the common need to convey that they are capable of effective functioning in society, the hard of hearing are caught in the paradoxical situation of also having to convince the public that they are disabled. Due to the lack of public knowledge it is necessary

for them to explain both the existence and the implications of their auditory handicap, the disabling effect on social interaction and the communication modalities and assistances which they require. In requests for services and devices they must stress the disabling aspects, in requests for employment they must stress their ability to perform as well as others. They are in a situation of needing to create a visible identity which belies the existing stereotype.

One of the most significant problems which must be addressed by the disabled, in attempting to influence the cultural production of their group identity, is that mentioned earlier [Benge,1972]: the people who "do not want to know" and are content with a pre-conceived or incomplete picture. In the attempt to educate such people, and indeed to inform the public as a whole, it is necessary for the disabled to expose themselves to the public, to articulate many of those things which they would prefer to keep private or hidden. The manner in which public social institutions receive and perceive these revelations, and the manner in which they interpret them to the public, is the topic of the next Chapter.

CHAPTER IV

THE INFLUENCE OF SOCIAL INSTITUTIONS ON
THE CULTURAL PRODUCTION OF THE DISABLED IDENTITY

This Chapter will consider the role of contemporary public institutions, modern technology, and mass communication in shaping the meaning of the disabled role identity in contemporary Canadian culture. While the focus will be on the cultural production of the disabled identity, attention will also be paid to those elements of cultural reproduction which are evident: the dynamic tension between a group attempting to shape a new and more authoritative meaning to their identity and the need of social institutions to maintain their existing role in a culture.

Modern Technology

The technological super-culture throughout the world is reflected in the western world view that humanity will eventually triumph over physical limitations through intellectual mastery of the material world. Modern systems of transportation and communication are designed to transcend existing boundaries of time and space. The focus seems always an attempt to overcome the natural, to replace the imperfect with the more nearly perfect. Such a view implies that eventually all disabilities can be compensated for through the utilization of technological means. While a laudable goal, it also conveys a subtle denial of human limitations and mortality, a persistent experience which is the social reality of the disabled person. In such a way,

social reality is created and managed through social acts informed by cultural beliefs [Pearce and Cronen,1980].

Until the end of World War II the technology applied to disabling conditions was almost entirely related to limb prosthetics. Since that time other areas of technology have been developed, often in conjunction with concerted representations from consumer advocacy groups. Modern technology can be said to have both contributed to an increase in numbers of the disabled population as well as to making positive contributions to the treatment and amelioration of disabling conditions. Increasing leisure time and activities, more sophisticated equipment for sports, play and travel have resulted in an increase in the disabled population due to motor vehicle and sports related injuries. Some modern work environments which generate unusual hazards, also result in an increase of the disabled population. Technological advances in medicine, biomedical engineering and rehabilitation have resulted in more disabled persons being kept alive and restored to partial functioning. Technological advance has also resulted in the maintenance of life of premature and high-risk newborn babies, often with attendant disabling conditions. A greater number of people are surviving, and living longer, and consuming specialized services and equipment.

Technology has contributed to the creation of a client population and then created a specialty to serve this population. The development of the discipline of biomedical engineering, and the sub-discipline of rehabilitation engineering, is a response to the need to assist the

functionally impaired by technological processes which will restructure the environment and/or provide the assistive devices which will enable them to adjust to their environments. Since the target population is relatively small and the products highly specialized, complex problems of design, development and distribution occur.

Federal and private funding sources support scientific research and invention of devices which are then turned over to private enterprise for manufacture, distribution and sale. Moreover, certain industries transfer their technology to development of devices for the handicapped, an example being that of the National Aeronautics and Space Administration [NASA] in developing a switch that operates controls by eye, and breath-actuated switches to operate television sets and lights. The technology and the potential now exists to provide a variety of increasingly sophisticated prosthetics, orthotics and aids to the handicapped. Lacking are adequate mechanisms to coordinate costs, funds, transfer of the technologies, and marketing of the devices [Parsons and Rappaport, 1977].

Technology has also contributed to an improvement in the self-perception of the disabled individual. A number of theorists have shown that social interaction has a function of creating the self-concept of the actors, as well as defining both the symbols used and the symbol users. The invention and availability of increasingly sophisticated assistive devices for the disabled give the disabled individual greater independence and access to societal norms of behaviour. This has also led to a more educated population,

better able to develop skills of advocacy and self-determinism. Increased mobility, increased capabilities of independent functioning, and greater access to communication modalities has meant that the disabled can begin to take their cause into their own hands. The provision of devices means that in many cases they can become independent wage earners, no longer dependent upon governmental support.

Cole's conclusion that the new interactive media provide more choices, more opportunity to be masters of their own lives, is particularly applicable to the disabled [Cole,1980]. New systems of communication technologies have led to increased communication between individuals and groups. This is particularly notable with the hearing impaired who so far have made more use of telecommunication devices, and electronic and computer messaging than have the other disability groups. Specialized amplification systems permit the hard of hearing for the first time to meet and hear in groups. This capability has been a prime factor in the formation of their disability group.

Since the disabled have been enabled to functioning more effectively, there has been a consequent attitudinal change apparent in the rehabilitation field. There is a recognition that disabled individuals can perform more competently than was previously accepted, given the appropriate aids and training. A review of rehabilitation literature reveals that twenty years ago the rehabilitation and education personnel who developed programs for the deaf prophesied that they could learn to be blue collar workers, maintaining

the computer equipment. Now they train the deaf to design and operate sophisticated equipment.

Social actions and technology have therefore affected what is social reality for the disabled. We should note, however, that sophisticated equipment does not make the disabled person more "normal" in the eyes of society. The disabled person simply becomes a disabled person who uses sophisticated modern equipment to cope with his or her disability. The reaction of the nondisabled person is typically to marvel at what the disabled person can do with such a piece of equipment. The perception of competence is shaped more by the reaction to the technology than to the individual. The mental image, the message, is preset to an existing code; that is, the code which says that the disabled person is not competent, the equipment, the technology, is.

Tofler [1983,p.133ff] discusses the coded and uncoded messages which we receive from our environment. Uncoded messages arise simply from environmental happenings, independent of any social code. Coded messages depend upon an implicit social convention for their meaning. The prevalent sociocultural attitude towards disability is that of deviance, though it is social convention that it is a taboo to openly deride or reject the disabled person. Uncoded messages we may pick up and convert into mental images. The typical response to gadgetry of, "what will they think of next?" contains elements of both coded and uncoded messages which conveys marvel at new technology but also an element of fear of individuals being dependent upon machinery for functioning. So that comments such as, "If they are that

crippled they shouldn't be out in public", or the "does he take sugar?" syndrome, or the "isn't it marvelous what they can do with that equipment nowadays " still represent a typification of social response to disability.

By the provision of prosthetics, orthotics and aids, and by all of the functions attendant on this provision, modern technology contributes to the shaping of the group identity, to its visibility in society and to increased access to society. Such contributions help to break down existing barriers to access to society and communicate the unspoken message that the disabled are able to be contributing members of society. However, McQuail points out that a new ease of communicating by way of new technologies does not mean that the messages which the individual or the group wishes to transmit to society will necessarily influence the culture and the way of life of others who are reached [McQuail, 1974 p.96ff].

McQuail's discussion of the basic factors which shape the pattern of communicative interaction between individuals and between groups can be applied to the dynamic tension evident in the cultural reproduction of existing social structures. Merely having access to society and barriers removed does not mean that the deviant group or person is integrated into normal society. While factors such as spatial nearness, social nearness, association in everyday activities, cooperation and collaboration, and even conflict necessitate increased communication, it is the context of the communication situation which takes precedence in defining what meaning will be attached to that communication. Moreover, the ability to communicate with

ease over great distance now means that individuals can keep closer communicative contact with members of their primary reference group, or their own social class than ever before. Since they can maintain close contact with their preferred group or class there is no great motivation to develop increased contacts with other groups. Social communication, whether formal or informal, between those of different groups or social classes can therefore remain largely superficial.

Technology has however opened up more channels to effective communication, more opportunities for effective face to face contact, more opportunities for interpersonal communication, a greater opportunity for the disabled to articulate the meaning of their identity at the varied levels of communicative interaction within the social structure, formal and informal groups and institutions. These opportunities include access to power and authority structures.

"Without massive support from other power and authority structures, these attempts to transmit messages are ineffective...The channels cannot be easily "opened" nor can the norms defining new communication links be readily invented " [McQuail,1974 ,p.140].

Public institutions

a] health care professionals and other service providers

Probably the most useful theoretical stance to adopt in discussing the effect of professional institutions upon the cultural production of the disabled

identity is to specify that the professional and the lay person function out of different provinces of meaning. Vocabulary, terminology and roles are approached from finite, interior provinces of meaning as well as from an obviously different experience of what constitutes social reality. The following perspective draws heavily on Derksen's [1981] description arising from within the province of meaning of the disabled groups.

The permanently disabled person is expected to accept the permanent nature of the disability. Yet the helping professions which cluster around him, and society itself, continually reinforce the idea that he or she is in fact sick, and expected to get better. The very nature of the medical and professional model of care creates and enforces this paradox. The implication is conveyed that disability is a problem which can be remedied through accepting rehabilitation. Implicit in this remediation is acceptance of the advice and counsel of a wide variety of professionals ranging from doctors to social workers. In accepting this model of care the disabled person may find that most or all decisions have been made for him or her.

In the medical/sick role model the disabled person is a "patient" and expected to behave as a grateful and passive recipient of care who follows orders. This model maintains, reinforces and probably has caused some of the attitudinal barriers disabled persons encounter in society. The implications of this model and its terminology communicate, sometimes in subtle and pervasive ways, that the person should and can become "well", meaning able-bodied.

A proliferation of secondary medical professions has occurred in the area of rehabilitation services. Such occupations as physiotherapy, occupational therapy, music and recreation therapy, rehabilitation psychology, all define the recipient of care as a "client", a term which indicates a passive acceptance of services. Newly created titles in rehabilitation service also include the rehabilitation social worker, rehabilitation service administrator, professional social service program director, and the professional fund raiser. The field of biomedical engineering also services rehabilitation.

It is a characteristic of professional groups that they each maintain control over the specialized information in their own field, often by the use of a special professional jargon. They create an exclusivity of both information and of decision-making in their particular area of expertise. Two main results of this exclusivity and proliferation of professions in the same field are first, that they create, maintain and deepen the dependency of the disabled upon the profession; and secondly, that there occurs a proliferation of separate programs, which are sometimes counterproductive and which all need clients to justify their existence.

The medical ethic has traditionally influenced service provider policy and program formulation and design. The medical profession embodying as it does the perceptions and values of highly educated, traditionally accepted authority has had great influence upon governmental decision-making processes in allocating funds to programs. The bulk of direct government

funding for rehabilitation has gone into rehabilitation hospital centres or wards and nursing homes. Consequently many people were confined to the chronic patient role in nursing homes at great social/human cost, with no attempt made to effect a more full integration into society.

The role of the professional bureaucrat who administers the service programs and policies presents specific problems which impact upon rehabilitation service provision. This problem is generated when the bureaucracies' need to expand requires an ever increasing number of programs to administer. This often results in separate special programming of various agencies rather than a coordinated effort between bureaucracies. Again, a proliferation of programmes requires a clientele to sustain the programmes, which leads to a tendency to keep clients in programs for an extended period of time.

The role of the professional fund-raiser has great impact in shaping public perception of disability. The professional fund-raiser, or the person who does fund-raising for the service provider, has as the target population the charitable giver. Various charity drives use disabled children, usually with highly visible disabilities, who are both appealing and pathetic, to solicit funds from the public. The symbolic message is that the disabled person is a worthy recipient of charity. More seriously, the message also associates an image of disability with childlike qualities of dependence, passivity, asexuality, and inability to assume responsibility in society. Cognitive systems influence one another, the "cause and effect" system is operative. [Kelly, 1981]. Where images of disability are associated only or primarily

with children, oversimplified, overgeneralized notions are formed and internalized, resulting in stereotyping.

Recently some of these funds have been used for services to adults as well, but the use of children to raise funds is still popular. The type of publicity used also emphasizes the gap between the disabled recipients and non-disabled givers. Giving to charity, and raising money for those less fortunate, is a socially constructed and accepted typification of behaviour in our culture. It enhances feelings of wealth, generosity, self-esteem, status, health and power in the giver, and assuages any guilt feelings the giver may have about isolation of the disabled. It may be said then that charity giving benefits the giver more than the recipient. It also creates an interdependence between the charitable givers and the service agencies so that the quality of interaction, in not offending the charitable giver may become more important than the quality of interaction with the client. Community groups which serve as volunteers and charity fund raisers for service agencies become extremely important to the agencies.

Institutions such as health professions, politicians and the press all give credibility and weight to the charity ethic. A recent phenomenon in the charitable giver area is the alliance of business with high status public persons and specific service providers. An example of this is the Jerry Lewis /Seven-Eleven Stores relationship. While this represents a magnanimity of time and effort on the part of the givers, it still has a distorting effect upon the perception of the place of disabled people in society. The images which are juxtaposed, the ambiguity of the symbols involved makes possible

the production of multiple meanings and emotions which may even be contradictory.

The disabled child chosen is helpless and appealing. The use of such "stars" both the celebrity "star" and the child "star", indicates an awareness that what the public is responding to is the "star" quality of the appeal. The generosity of the star and the business are to be admired and emulated. The coded message which is transmitted can largely supersede and eliminate any need to pay attention to the disabled condition at all. The employment of the types of tactics discussed here for fund raising contains elements of what Lonergan calls the "social surd" [Kelly,1981]. Social surd are those unintelligent and unintelligible elements which become mixed in with the intelligent and intelligible in social order. Social surd become included in the data which are a basis for further thought and social action. This leads to distortion and the reinforcement of group bias and stereotyping. Images equate disability with childlike behaviour and infantile condition, a minor role, while the healthy normal star has the spotlight, status and prestige. And the corporation bestows munificence upon all. Helping the disabled also becomes a form of entertainment, a fun thing, a built-in reward system for the participants.

While social institutions have a need to construct and reproduce a social reality which maintains their own existence, they are also responsive to the expressed needs of their client population. Since the 1970's when disabled people in all parts of the world began to organize to advocate for themselves, and particularly into the 1980's, professionals and service

providers have begun to confront and address the needs and abilities of handicapped persons. The literature reveals a greater response on the part of rehabilitation personnel to improve educational and vocational opportunities for disabled persons and to advocate actively on their behalf for the removal of major barriers which prevent assimilation into society. Helping professions and physicians in particular, have come a long way in their changes in attitudes toward the disabled, as may be seen in the growth of rehabilitation medicine.

While these are highly laudable traits, it must also be pointed out that this progressiveness still complies with the construction of a social scene which furthers the reproduction of the professional groups. While the disabled are encouraged to greater independence and self determination, new service roles are also created: group homes have staff and managers and visiting social workers; there are educators and trainers for the service personnel; there are medical consultants for new devices. As well, professional advisory groups and task forces are formed to study new needs and concepts.

As a result of the actions of the disabled themselves, the professionals and service providers have responded with the creation of an environment of supportive attitudes, beliefs and concepts which represent a hopeful step toward the nurturing of positive values towards disabled persons in our society.

b] government

No other social institution has been as responsive to representations from the disabled as has the Federal Government. It is safe to say that this response is largely due to the strategies used by disabled consumers in organizing themselves into a modern goal-oriented movement including the use of cross-disability coalitions on a national basis. Theories of both ritual and transmission views of communication can be applied here [Carey, 1975] in that while the entire struggle of the disabled is toward the representation, understanding, and acceptance of their shared beliefs for equality in society, they are making knowledgeable use of communication as a major human and technological resource to bring this about.

Government responds to any voice which represents a significant segment of the voting population, particularly when such a segment is visible, vocal and equated with a "motherhood" cause. Declaration of The International Year of Disabled Persons [1981] was followed by Proclamation of the Decade of the Disabled. The Government responded by creating a Secretariat for the Disabled under the Secretary of State, and a Disabled Persons Participation Program [DPPP] to coordinate funding grants to the disabled groups and persons serving the disabled. The government thus provides incentives to declare oneself disabled, and incentives to develop projects worthy of fund grants from the DPPP. The main goals are to facilitate self-help for the disabled by addressing their two main obstacles: the physical effects of their disability and the attitude of an unenlightened society [Obstacles Report, 1982].

Numerous task forces, committees and reports deal with issues of disability and health, rehabilitation, vocation and education. Results are closely monitored and responded to by disabled groups. There is evidence of cultural struggle and dynamic tension between the consumers and the social institutions which serve them. Disability has become a big business. Jobs are created to service this area. Much time is spent by the disabled and by service providers in conceptualizing and writing grant applications to get some of the money in the DPPP budget. Persons who have been hired to do this work must continue to justify their existence by producing more projects worthy of funding, in effect, feeding off the disabled. There are elements of social surd in this process also. Mere bright ideas, partial distortions of schemes that were once reasonable, otiose projects do somehow get accepted along with those plans which represent reasonable and coherently developed sets of ideas.

An understanding and a use of the concepts of power and influence in communications is evidenced in the strategies used by the disabled groups in approaching government. The groups use the symbolic means of persuasion to influence attitudes, opinions and responses of the government. The government in turn uses the resources of power through declarations and legislation of change which mandate compliance. Legislation is providing the disabled with improved transportation, housing, education, employment and recreation.

The role of the government has been to support and encourage the self-determinism and independence of the disabled citizen, and much of this

is achieved by providing the funding which not only assists the disabled themselves but which makes them more appealing to the rest of society as, in effect, a new industry.

The mass media

Numerous theorists and researchers aver that one cannot legislate attitude change. One can legislate behavioural change and then hopefully changes in attitude will follow. Attitudes, beliefs and misconceptions of society constitute a major barrier. Attitude change can follow on a heightened awareness, an increased contact and increased meaningful communication between the disabled and non-disabled. Although personal interaction is the most effective medium for sharing the interior meaning of one's experience, the mass media should be both a vehicle and a forum for bringing about greater understanding of the disabled and a consequent attitude change.

A thoughtful review of our cultural forms of expression reveals however that they have been less than kind in their treatment of the disabled. It is a convention of all literature and art that physical deformity, chronic illness or any visible defect symbolizes an evil and malevolent nature and monstrous behaviour. Thurer [1980] provides a summary look at literary distortions of handicapping conditions: Captain Hook [Peter Pan] is intentionally an amputee with a prosthesis; Shakespeare links Richard III's hunchback to his evil lust. Somerset Maugham uses Philip's clubfoot [Of Human Bondage] to symbolize his bitter and warped nature.

Occasionally a type of reaction formation is invoked and the literary association to disability is instead quite sentimental. For example, Hans Christian Andersen depicts the "Little Lame Prince" in maudlin tones, and some other childhood tales use the stereotype of the selfless dwarf, or the blind seer. Occasionally the protagonist copes nobly with a disability but even then it is depicted as a "curse" to bear. Cyrano de Bergerac with his grotesque nose and Quasimodo with his hunchback are remarked not for their deformity but because they are both deformed and good [as though one precludes the other]. Rarely does there appear an average or ordinary person whose disability is incidental. The use of disability as a metaphor for that which is monstrous and immoral has a long and firmly entrenched literary and artistic tradition. Although the disabled are not always stereotyped as sinister, yet authors from Swift to Dostoyevsky take liberties with the symbolic use of disability.

Thurer theorizes that such literary and artistic distortions reflect the Judeo-Christian ethic that equates physical defect with compensation for sin. The Bible "marks" Cain for his sin, thus disfigurement is interpreted by many as retribution. Disability is a handicap to productivity and our culture values accomplishment. Thurer posits that we identify with and project our own sense of sin upon the sufferer who vicariously bears our pain and relieves our guilt. Hence we are both repelled and intrigued by the cripple as metaphor.

Children's classics are particularly graphic and concrete in this regard. Villains are always ugly and deformed in some manner, heroes and heroines are

possessed of beauty and grace. Fellini in film used freaks and disabilities to cue people to respond with revulsion and disgust. Disney frequently promoted disability as metaphor. More recently Hollywood has tended to sentimentalize the disabled with stock movies of two-dimensional characters who "learn to cope" and "live happily ever after". The deaf [Voices], the blind [Ice Castles], and quadriplegics [The Other Side of The Mountain], have all been treated with this formula.

Both film and television have also employed the metaphor of the disabled as helpless victim. For example, roughing up a cripple or a blind man is a device used to show a villain as a particularly evil person. At times television has tended to transform the metaphor by endowing the disabled person with superhuman characteristics, such as the Bionic Man and Bionic Woman, while in Ironsides, the paraplegic was given a brilliant mind.

Research into the relationship between physical attractiveness and crime in the various media found that physical ugliness and physical differences are often associated with media depictions of violence and crime [Needleman and Weiner, 1974]. Horror movies make free use of this strategy. In 1975 Gardner and Radel analysed American newspapers and television for references to disabled people. They concluded that about one-half of the items portrayed the disabled as dependent persons. A tenth of the items portrayed the disabled as being in some way deviant: "strange, antisocial or bizarre". Only about one quarter of the items portrayed the disabled as a person capable of independent living and of contributing to society [Gardner and Radel, 1978].

Cartoons and comic strip captions are important carriers of prejudicial and discriminatory language as well as images of evil cripples. Words such as "stupid moron", "idiot", "crazy", are common jargon in strips such as "Beetle Bailey", and the various "animal" comic strips. Everyday words which refer to specific conditions have become standardized as curse words, and stereotypes of conditions are reinforced.

In recent years there have been many American plays and films which present a more sympathetic and romanticized view of the disabled. Gussow [The New York Times, 1979] labelled the phenomenon "the time of the wounded hero". Some of the examples are The Elephant Man [congenital deformity], Wings [stroke], Whose Life is it Anyway [paralysis] and Children of a Lesser God [deafness]. The latter play, since it originated in deaf theatre, and was acted in by the deaf, contained considerably more authenticity in its portrayal, and less sentimentality.

It is also noteworthy that there have been recent attempts to portray the disabled as "incidental" characters. A policeman in a wheelchair on Cagney and Lacey portrays an "average" role. The elderly, the ugly are seen more often as "normal", the deaf who "sign" may have a comparatively average role. Made for TV films in the 1980's have portrayed sensitive and realistic stories of schizophrenia and Alzheimers victims.

However, the media continue to promote certain images of the disabled by selectively covering certain events and ignoring others. Bogden and

Birklen quote Jernigan, President of the National American Federation of the Blind, who reported that reporters invited to a press conference on a highly political topic, ignored the political topic and wanted instead to photograph and report on the various walking aids, lead dogs, and other stereotypical symbols of blindness [Bogden and Biklen, 1977]. Similarly, when the hard of hearing hold press interviews, the picture which appears in print is invariably one of someone using the gestural language of the deaf, even though the content of the interview will stress the different identities of the two groups.

The selective coverage of disability has led to the creation of "heroes by hype". The power of the media in manipulating public response is seen in the media coverage of the disabled marathoners who are a contemporary phenomenon unique to Canada. It has been speculated that Canadians set out to run, walk, roll or skip their way across Canada to raise money for or draw attention to worthy causes because the concept of traversing the length of the Trans-Canada Highway is a part of our national psyche, embedded in our cultural self. "Part of the emotional power aroused by the epic journeys of Terry Fox, Steve Fonyo and Rick Hansen stemmed from their visual association with the Trans-Canada". Night after night the television reports "dramatized the heroes against panoramic shots of the long road" [Graham, 1987].

While many other marathoners crossed Canada for causes it was only the young and attractive men with dramatic visible disabilities who received orchestrated backing and media coverage. Promoters and handlers "package" the young man and direct the programs and publicity enroute. A star is created.

Increase in coverage puts pressure on large corporations and politicians to be seen giving generously to the hero's cause. Public sentiment is whipped up and disabled groups who deplore this false picture of the disabled as superstar, are forced to keep silent in the face of appearing envious or critical of the young hero.

The conflict created by this manipulation is what Boorstin calls the difference between a celebrity and a hero. A hero is "one who has appropriately reacted to the demands of the situation in a way which makes us all feel that important values have been upheld" [Gumpert and Cathcart, 1982 p.458]. The hero is therefore a useful role model. A celebrity occurs when the media situation is manipulated to make events appropriate to the role. Events are staged to showcase the role image. Values are bound with role-modelling and role-taking. The disabled achiever is a valuable role model for disabled who identify with him or her, but may be a source of increased alienation for young people as they discover that these role images are inappropriate for day to day living [Gumpert and Cathcart, 1982 p.458].

There is much evidence that the mass media play a role in perpetuating stereotypes of disability through their portrayals of characters. But there is no evidence that the mass media has any major effect on manipulating the attitudes and opinions of its audience. Researchers state that it is difficult to discover what are the precise effects of the media on public opinion. It is possible that attitudes and opinions are affected, but there is no evidence that attitudes and opinions change dramatically as a result of what is seen or read. There are indications of selective perception

of what is viewed, namely that audiences tend to identify with that which reinforces their existing beliefs. On the whole it appears that "the potential of the mass media to create false impressions... is tempered by a tendency of the public to neglect the mass media in favour of other sources of understanding social reality" [Howitt, 1982 p.179].

If the disabled relate to the disabled hero as a role model, they are also exposed to the negative stereotyping of the disabled in the media. The repeated portrayal of the disabled as evil and repellent can only serve to reinforce in the mind of the person the impression of stigma and low self-worth. To see oneself labelled and cast always in the role of the villain or the helpless dependent or victim is not an enviable fate.

Although there is no specific data showing attitude change in response to media communication, people tend to believe that the manner in which characters are portrayed is important. Characters presented on screen are sociological and sociocultural stereotypes designed to appeal to the majority of viewers and reflect widely held values [albeit mostly American]. Minority groups have organized Media Watches and responded assertively to any inappropriate depictions of their particular segment of the population. Deaf groups objected strongly in letters to an inappropriate portrayal of a sign language interpreter and her deaf client in a televised court drama. The hard of hearing at an international conference [IFHOH Congress, 1986] passed a resolution calling for the portrayal of persons of various ages wearing a hearing aid as a part of a normal life style.

Sign language and the deaf have acquired a somewhat glamorous aura on television as a result of increased depictions of both. The repetitious depiction of the symbol for closed captioning on the television screen is now well recognized and understood.

It seems apparent that the repeated presentation of images in an acceptable and palatable manner will result in those images becoming a part of the typification of everyday existence. The media are efficient in implanting new information and in contributing new ideas and values where they are not in conflict with strongly held views. The effect of mass communication on society is often more a contributory than a sole effect [Schramm,1973].

It is clear from the evidence then that the individual and the group is not a malleable clay, helplessly at the mercy of the manipulations of the mass media. The many layers of social structure, personal, group, and cultural, intervene between the person and the mass media of communication. "Media images, however, can help to shape the meanings we find directly in the situation and what we discover in the actual situation can influence the way we look at the media." [Kelly,1981 p.167]

Summary

Contemporary social institutions play both a restraining and a facilitative role in the cultural production of the disabled identity. Modern technology has the resources to provide the technical means of access for the disabled to society. Paradoxically though some of the technological advances result in

even greater handicapping effects. For example, the addition of a "voice" element to computers bars the deaf, and changes to the telephone system removed the flux coil which gave hearing aid compatibility in telephone receivers.

A certain amount of humanitarianism and good will is required of the manufacturers since devices for the disabled do not lend themselves to profitable marketing based on mass production. Devices consequently are expensive, and the disabled are not usually wealthy. Government and society therefore are called upon to pay.

Governments are influenced by public opinion, their own political philosophy, and economic conditions. The situation of the disabled fluctuates with the changing interplay and dominance of these three factors.

The health professions and other service providers, while most directly concerned with the well being of the disabled, are also the ones most profoundly affected by the disabled claim to greater self-determinism. Charges of "paternalism" on the one side vie with charges of "ingratitude" on the other. Both populations need one another to remain viable.

It is evident that increased contact between the disabled and the non-disabled has brought about a heightened awareness of the problems and needs of the disabled in our culture. The facilitators have been the improved use of the various channels and means of communication at all levels. There is a greater receptivity on the part of social institutions, an increased

sensitivity and willingness to accommodate the demands, and to meet the needs of the disabled for self-determinism and independence.

Humanitarianism, philanthropy and altruism are all embedded in our value system. The work ethic and achievement remain as basic values in our culture. The disabled appeal to "right value systems" by claiming the goal to work toward becoming self-supporting and productive members of society. Such causes are particularly acceptable when they do not interfere with, and indeed even enhance, the cultural reproduction of existing institutions.

The role of the mass media relative to the disabled identity has been that of the unthinking perpetuation of stereotypes. The use of disability as a quick metaphor for sin and its consequences is ingrained in our culture. This typification of disability is being gradually altered by the repeated presentations of sentimentalized and romanticized versions of the disabled as "noble copers". The mass media affects public opinion and public perceptions of social reality by its ability to create typifications. Careful use of appropriate terminology and appropriate visual images of the disabled can gradually create a more acceptable and realistic typification of the disabled as "average" people.

Within this context one should also consider the role of symbols in creating the total image, and communicating the contemporary meaning of the disabled identity. This will be explored in the next Chapter.

CHAPTER V

THE ROLE OF SYMBOLS

IN THE CULTURAL PRODUCTION OF THE DISABLED IDENTITY

This Chapter will consider the role of symbols in the contemporary production of the disabled identity. It is recognized that the concept and process of the symbol and symbolization have involved entire traditions of study. Sociologists, anthropologists, and philosophers have devoted considerable thought and analysis to address the limitless potentials which are operative in symbolic systems [Barthe, 1975]. The entire field of semiotics explores the significant meanings of cultural symbols [Eco,1975]. The treatment in this Chapter however is specific in its concern and focuses on those graphic indicators which are used in contemporary society to indicate access for the disabled. In this Chapter, I will explore the function of graphic indicators both as utilitarian signs with a specific meaning and as symbols which communicate a broader interpretive meaning.

We shall see that in the choice of a graphic indicator for hearing disability, the concept of self-determinism is operative in the contemporary disabled consumer group, as is the awareness that the use of symbols and signs in the cultural production of any group identity is now a common societal norm. Moreover, it will be noted that the use of a graphic indicator, either to indicate access for the hearing disabled population, or to identify the disability itself, or to connote a group identity, carries many more permutations of meaning than that of its nominal designated task.

I shall begin from a communications perspective, with the philosophical position of John Kelly who defines symbols broadly as "carriers of meaning in the world of immediacy" [Kelly, 1981 p.83 ff]. Kelly reviews the theories of Alfred Schutz, Bernard Lonergan and Susanne K. Langer in developing an interpretive analysis of the role of symbols in communication. While Schutz places emphasis on symbols as conveyors of intellectual knowledge, or ideas, Lonergan and Langer both emphasize the function of symbols as carriers of feelings and emotions. The sharing of emotions is an important part of sharing meaning. The feelings and emotions aroused by a symbolic form are powerful as human motivators particularly when taken in conjunction with the concepts or knowledge conveyed by the symbol. One can think of the surge of patriotic feeling in response to the flag of one's country. The flag symbolizes many more things than just being an indicator of a geographical area. Symbols appresent the meanings which transcend the realities of the everyday world.

Kelly also theorizes that the ambiguity found in symbols is more advantageous than it is harmful. A symbol may convey multiple levels of meaning, and even contradictory meanings simultaneously to each individual. Kelly argues that since the individual consciously experiences contradictory emotions, ambiguity in symbols makes it possible for one to unify that experience [ibid, p. 114]. Feelings of grief at sight of a flag draped coffin can mingle safely with feelings of patriotism and pride.

" The need of symbols is the need to unify. It is the need to bring to a healthy fulfillment and harmonious operation the manifold and multiple experiences of the incarnate intelligence, instinct with emotion, which is a human being. Such a unification is necessary so that men and women may be capable of responsible decision and action. Lonergan calls this use of symbols 'internal communication'. Symbols enable our minds and bodies, our minds and hearts, our hearts and bodies, to communicate" [ibid p.115].

Terminology

In the modern sense, "symbol" is frequently used as a generic term and includes all that is meant by a sign, mark or token. Kelly refines this interpretation to indicate that the meanings of signs, marks and tokens pertain merely to those events and actions of the everyday world, which "transcend the limits of Self", while "symbols appresent meanings which transcend both the Self and the everyday life" [ibid 1981 p.93]. A sign, mark or token then is a functional indicator, though part of its function is to relate the past to the present, and sometimes also to the future. The indicator becomes a symbol when people begin to attach transcendent meanings to it. These transcendent meanings unify the inner realm of cognition, emotion and feelings.

Tillich, in discussing six characteristics of symbols, posits that symbols have one characteristic in common with signs, they point beyond themselves to something else. Signs however do not participate in the reality of that to which they point, while symbols do. Therefore, signs can be replaced for reasons of expediency or convention, while symbols cannot [Tillich, 1957 p.42].

It is important to be clear about commonly used terminology. Terms which are commonly used, often interchangeably, are "symbol", "sign", and "logo".

Actually these terms have well defined and distinct meanings. A symbol is generally regarded, in various spheres of thought, as "that which stands for something else". The symbol is either an object that stands for another object, or an object that stands for an idea [Whittick, p.31].

A logo is a graphic indicator of a corporate identity. Its function is to say something about what the organization is, in a form that is highly visible, comprehended quickly and remembered easily. Logos and trademarks have become increasingly important in our society for political organizations and non-profit groups, as well as small and large businesses, professions and industries. They have become essential in techniques of promotion, advertising and public relations [Cleary,1981].

Capitman describes the power and purpose of trademarks as visual symbols which attempt to imprint on our minds positive associations with a product which is essentially complex and impersonal. A trademark for a vast corporation is a face, a personality, an anthropomorphization of something which is otherwise almost intangible [Capitman,1976 p.vii].

A sign is a mark, a design, or sometimes a picture that is commonly used to represent an idea or to convey certain information. Signs are often called symbols, but, as I have just discussed it, a symbol is not the same as a sign. Both Kelley and Tillich define symbols as appresentors of transcendent meanings. Schramm 's definition is much the same, in that he presents the

central idea of the sign as that of "representation" [Schramm,1973,p.58ff].

A sign merely represents something, it stands for something and it comes to represent this certain meaning for us through experience. I will differentiate this from the symbol by saying that the sign becomes a symbol when it takes on added meanings, when aside from merely standing for something, it begins to stand for something else as well.

To use an example, when we talk about an "access sign for hearing impairment", we are talking about a sign intended to convey certain information, whether it is to convey the information that the person under consideration has a hearing problem, or it is to convey the information that in this site there are certain services available to the person with a hearing problem. The sign becomes a symbol when it takes on added meanings, to any persons, aside from its original purpose.

Characteristics of effective signs

Studies have been undertaken to determine the characteristics of those signs which have proven to be the most effective communicators. Helfman [1967] presents the following conclusions. The simplest design communicates the best. The most effective sign is clean and contains the fewest lines possible, with the design based on a circle, square or rectangle. It should be reproducible in large or small sizes and work well in both colour and black and white. Straight vertical lines suggest strength and purpose. Horizontal lines suggest quietness. Diagonal lines give an impression of motion.

A sign does not necessarily need to be a pictograph of what it represents. A completely abstract design can have a very positive meaning. A sign may denote only by vague suggestion. However, people have to be educated as to what any sign means, and the educational task is made easier if the design is related to the information it is intended to convey. Once signs are adopted, even for use in just a few places, they are difficult to change and bad signs are as hard to change as good ones. The most effective and enduring signs have become simplified with the passage of time. Extraneous lines have been removed and only the basic outline suggests the meaning [ibid].

The Wheelchair Sign and its Symbolic Role

Let us now consider graphic indicators for disability in our culture, within these terminological limitations. Disability has many facets which contribute to its total image. These many facets are medical, legal, economic and bureaucratic. We have considered the psychological dimension [the impact of disability upon the individual], the sociological dimension [roles, statuses, normative and group frameworks] the sociocultural dimension [communications framework, disability as a carrier of meaning].

The most prevalent and universal image of disability is conveyed by the graphic of the stick figure in the wheelchair which appears on access to facilities signs and on car stickers. While the white cane to indicate severe visual impairment has been long in existence, the wheelchair graphic has come to be the visual indicator of disability in our culture.

This graphic has acquired the characteristics of a sign, a logo, and a symbol. It is a unitary visual concept which represents a diversity and range of people. However, in actual usage, it indicates a mobility impairment, or access for a mobility impairment, and therefore is of no practical assistance as an indicator for the sensorily impaired, and most specifically in this instance, for the hearing impaired. As a carrier of meaning therefore, it may be said to actually do a disservice to the hearing impaired in that it equates, in the social mind, the concept of disability with a mobility impairment.

There has been no universal sign or symbol to indicate access for the hearing impaired in our culture. Since a graphic indicator such as the wheelchair sign has proven so effective in indicating mobility impairment, in providing a visual image for a specific segment of the population, it is evident that the hearing impaired population would benefit by having a similar unifying and visual indicator for their condition.

The Cultural Production of a Sign for Hearing Disability

Since the concept of one access sign for hearing impairment is presently being developed and promoted in Canada and internationally, it is possible to examine the process of the creation of a sign, and the evolving of its symbolic role in the cultural production of a disabled group identity. The access sign referred to here is the ear with the broken bar, white on a blue background, presently being referred to, and promoted in some areas, as "The International Symbol of Access for the Hearing Impaired." [see

Appendix B, sign #2] Since a written history did not exist, I have compiled a brief account of the history of this sign and its introduction into Canada. This history is provided in Appendix A.

Research into the matter indicates that a great deal of emotion and controversy pervades the issue of signs and symbols for hearing impairment. The basic issue relates to the question of separate identities for the deaf and the hard of hearing populations in society. The population with the greatest expression of emotional involvement are the hard of hearing who, as discussed earlier, claim a separate group identity from the deaf based upon their communications modality. In reviewing letters, published articles and documentation from personal interviews, it is evident that for the hard of hearing, the issue of choosing a sign for hearing impairment parallels, and is closely interwoven with, the issue of public recognition and acceptance of their separate and unique identity. The issue is also self-determinism, in the choosing of what should signify their identity in society, and who should make that choice.

It is also evident that neither the service providers and professionals who first developed and promoted the access sign, nor the hearing impaired population themselves had any clear conception of the difference of function and meaning between a sign and a symbol, or a logo. It is apparent that I could not expect an objective response in a survey of hard of hearing people, concerning the most effective indicator to use for the hard of hearing identity, or for access for hearing impairment. They are already emotionally involved. The question of an appropriate graphic indicator cannot

be separated from the interwoven layers of emotion and feeling related to issues of identity and self-determinism. Interviews and correspondence with hard of hearing persons across Canada appear to show people quite divided on the issue. The same can be said of service personnel associated with the field of hearing impairment. They have formed an opinion based upon their own frame of reference.

A sign to indicate access for hearing impairment serves two functions. First, it informs the hearing impaired person that some mode of listening or communication access is there available. Second, by its repeated visible presence in society, it presents access for hearing impairment as a typification of everyday experience. The sign educates and informs the public. There is nothing in public literature to provide any data as to public opinion of signs for hearing impairment. I decided therefore to sample public response to certain existing signs to determine which sign, to them, was the clearest and most easily understood sign of hearing impairment, and if this sign was equally recognized as meaning hard of hearing. I could not design a proper statistical study because that was not the main purpose of the exercise. Rather, the study was intended as exploratory interviews of a sample population to determine if there was justification for a proper statistical study.

Since health care is a crucial area to the hard of hearing, who are susceptible to being both misdiagnosed and misinformed due to the effects of their impaired hearing, I first interviewed a number of nurses who were institutional care-givers and educators. Their consensus was that it would

be realistic and quite adequate to have only one sign to indicate that the patient has a hearing problem. At that point the staff would be alerted by the sign to find out what the patient's communication need was.

Since the sign is to be an indicator of hearing impairment to society, and since it is desirable that this indicator be one which is understood, visually appealing and socially acceptable, it seems reasonable to have a representative public choose the sign. I decided to take some signs which have been used by the hearing impaired in certain capacities and test the response of an uninvolved public to these signs in a market research context. For purposes of the survey two signs were selected. The one, a hand behind an ear, I will name #1 [see Appendix B]. Sign #1 is an action sign, and is, in our culture, a common gestural indicator that a person is having difficulty hearing what is being said, literally cupping the pinna of the ear to catch the sound waves.

It has been said that this type of gesture is in universal use in all societies. It has been in use for some time as a logo by several hard of hearing clubs in North America and Europe. However, Birdwhistell argues that "there is no body motion or gesture that can be regarded as a universal symbol", so I will qualify that statement to say that it is a gesture generally understood in our culture as striving to hear [Birdwhistell,1970]. The other sign, #2, is the graphic of an ear with a broken bar diagonally. It is a neutral symbol in the sense that it is not an action or gestural graphic.

A shopping mall was selected as the site for the interviews because the contemporary shopping mall serves a "Town Square" function. It is replete with signs and symbols of various kinds. The wheelchair access sign is used here, and the hearing access sign would be also used here.

The interview data is provided in Appendix B. Regretfully, space does not permit a detailed analysis and discussion of all the varied levels of meaning and symbolization evident in the responses of the participants in this study. That topic would represent a thesis in itself. I will discuss only those indications of social typifications evident in participant responses.

The fact that people voluntarily cooperated with the interviews indicated their acceptance of the concept of a sign for hearing access. The use of logos, signs and symbols is a part of the normative framework of our culture. The concept of a visual indicator for access for disability is also now well accepted, with the social attitude being that it is indeed desirable.

Most people [93/100] identified #1 as meaning a hearing problem, and having to do with listening or speaking up for the hearing problem. While half of the people interviewed identified #2 as meaning a hearing problem, one third of them also attached negative meanings to #2 because of the bar.

In line with symbol theory, the participants attached sometimes quite opposite meanings to the same graphics. It is interesting to note that people did not see sign #2 as a broken bar, indicating access but as a bar,

denoting a barrier. The diagonal bar is a common appresantor of the negative in contemporary signage, the obvious break in the bar was simply not taken into account. The difference here lies between "perceiving" and "apperceiving". The viewer attends to the object not in the context of that object's own meaning, but in the context where that meaning is of something else [Kelly,1981,p.81].

The results indicate that #1, the sign of the hand behind the ear is most easily and readily associated by the public, with the hard of hearing. On this basis, this graphic should be chosen as the sign for the hard of hearing identity. However, in choosing a sign to indicate access for hearing impairment, the public opinion is not the only fact which must be taken into account. Additional considerations are:

1] When presented with signs to choose from, the World Federation of the Deaf [See Appendix A] rejected the hand behind the ear, and their objection to the sign they did choose was that it also was too "ear-oriented", signifying "hard of hearing", more than "deaf".

2] Whatever sign is used, it requires an education programme for users. The ear with the broken bar is already in use, with a developed public awareness programme, in England, Australia, and is being promoted by a service agency in Central and Eastern Canada.

3] The graphic itself is not as important as the meaning which becomes attached to it, through education, usage, or the feelings which it produces.

The history [Appendix B], market research [appendix B] and a somewhat condensed version of Chapter V were presented as a "Report on the Symbol Issue" to the October 1986 annual meeting of the 14 member Board of Directors of the Canadian Hard of Hearing Association. They were instructed to read the report and be prepared to vote the following day on whether or not they would accept and support sign #2, the graphic of the ear with the broken bar as an access symbol for hearing impairment. The next day the Board of CHHA voted unanimously to accept and promote usage of this sign for purposes of indicating access for hearing impairment.

A follow-up survey of the CHHA Board of Directors as to why they voted for the #2 sign usage revealed that they no longer regarded the #2 sign as an indicator of their group identity, since CHHA now had a corporate logo of its own. The main reason for acceptance was not a positive feeling by anyone towards the graphic itself, but that they felt they were presented with "un fait accompli" since a service agency had already launched a widespread campaign to promote its use in Canada. Energies could be more reasonably expended in promoting its usage than in contesting its existence.

Since the hard of hearing group had themselves selected their own group logo, they were prepared for practical considerations to suppress their negative emotions about sign #2 and regard it as a functional sign. They would then perceive #2 as an object in the context of the object's meaning, not within the context of the meanings which had been "apperceived", that is which had become attached to it.

This apperception is more pronounced in the reactions of the CHHA Board members to the sign issue, in that they have a larger stock of intersubjective and emotional meanings to attach to the signage. Kelly makes two points which may explain the response of unanimous support by these hard of hearing persons whose emotional and subjective background could have led them to vote otherwise. He posits that carriers of meaning must occur in the world of immediacy so that meaning enters the daily life. He writes also that we assume reciprocities of perspectives and meaning between communicator and interpreter. For that reason, a written logical report and explanation of the symbol issue provided a common and immediate reciprocity of meaning of an issue, a sharing of an empirically identical scheme of interpretation which is the basis for the effecting of communication.

Summary

Signs, logos and trademarks are purposefully used in contemporary culture to communicate both functions and identities. They come to represent a certain meaning through a combination of declared meaning and receptive experience. It is safe to say that any such signs gradually assume a range of symbolic significance.

The examination of the conflict involved in the development and promotion of the "Access Symbol for Hearing Impairment" provides some indication of the emotional intensity and importance attached to significant symbolism in the use of signs, logos and trademarks in contemporary culture. To the hard of

hearing group, the acceptance of the access sign in itself became a less emotional issue when they could separate it from their group identity as represented by their own logo. Moreover, arriving at a joint decision within their group [the CHHA Board of Directors meeting] provided a sense of self-determinism, of having themselves made a decision about an issue of public significance.

The resolution of the conflict came through establishing a common carrier of meaning for the signs, the words, the issues involved. The role of sign #2 in the cultural production of disabled identity becomes that of providing a public typification of hearing disability.

The history of the development of the access symbol for hearing impairment also symbolizes the dynamic tensions between the paternalistic good will of the service providers who have the resources to achieve their own goals, and the disabled who may have a different perception of what those goals should be. Once more the point is made that the cultural production of a group identity is facilitated when that process does not interfere with, and indeed enhances, the cultural reproduction of existing institutions.

CHAPTER VI

SUMMARY AND CONCLUSIONS

I began this thesis with the argument that the cultural production of the disabled identity in contemporary society must be examined from within the whole of the communication process. Chapter One reviewed that literature which revealed the evolvement and emergence of a dynamic identity for the disabled within the social structure. Chapter Two explored the relationship of self and other in attempting to share and interpret the meaning of the human experience of disability. The process of self-definition, of self-production of identity for the individual and the group was discussed. Chapter Three addressed the encounters of the disabled with the larger social scene, within the context of the communication process. In such a context one becomes aware of the dynamic tension between the need for self-production of identity on the part of the emerging disabled group and the need for self-reproduction on the part of existing institutions. Chapter Four indicated that contemporary strategies in the presentation and marketing of an identity are also utilized by the disabled, with a realization of the significance of signs and symbols in communicating meaning.

In this final Chapter, I shall draw attention to the main conclusions of this thesis. In so doing I shall also highlight the connectedness of the cultural production of identity and relationships with contemporary media communications.

Conclusions :

1] The contemporary disabled consumer group defines itself from a sociocultural and sociopolitical perspective.

In Chapter Two, choice of self-label and adoption of the consumer ethic were discussed in this regard. Choice of a self-label is particularly applicable to the hearing impaired; the deaf and the hard of hearing, who define themselves according to their communication modality, how they wish to be perceived by and to function in society. McLuhan maintains that the prevailing mode of communication creates the mind with which the individual lives [McLuhan,1966].

Since a massive amount of time is taken up each day with mediated communication, perceptions of personal identity and interpersonal relationships are being profoundly impacted upon by the media. The self image is influenced by the mirror images of the media. The individual, the group, define and project a certain image, but this image has been developed in response to, and in a connection with what the media presents as images of the normal and the abnormal in our culture.

The definition of self and group is reinforced by mediated communication systems of contact with their disability reference group both locally and across the country. At the same time, media contact with the larger society may be challenging and change one's existing perception. Our relationships

must also coexist and interact with the media. Snyder points out that our values and belief systems can be influenced and modified by those external values presented by the mass media [Snyder,1966]. The disabled person who views the environment as presented by the mass media can then selectively create a reality as he or she sees it, and as he or she wishes it to be, and define the self within that reality.

Gumpert and Cathcart argue that the new media have erased the old barriers of time and space:

When concepts of time and space are altered, our perception of reality shifts. Knowledge and truth take on different dimensions. Our symbols have new or added meanings. And, our notions of self and other are affected. The very stuff of human communication is changed [Gumpert and Cathcart,1982,p.9].

It is therefore increasingly realistic to think of oneself and of one's potential in a greater role from that which was once considered achievable. One of the most powerful effects of time and space alteration on the perception of reality is the effect of immediacy. What is happening is happening right now and calls for an immediate response. We accept or reject what is presented, whether it is the overt message or the covert interpretation conveyed. We cross check with our prevailing value system, but those images which are repeatedly projected become the typification of that particular image or symbol. It is therefore important for the disabled to ascertain whether or not the images of disability in the media are positive and realistic images.

2] The contemporary disabled consumer group takes a proactive stance in the cultural production of their identity. The intent is to attack physical and attitudinal barriers.

In this context, the role of mediated communication is evident in both the formation of attitudes and the politicization of the disabled individual and the disabled group. Rapid, efficient and extensive communication through the written word, electronic connections and the mass media influence the formation of self identity and the production of group identity. A wider audience can be reached with both ease and rapidity. The exchange of opinions and attitudes, through teleconferencing, telecommunicating, phone-ins to talk shows, and television audience participation shows permit people to identify with those of like opinions, and to locate themselves at some place within a particular social scene. The disabled also have the opportunity to present their cause, their needs and problems, and to role-model the sort of identity which they wish to be perceived by the public as the typification of their disabled condition.

3] The primary function of the disabled consumer group is to produce a knowledgeable consumer who knows how to use the system to have his or her needs met.

Basic to the success of this function is an understanding of the communication process, and how to use it effectively. An understanding of prevailing value systems, of the effectiveness of word, symbol and image in communicating meaning is essential. The cultural production of the disabled

identity is best effected through those strategies which use the system. First, the disabled individual and the group must have their consciousnesses raised, must be educated to understand the disabled consumer philosophy so that the disabled all communicate the same basic message in a united fashion.

Next, strategies of cooperation, consultation and networking on a partnership basis with existing structures and institutions are developed since all such social organizations are bent upon the maintenance and reproduction of their own unit. Effective communication is based upon understanding one another's frame of reference. While what is shared is the public worlds, there must be some sharing of the meaning of the private worlds.

The themes of human rights, justice, equality for all, and the social good run through all endeavours by the disabled consumer group, as well as by all minority groups. These themes have a specific meaning to the disabled that has not been experienced by someone outside their province of experience. Sharing the meaning of this private world is the greatest difficulty of communication. It is vital that enough people apprehend and comprehend this private reality to grasp and give assent to the public reality of these needs. Only in this way can a consensus arise to construct a society which permits equal participation by the disabled.

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Appendix A

History of the "International Symbol of Access for the Hearing Impaired"

This history as here provided offers a pertinent illustration of both the emotionalism involved in the selection of a sign or symbol by a group, and the motivator of self-determinism at work in the process.

The symbol referred to here is the ear with the broken bar, white on a blue background, presently being referred to and promoted in some areas as, "The International Symbol of Access for the Hearing Impaired." In Chapter V of the thesis and in Appendix B it is referred to as sign #2. While writers and speakers on this topic popularly refer to it as a symbol, I shall, except where quoting, refer to it as a sign, or as sign #2, in line with the definitions provided in the body of the thesis.

History of this sign:

In 1976, Gallaudet College and the Model Secondary School for the Deaf, in cooperation with the National Association of the Deaf [NAD], USA, established a Task Force on The International Symbol for Deafness, to recommend a suitable sign to represent deafness worldwide. In 1978 this Task force recommended three proposed signs to the Board of Directors of the NAD. This Board voted in favour of one which showed a bar across an ear, all enclosed in a circle.

In 1980, the 8th World Congress of the Deaf [WFD], in Paris, France, chose this sign as a conceptual model for an International Symbol for Deafness. The Task force design then turned the sign over to "Jack Weiss Associates" a Chicago based design company, to produce an artist's rendition of the graphic. Jack Weiss Associates is the design partnership that was involved in perfecting the Wheelchair Symbol for Access, and it now produced the ear graphic as it presently is employed [See figure #2, Appendix B].

In reporting on the results in THE DEAF AMERICAN, April, 1980, the chairman of the Task Force, Herbert C. Bounds Pearson, does not use the term "access symbol". Nor does he refer to it as a sign, but calls it "The International Symbol for Deafness". Nevertheless, he discusses the suitability of the symbol as an indicator of deafness. He also uses the term "deafness" interchangeably with the term "hearing impairment". He also discusses its usage in the context of the ways the Wheelchair Symbol is used. The term "hard of hearing" is not used once in the report. It must be acknowledged here that the term he does employ is "deafness", which often has been used to indicate the spectrum of hearing loss, and not only to indicate the deaf identity.

Later, in June 1980, the International Federation for the Hard of Hearing [IFHOH] at its annual meeting in Paris, France, also accepted and endorsed this sign as the International Symbol of Access for the Hearing Impaired. The IFHOH decision was based on the conclusion that since the WFD had accepted the sign it would be more diplomatic to accept it than to set the stage for a controversy by seeking to introduce an alternate sign.

Unfortunately, this decision on the part of IFHOH was not publicized in North America. And the file of letters and published articles indicate that it is at this point that emotion rears its passionate head as hard of hearing people began to attach symbolic meaning to what had up until now been primarily a sign. The sign had become a symbol. The emotional issue related to the significance of who was choosing what identity for the hard of hearing people.

At this time, the hard of hearing people in North America were beginning to organize with the intent of promoting a specific hard of hearing identity both in Canada and the United States. The Speak-Up sign was being promoted as an identity symbol for the hard of hearing by the Speak-Up Institute and a Consumers Organization of the Hearing Impaired [COHI] in the US, and various hard of hearing clubs and individuals across Canada were initiating contacts with the two US groups.

At a crucial time, when the hard of hearing were calling for recognition of their separate identity from the deaf, the Canadian Hearing Society [CHS], a large, Ontario based service agency, in its newsmagazine introduced sign #2 as the "International Symbol for Hearing Impairment", terming it "At last. One symbol for deaf and hard of hearing people all over the world" [Vibrations, 1981].

The timing of the introduction of this sign in Canada was particularly unfortunate, as were the words of the advertisement and the fact that the hard of hearing Canadians were taken by surprise at its appearance. A great

deal of correspondence was generated as the hard of hearing deplored the introduction of a sign whose role seemed to be to merge the two groups into one at a time when both were agreeing on the need for separate identities. The CHS Executive Director protested that the sign was meant to be an access symbol for hearing impairment, not a group identifier, but the damage was done. The sign #2 had acquired a great deal more symbolic meaning. The Director then pressed the Canadian Hard of Hearing Association [CHHA] to either endorse the sign #2 as an access sign or else to propose a new access sign which would be more acceptable to the hard of hearing, within one year.

In Europe meanwhile, the British Association of the Hard of Hearing proceeded with implementing an access programme primarily for the hard of hearing based upon sign #2. In Australia the sign #2 is used in a similar manner, and quite effectively in a hospital hearing awareness programme.

In May 1984 the CHS introduced another well developed public advertising programme to promote sign #2 but without seeking any further endorsement from the now well organized CHHA. Again, the reaction to the move was a mixed one, with some hard of hearing groups in the Eastern and Atlantic provinces accepting it and others areas in Canada refusing it.

A CHS presentation to the Board of Directors of CHHA in August, 1985 provided a factual plan for the ways and means of using the sign but did not deal with the varied meanings which the sign had symbolically acquired for the various Directors. The issue of whether or not to accept and promote sign #2 as an access sign was therefore tabled for further study.

Basically, two issues surround the sign. First, the hard of hearing want a sign to indicate a hard of hearing identity, as differentiated from that of the deaf. There are now many logos to indicate hard of hearing group identities, each one having a band of supporters. The IFHOH also has its own logo. Second, the sign is not meant to indicate a group identity. It is actually meant to function as a sign, indicating that a person has a hearing impairment and needs certain considerations, or to indicate that there have been certain modifiers to the environment to permit communicative access for the hearing impaired person.

A graphic sign such as this does not tend to indicate precisely what level of hearing loss it is suited for. For example, the wheelchair sign may indicate a ramp whether the disabled person coming to use it is in a wheelchair, a stretcher, or on crutches. A wheelchair sign on a washroom door will not indicate whether a toilet seat is accessible from the left or the right. Some measure of uncertainty is left for the individual to deal with. Similarly if the sign is used to indicate that a person has a hearing problem, it is up to the actors in the situation to clarify what the communication problem is and therefore what the communication modality must be.

Appendix B

THE RESEARCH:

It was decided to sample public response in a market research context, to certain existing signs to determine which sign, to them, was the clearest and most easily understood symbol of hearing impairment, and if this was equally recognized as meaning hard of hearing.

For purposes of the survey two signs were selected. Sign #1, a hand behind an ear, is an action symbol, it is a common gestural indicator that a person is having difficulty hearing what is being said, literally cupping the pinna of the ear to catch the sound waves. It has been in use for some time as a logo by several hard of hearing clubs.

Sign #2 is the outline of an ear with a broken bar diagonally. As mentioned it was selected as the International Symbol for Deafness by the WFD and has been promoted as the International Symbol for Access for the Hearing Impaired in Great Britain by the BAHOH and in Canada by CHS. It has not been actively promoted for public use in British Columbia and so is not well known locally. It is a neutral symbol in the sense that it is not an action or gestural graphic.

The population approached were patrons of a large shopping mall in the Greater Vancouver area. Since such a sign would be in use to denote access for the hearing impaired in public market and social situations this represented an appropriate type of population. Persons were interviewed at random by approaching every third person passing by a particular spot where the interviewer was stationed. A total of one hundred responses was sought [Fleiss, 1973]. Persons were asked to complete a standard questionnaire, including a section for comments [Moser, 1958]. A sample of the form is included in this Appendix.

The interview participants included all age groups and both sexes. Since the public usage of this type of symbol is aimed at the entire spectrum of the population, as represented by the segment of users of this type of mall, a variety of user responses was desirable and was achieved. The results are presented in Table 1 on the following page.

SUMMARY OF RESULTS:

Roughly 75 % of the people had seen both symbols before, slightly more of them being familiar with #2. While 93/100 indicated that they would use #1 to signify a hearing problem or something to do with hearing, 76/100 also indicated that #2 could be used to signify something to do with hearing or a hearing problem. One quarter of the people [26/100] attached negative meanings to # 2 such as "don't listen", "leave alone", "confusing".

75 % of the people chose # 1 as a sign to indicate "hard of hearing".

Table 1

<u>Question</u>	<u>Sign #1</u>	<u>Sign #2</u>
1. Have you seen this symbol before?		
a. yes.....	74.....	86
b. no.....	22.....	7
c. don't remember.....	4.....	7
2. What does this symbol mean to you?		
a. information available here.....	5.....	5
b. hearing problem.....	70.....	56
c. listen.....	11.....	3
d. speak up.....	10.....	5
e. other	4.....	31
[stated]		
= "nothing".....	1.....	13
"like a spy--spying.....	1.....	
"don't hear".....	1.....	1
"quiet zone".....	1.....	
"confusing bar".....	5
"aid for hearing".....	2
"looks like a road sign".....	1
"looks like a question mark".....	1
"totally deaf".....	2
" no ears", "no sound".....	2
" noise level too high".....	2
"light bulb".....	1
" lightning strikes".....	1
3. Which of the following do you think would be the most correct use of the above symbol ?		
a. "hearing problem ".....	67.....	42
b. "something to do with hearing".	26.....	25
c. "information centre".....	6.....	7
d. other.....	1.....	26
[stated]		
= "nothing".....	1.....	26
4. Which symbol would you choose to indicate, "hard of hearing" ?.....	76.....	24

5. Comments offered were:

"# 1 is a natural gesture if you can't hear but the bar across the ear in #2 is confusing".

"# 1 just means listen but the bar on #2 helps to indicate "stop and listen, hearing problem".

"#1 makes a better connection to hearing problem when you look at it".

"A good idea to select a symbol for hearing impairment."

"I am a graphic artist for a living and I think that #2 looks the best as a graphic. It is visually the most appealing".

"Think this is a good idea to have a symbol for a person with a hearing problem to show that they have the problem so that others can know what to do. How to react to an invisible problem [to know the person has it]. Like if I was driving a car and I saw this symbol on the car window and knew that the other driver couldn't hear I could react accordingly".

"I would choose #1 as "speak up" goes with "hearing problem".

"#2 is too vague".

"I think #2 looks more sophisticated than #1".

"# 2 is confusing-- the extra curve inside the ear and the stripes outside.

It should be made different to be clear as an ear".

"Neither of these graphics seems to be particularly clear as to meaning. Neither seems to conform to the International Symbols or North American Standards for symbols".

"Both graphics are confusing. My own understanding comes from my involvement with a hearing impairment exhibit for a display".

"It is a good thing to choose such a symbol-- need one for hearing problem".

"A good idea to get a symbol for this purpose"

"#1 you can tell when you look at it, has something about trouble hearing.

#2 doesn't tell you this...hard of hearing...when you look at it".

"To me both symbols seem as though they could stand for a wide variety of things to do with hearing".

"People would be most likely to identify with #1 but they would need a lot of educating to be ready to recognize what any symbol means. They would need more educating to understand #2".

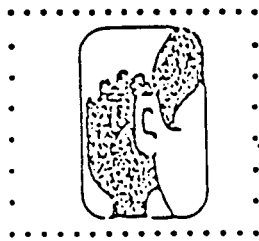
"I find #2 confusing because of the bar".

SYMBOL CHOICES - IDENTIFICATION AND MEANING

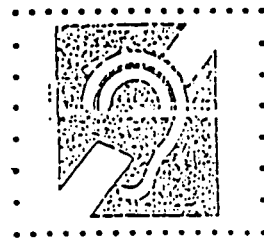
INFORMATION FOR PARTICIPANTS:

This questionnaire is part of a research study to select symbols which are effective to indicate a particular disability, or 'access' for a particular disability. This questionnaire looks at hearing disability. Thank you for your participation.

SYMBOL #1



SYMBOL #2



PLEASE CHECK ONE ANSWER TO EACH QUESTION

- | | | |
|--|---|--|
| 1. Have you seen this symbol before? | : | 1. Have you seen this symbol before? |
| a. <u>74</u> yes | : | a. <u>86</u> yes |
| b. <u>22</u> no | : | b. <u>7</u> no |
| c. <u>4</u> don't remember | : | c. <u>7</u> don't remember |
| 2. What does this symbol mean to you? | : | 2. What does this symbol mean to you? |
| a. <u>5</u> information available here | : | a. <u>5</u> information available here |
| b. <u>70</u> hearing problem | : | b. <u>56</u> hearing problem |
| c. <u>11</u> listen | : | c. <u>3</u> listen |
| d. <u>10</u> speak up | : | d. <u>5</u> speak up |
| e. <u>4</u> other [state]..... | : | e. <u>31</u> other [state]..... |
| | : | |
| 3. Which of the following do you think would be the most correct use of the above symbol ? | : | 3. Which of the following do you think would be the most correct use of the above symbol ? |
| a. <u>67</u> "hearing problem" | : | a. <u>42</u> "hearing problem" |
| b. <u>26</u> "something to do with hearing" | : | b. <u>25</u> "something to do with hearing" |
| c. <u>6</u> "information centre" | : | c. <u>7</u> "information centre" |
| d. <u>1</u> other [state]..... | : | d. <u>26</u> other [state]..... |
| | : | |
| 4. Which symbol would you choose to indicate, "hard of hearing" ? | : | |
| a. <u>76</u> symbol # 1 | : | b. <u>24</u> symbol # 2 |

5. Comments: