National Library
of Canada

Acquisitions and
Bibliographic Services Branch

395 Wellington Street
Ottawa, Ontario
K1A 0N4

Bibliothèque nationale
du Canada

Direction des acquisitions et
des services bibliographiques

395, rue Wellington
Ottawa (Ontario)
K1A 0N4

Your file   Votre référence

Our file   Notre référence

NOTICE

The quality of this microform is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us an inferior photocopy.

Reproduction in full or in part of this microform is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30, and subsequent amendments.

AVIS

La qualité de cette microforme dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de qualité inférieure.

La reproduction, même partielle, de cette microforme est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30, et ses amendements subséquents.

Canada

UNIVERSITY OF ALBERTA

AN EXPLORATION OF THE EXPERIENCE OF HAVING A DISABILITY 'SOMETIMES': THE UNCERTAINTY

by ©

Sherry L. Peters

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Arts.

DEPARTMENT OF SOCIOLOGY

Edmonton, Alberta
Spring 1994

National Library
of Canada

Acquisitions and
Bibliographic Services Branch

395 Wellington Street
Ottawa, Ontario
K1A 0N4

Bibliothèque nationale
du Canada

Direction des acquisitions et
des services bibliographiques

395, rue Wellington
Ottawa (Ontario)
K1A 0N4

Your file Votre référence

Our file Notre référence

The author has granted an irrevocable non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of his/her thesis by any means and in any form or format, making this thesis available to interested persons.

The author retains ownership of the copyright in his/her thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without his/her permission.

L'auteur a accordé une licence irrévocable et non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de sa thèse de quelque manière et sous quelque forme que ce soit pour mettre des exemplaires de cette thèse à la disposition des personnes intéressées.

L'auteur conserve la propriété du droit d'auteur qui protège sa thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

ISBN 0-612-11335-3

UNIVERSITY OF ALBERTA

RELEASE FORM

NAME OF AUTHOR:	Sherry L. Peters
TITLE OF THESIS:	An Exploration of the Experience of Having a Disability 'Sometimes': The Uncertainty
DEGREE:	Master of Arts
YEAR THIS DEGREE GRANTED:	1994

Sherry Peters

Department of Sociology
University of Alberta
Edmonton, Alberta
T6G 2H4

January 24, 1994
Date

UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled AN EXPLORATION OF THE EXPERIENCE OF HAVING A DISABILITY 'SOMETIMES': THE UNCERTAINTY submitted by Sherry L. Peters in partial fulfillment of the requirements for the degree of Master of Arts.

Lyle Larson
Dr. Lyle Larson

Judith Golec
Dr. Judith Golec

Ronna Jevne
Dr. Ronna Jevne

January 19, 1997
Date

ABSTRACT

Five individuals with physical disabilities, including multiple sclerosis, muscular dystrophy, lupus and spinal cord tumor, were interviewed at length to explore their experience of appearing to have a disability '*sometimes*' - namely, a disability that changes in how visible it is to others. As these individuals recount their experiences during times of change in the visibility of their disability, we can see how having a disability that *lacks consistency in its visibility* can make having a disability '*sometimes*' unique and make the ever-changing responses of others perplexing. Together, the fluctuations in the visibility of the individuals' disabilities, the fluctuations in feedback from others, and the individuals' own 'distancing-connecting' of their disability with their self amplifies the *uncertainty* of having a disability.

ACKNOWLEDGMENTS

I wish to express my gratitude to Dr. Lyle Larson and Dr. Judith Golec for their guidance, suggestions and support throughout this investigation. In addition, I thank Dr. Ronna Jevne for her assistance.

I thank my parents, Art and Fran Olson, sister, Cathy Olson, and friend, Don Lawrynuik, for their support. I am especially grateful to my husband, Randal Peters, for his encouragement and patience.

I am indebted to all the organization officials who assisted me in locating individuals, especially Marion Vosahlo, the director of Disabled Student Services at the University of Alberta, for her time and ideas. I also wish to thank my friend Cathy Leddy for participating in an interview simulation. Most of all, to the individuals whose stories I tell, I give my sincere gratitude. Their willingness to give so much of their time and themselves was remarkable.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

Chapter One

INTRODUCTION

I am an individual with a disability exploring the experience of having a disability. For some, including myself, this experience is *not only* the experience of having a disability, it is the experience of appearing to have a disability *'sometimes'* in the eyes of others. In this investigation, I have sought to explore the uniquely *uncertain* experiences of disabled individuals[1] who have an injury or condition that fluctuates in visibility. Throughout, I am addressing the disabled individuals' *perceptions* of other individuals' appraisals of them and their disability. While some may argue that the individuals' perceptions are not necessarily accurate, they are nonetheless real for the individuals who perceive. I am concerned only with their relationships and the "others" as they are *perceived* by the disabled individuals.

The direction taken in this thesis has changed considerably over the course of the analysis. In addition to examining the experiences of individuals who have a disability that fluctuates in visibility, my original aim was to explore a 'Response Systems Model of Disabled Individuals in Transition' (See Appendix D). As I gathered stories from individuals with disabilities, however, I found it necessary to abandon the model as the participants were not able to recall or describe their past experiences or the impact of each experience on their self-understanding in the detail required by the model. The ideas that have been explored throughout this work have unfolded from the stories of the participants rather than from the model. Although I first called the individuals I was considering "disabled individuals in transition" because they wavered between one type of visibility and another, the designation "individuals who have a disability *'sometimes'* " was adopted because it seems to capture the participants' experiences better.

My experience with having a disability 'sometimes' has been instrumental in eliciting this research. Throughout my examination of disability-related literature since I sustained injuries in a car accident eight years ago, I have been unable to 'find myself'; that is, I do not fit into any of the medical categories around which disability research is largely oriented, nor have I found my experience with a disability fully reflected in these works. Many writers and researchers choose to focus on one particular medical category such as multiple sclerosis (i.e., Brooks and Matson, 1987; Coleman, 1989; Russell, 1989; Riessman, 1990; Robinson, 1990), rheumatoid arthritis (i.e., Bury, 1982; Williams, 1984; Wiener, 1975), spinal cord injury (i.e., Yoshida, 1993) and others. In such disability-specific literature, common themes across disabilities may be lost. In this regard, Conrad (1987) in his article *The Experience of Illness: Recent and New Directions* recommends that researchers "begin systematically to develop sociological conceptions of the illness experience. The crux of this analytic strategy is to develop meaningful comparisons among illnesses on sociological grounds" (27). *Having a disability 'sometimes'* is such a category. It is sociologically interesting as those who have a disability that fluctuates in visibility have many similar social experiences. As well, this category is not restricted to any medical illness or injury but rather includes all disabilities that fluctuate in visibility. While not denying that every condition or injury has unique aspects, it is important to investigate common experiences across disability types. Four specific disabilities have been included in this investigation: lupus, muscular dystrophy, multiple sclerosis and tumor on spine. Through the disabled individuals' rich description of their experiences, I have considered one central question: What is the experience of having a disability that fluctuates in visibility - a disability 'sometimes'?

Methodology

Although qualitative and quantitative methods can both be used to learn about individuals' *perceptions*, a qualitative approach has allowed me to gain a more extensive picture of the individuals' subjective realities. Through in-depth interviews I have been able to gather not only the individuals' *perceptions*, but also the framework which gives meaning to their perceptions of self and to their orientation to the world. Open-ended in-depth interviews permitted the participants to give detailed accounts of their experiences with others and allowed me to question and probe more extensively about the many facets of the experiences.

Data Collection

The data for this investigation came from one primary source: twelve in-depth open-ended interviews with five individuals (4 females, 1 male) that have a disability that fluctuates in visibility. Each of these individuals was chosen based on four central criteria: the individual had a physical disability; the individual's disability fluctuates in its visibility, be it situationally-based, physically-based or aide-based; the individual's disability is permanent; and the individual's disability does not involve a sensory-impairment[2].

Over a six month period (July 1992 to December 1992), nine organizations were approached to assist in locating individuals with disabilities. These included a number of disability-related organizations [Multiple Sclerosis Society of Canada, Muscular Dystrophy Association of Canada, Arthritis Association of Edmonton, Premier's Council on the Status of Persons with Disabilities, and the National Educational Association of Disabled Students (N.E.A.D.S.)] and two educational institutions [Northern Alberta Institute of Technology (N.A.I.T.) and Alberta Vocational College]. Advertisements were also placed in the volunteer section of a community newspaper [The Edmonton Examiner] and posted at a recreational facility for individuals with disabilities [A.C.T. Recreational Center] (See Table 1.0 for timeline of promotions). My direct experience with having a disability assisted in validating the project with the organization officials and facilitating access to participants. While a sufficient number of individuals were located, this promotion strategy did not yield the number of volunteers expected (See Table 1.0). The best response came from individuals who were contacted on my behalf (i.e., all of those contacted on my behalf by an organization official responded and returned the questionnaire), and the poorest response came from postings in disability-related facilities. The other two advertising strategies (advertising in publications and distributing letters to individuals) attracted a moderate number of participants in comparison. In retrospect it seems that having officials at each of the organizations contact individuals on my behalf would have improved the response rate. As well, distribution of a variety of advertisements (i.e., more personal, more detailed) may have attracted a greater number of volunteers. Two sample advertisements follow. The wording varied only slightly from organization to organization.

Table 1.0 Timeline of Promotions

ORGANIZATIONS APPROACHED TO ASSIST IN LOCATING PARTICIPANTS	MONTHS • Advertisement in Publication - Advertisement Posted in Office • Letters Distributed to Individuals ^ Individuals Contacted on My Behalf										NUMBER OF RESPONDENTS (who returned questionnaire)
	07	08	09	10	11	12	01	02	03	04	
Multiple Sclerosis Society of Canada	•		•								10
Muscular Dystrophy Society of Canada		^									7
Premier's Council on the Status of Disabled Persons					-			•			1
Arthritis Association of Edmonton						•					1
N.E.A.D.S.		•									0
ACT Recreation Center				-							0
The Examiner		••		•	••						11
Alberta Vocational College			•								1
N.A.I.T.		•	•								2
INTERVIEWING			X	X	X		X	X	X	X	Total = 33

Figure 1.0 Long Version of Advertisement

HELP NEEDED FOR A RESEARCH PROJECT

Sherry Peters is a researcher with a physical disability at the University of Alberta, who is working towards a Master's degree. For her research project, she is exploring the situation of other individuals who also have a disability. She is looking for individuals with a physical disability who would be willing to help with her research by talking about some of their experiences. If you are interested in helping, you will be asked to fill out a very short questionnaire. After the questionnaires have been received, some individuals will be asked to take part in an interview. The interviews may be conducted in your home, if you wish, or at a place and time that is acceptable to you. If you would like to participate or if you have any questions, please call Sherry at 484-0463.

Figure 1.1 Short Version of Advertisement

HELP NEEDED

A researcher at the University of Alberta is looking for individuals with a physical disability who would be willing to talk about their experiences. For more information call Sherry at 484-0463.

Forty-five individuals responded by phone to these promotions and were asked about the nature of their disability. Five individuals (2-sight impaired, 1-hearing impaired, 1-did not have a disability, and 1-child) did not fit within the criteria used for selection of participants and therefore were not asked to participate. To ensure that these five respondents remained positive about answering the promotion, the general objective of the study was explained and great appreciation was expressed for their response. Forty adults who seemed to fit the general criteria were asked to complete a short questionnaire (See Figure 1.2), which was mailed to them with a self-addressed stamped envelope. Of the forty questionnaires, thirty-three[3] were returned (82.5%). These provided the general characteristics of those who responded, whether or not they were later selected for an interview (See Appendix A). More importantly, the

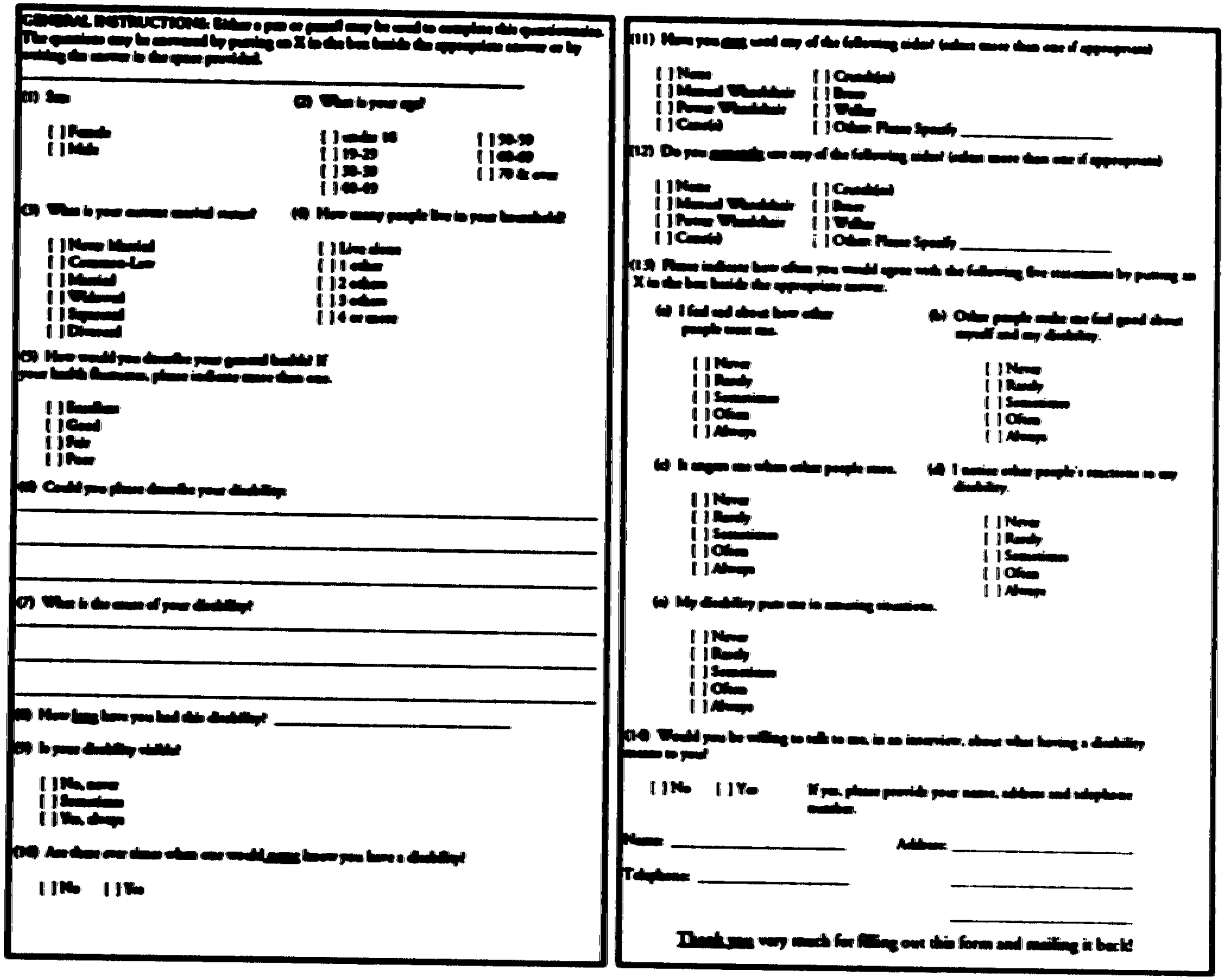


Figure 1.2 Questionnaire (reduced size)

questionnaires were used to determine the nature of the individuals' disabilities and their suitability for interviewing.

In addition to the individuals' descriptions of their disabilities, four questions were specifically included on the questionnaire to provide general information about fluctuations in the visibility of the individuals' disabilities (See Figure 1.2: questions 9-12). Although the exact nature of the individuals' disabilities could not be determined until the first interview, several responses would suggest that a fluctuating nature is present. For example, a *Sometimes* response to question nine would suggest that the visibility of their disability fluctuates. Similarly, a *Yes, always* response to question 9 together with a *Yes* response to question 10 suggests that the visibility may fluctuate in some way. Likewise, any discrepancy in response to questions 11 and 12 shows a change in the mobility aides an individual has used - a change in visibility. On the other hand, an individual that responds that they have never used and do not currently use a mobility aide, as well as responding negatively to question 9 -*No, Never*- and positively to question 10 -*Yes*-, does not likely have a disability that fluctuates in its visibility. The individuals' responses of these four questions, a summary of the nature of their disabilities, and my judgment as to whether or not the individual has a disability 'sometimes', follows in Table 1.1. Of the thirty-three respondents, 72.7% (24/33) appeared to have a disability that fluctuates in visibility.

While I was looking for a homogeneous group that all had a permanent disability that fluctuates in visibility, the questionnaire was designed to allow the differences between participants within this group to be maximized. Question thirteen (See Figure 1.2) was included in the questionnaire to ensure that enough information was retrieved from the respondents to maximize their differences in the selection process. Nonetheless, sufficient variation was found across the nature of the individuals' disabilities so that question thirteen was not used for selection purposes.

The respondents' answers to these five statements were useful during the interviews as a way to help the individuals to recall and reflect on a variety of experiences (See Appendix B for the respondents' answers).

Table 1.1 Questions Used to Judge if the Individual has a Disability 'Sometimes'

PARTICI-PANTS	DESCRIPTION AND\ OR CAUSE OF DISABILITY	QUESTIONS 9	10	11	12	DOES THE INDIVIDUAL APPEAR TO HAVE A DISABILITY 'SOMETIMES'?
1	Leukemia Necrosis of Hip Joints	Yes, always	No	Manual Wheelchair, Cane(s), Walker	Cane(s), Walker	Yes
2	Failed Back Surgery Syndrome	Sometimes	Yes	Crutch(es), wheeled bed	Crutch(es), wheeled bed	Yes
3	Leg Amputee (both)	No, never	Yes	Manual Wheelchair, Cane(s), Walker	Manual Wheelchair, Cane(s), Walker, Prosthesis	Yes[4]
4	Lupus	Sometimes	Yes	None	None	Yes
5	Muscular Dystrophy	Yes, always	No	Manual Wheelchair, Power Wheelchair	Power Wheelchair	No
6	Spina Bifida	Sometimes	No	Custom-made Shoes	Custom-made Shoes	Yes
7	Muscular Dystrophy	Yes, always	Yes	Manual Wheelchair, Crutch(es), Scooter	Crutch(es), Scooter	Yes
8	Multiple Sclerosis	Yes, always	Yes	Manual Wheelchair, Cane(s), Walker	Manual Wheelchair	Yes
9	Polio	Yes, always	Yes	Manual Wheelchair, Cane(s), Crutch(es), Brace, Orthopedic splint	Orthopedic splint	Yes
10	Muscular Dystrophy	Yes, always	Yes	Brace	None	Yes
11	Whip Lash	Sometimes	Yes	Cane, Brace	-	Yes
12	Muscular Dystrophy	Yes, always	No	Manual Wheelchair, Power Wheelchair, Walker	Manual Wheelchair, Power Wheelchair	Yes
13	Cerebral Palsy	Yes, always	No	Cane(s), Crutch(es), Brace	Brace	No
14	Polio	Yes, always	No	Cane(s), Crutch(es), Brace	Cane(s), Crutch(es), Brace	Yes
15	Poor memory & loss of coordination due to MVA	Sometimes	Yes	Manual Wheelchair, Cane(s), Walker	None	Yes
16	Multiple Sclerosis	-	Yes	None	None	No
17	Multiple Sclerosis	Yes, always	No	Manual Wheelchair, Cane(s), Walker	Manual Wheelchair, Cane(s)	Yes
18	Multiple Sclerosis	Sometimes	Yes	Manual Wheelchair, Power Wheelchair	Power Wheelchair	Yes
19	Multiple Sclerosis	Yes, always	Yes	[illegible]	None	Yes
20	Multiple Sclerosis	-	No	Manual Wheelchair, Cane(s), Walker	Manual Wheelchair, Walker	Yes
21	Multiple Sclerosis	Yes, always	No	Manual Wheelchair, Power Wheelchair, Cane(s), Walker	Manual Wheelchair, Power Wheelchair, Scooter	Yes
22	Head injury due to MVA	Sometimes	Yes	Manual Wheelchair, Cane(s), Crutch(es), Walker	None	Yes
23	Multiple Sclerosis	No, never	Yes	None	None	No
24	Chronic Depressive Disorder	Sometimes	Yes	None	None	No[5]
25	Tumor on Spine	Yes, always	No	Manual Wheelchair, Cane(s)	Manual Wheelchair, Cane(s)	Yes
26	Muscular Dystrophy	Yes, always	No	Manual Wheelchair, Power Wheelchair, Crutch(es), Brace	Manual Wheelchair	No
27	Amyotrophic Lateral Sclerosis	Yes, always	-	Manual Wheelchair, Power Wheelchair, Cane(s), Walker	Manual Wheelchair, Power Wheelchair, Walker	Yes

28	Muscular Dystrophy	Yes, always	No	Manual Wheelchair, Power Wheelchair	Power Wheelchair	No
29	Muscle pain and weakness (cause unknown)	No, never	Yes	None	None	No
30	Multiple Sclerosis	Sometimes	Yes	None	None	Yes
31	Neuro Muscular Disorder	Yes, always	Yes	Manual Wheelchair, Power Wheelchair, Brace	Manual Wheelchair, Power Wheelchair	Yes
32	Rheumatoid Arthritis, Spinal Cord Tumor	Yes, always	No	Manual Wheelchair, Cane(s), Walker	Cane(s)	No
33	Multiple Sclerosis	Sometimes	Yes	Manual Wheelchair, Cane(s), Walker	Manual Wheelchair, Cane(s), Walker	Yes

- No answer given

Although ten individuals were interviewed, only five have been included in this investigation. While the questionnaire was helpful in identifying if the individual had a disability that fluctuated in visibility in any way, it was difficult to establish with complete certainty the nature of the individuals' disabilities prior to speaking with them at length. Two individuals who were interviewed are not included as I was unable to determine until after the first interview that they did not fit the criteria for having a disability 'sometimes'. One of these individuals, a woman with rheumatoid arthritis, had no appreciable change in the visibility of her disability around the time of the interviews, although she had fluctuations in visibility in the distant past. The other individual had been confined to a wheelchair for over ten years without any fluctuation in the visibility of her disability. Another individual, who appeared during the first interview to have a disability 'sometimes', has not been included as a second interview was not possible. Finally, an additional two individuals who were interviewed have not been included in this investigation. One of these women had a great deal of difficulty recalling experiences. She identified this difficulty as a symptom of her illness. The other individual related to me during the first interview that in addition to her physical disability, she has been diagnosed with a mental illness. As I am focusing on individuals who have a physical disability only, she was not interviewed further or included in this study. Therefore, of the ten individuals interviewed, only five have been included in this exploration.

The Five Participants

The five individuals (4 females, 1 male) included in this investigation were found through promotions at the Muscular Dystrophy Association of Canada, Arthritis Association of Edmonton, Multiple Sclerosis Society of Canada, Northern Alberta Institute of Technology (N.A.I.T.), and in The Edmonton Examiner. Initially, I selected only women. While both males and females were appealed to in the advertisements, I found that I was uneasy about interviewing males in their homes and found it inappropriate to request that a person with a disability make the effort to meet me elsewhere. Only one man has therefore been included. He was personally recommended by my contact at the organization, and the interviews were conducted at his place of employment. The participants also vary in age and type of disability. Their ages range from twenty-eight to fifty-four, with most falling between twenty-eight and thirty-eight. Their disabilities include muscular dystrophy, multiple sclerosis, tumor on the spine, and lupus. They were selected based on their appearing to have a disability 'sometimes', as well as trying to include a variety of disability types. The onset of the individuals' conditions or injuries varies from birth to adulthood. Of the five participants, one was single, one was married, one was separated, one was divorced and one was widowed. At the time of interviewing, three of the individuals were employed full-time and two were unable to work. I made no attempt to ascertain the individuals' socio-economic standing. Each of the participants was interviewed at least twice during an eight-month period from September 1992 to April 1993 (See Table 1.2). This group is not representative of the population of individuals with disabilities, nor is it intended to be. There are likely many other disabilities that fall within the category *having a disability 'sometimes'* than the ones explored herein. Although this group is small, it does allow us to begin an exploration of the experience of having a disability 'sometimes'.

Table 1.2 Span of Interviewing

PARTICIPANTS	MONTHS SPENT INTERVIEWING							
	09	10	11	12	01	02	03	04
Donna		XX					X	
Joann						X	X	
Cheryl	X				X			
Paul			X			X		X
Ivy					X	X		

The Interviews

On the questionnaire, the individuals were asked to indicate if they would consent to being contacted at a later time for an interview, and those who responded positively and who were most suitable were contacted for an interview. Following verbal confirmation that both audio-taping and transcription of the interview were acceptable, a first meeting was scheduled. The majority of the interviews took place at the individuals' homes, with several being conducted at one individual's place of employment (Paul). The three interviews with Paul seemed to some degree different than those with the four women. While he was positive about participating in the project and willing gave his time with each request, Paul kept me at a distance in the way he spoke about himself (i.e., he talked less about his feelings) and kept the interviews short. For Paul and another participant (Donna), the interviews lasted between half an hour and one hour. As a result, I spoke with Paul and Donna on three occasions rather than two. The interviews with Donna were kept short as she tired easily. For the other three participants (Joann, Ivy and Cheryl), each interview lasted between one to two hours. Overall, I gathered a great deal information from the participants about their experiences in these two to three interviews. While the participants would likely have been able to tell of more of their experiences if interviewed again, it was felt that the extensive amount of data collected was more than adequate for this exploration.

All interviews were tape recorded for verbatim transcription at a later time. While verbatim transcriptions of all interviews were made, the quotations included herein have been slightly modified by removing repetitive words and other non-meaningful expressions such as 'Mm' that occur naturally in speech. Although I have not included indicators of hesitations, pauses or drawn out words made by an individual, words that were strongly emphasized by an individual are italicized and repetitive words have been left in when they are important to the meaning. As this analysis is not linguistic in nature, it is more important to preserve clarity of meaning than a faithful representation of utterance. Several of the quotations reported in this study include my question to the interviewee or probes made during their response. Again, these were included only when they are needed for the reader to fully understand the individual's account. As well, in the original transcription of the interviews, punctuation was largely omitted as the individuals' speech was in many instances continuous. Punctuation was included only at points where the individuals made a definite pause as they spoke. As this lack of punctuation makes it awkward for the reader, punctuation has been added to the passages to separate the individuals' thoughts. To illustrate, the two following quotations are the same passage, first the original transcription and second with punctuation added:

> [P]eople will open the doors more if I'm using the scooter than if I'm walking I think generally older people are more *rude* like they will be the ones that are staring more... (Cheryl, I: 214-218)[6].

> [P]eople will open the doors more if I'm using the scooter than if I'm walking. I think generally older people are more *rude*, like they will be the ones that are staring more... (Cheryl, I: 214-218).

Throughout, I have sought to maintain the individuals' meanings.

In order to allow the participants as much room as possible in discussing their experiences, general interview questions were used (See Appendix C). The questions focused on issues pertaining to the individuals' disability-related experiences with others and their own feelings towards their disability. The wording and order of the questions varied with each interviewee and depended on their particular disability. In general, the interview questions encouraged the participants to relate their experiences chronologically beginning with the onset of their disability. The participants were also asked to describe their experiences within specific environments (i.e., work or school) and with specific others (i.e., relatives or strangers). While the interview questions were flexible to allow for variation in the interviewees' responses, all of the interview questions were posed to each of the participants at some point. Overall, my interviewing technique improved with experience, and with each individual I was able to question and probe more effectively during the second interview.

While I expected, and came across, few problems getting the participants to talk openly about their experiences with others and their feelings about their disabilities, several participants had times when they found it upsetting to continue telling their story. At these moments, the tape recorder was turned off and the individuals were told, following a few moments of silence, that they did not need to continue if it was too painful. While several of the individuals took a few minutes to regain their composure, each of them wished to continue despite the difficult nature of many of their reflections. Paul was less visibly shaken as he talked about his experiences and was less able to discuss in detail his feelings about the others' responses. Overall, my having a disability assisted in authenticating the project with the participants. One of the individuals commented that she thought I could "totally relate" (Ivy, I: 1241) to the experiences she was telling me.

As discussed previously, while ten individuals were interviewed for this investigation, only five of these fit the criteria for inclusion. This fifty percent loss, as well as the extensive time necessary for interviewing and transcribing the interviews, played a role in the decision to conclude interviewing. As well, it was felt that "saturation" (Glaser and Strauss, 1967) or finding no new data which alters the nature of a category was ultimately unattainable as each new individual in fact brings with them a number of unique or additional characteristics which would need to be subsequently explored. Finally, as this investigation has been exploratory in nature, it was felt that ample data had been collected from the five individuals to begin to understand the experience of having a disability 'sometimes'. The decision to conclude interviewing was then made by myself and my committee following the tenth interview.

Data Analysis

Individuals with an injury or condition that fluctuates in visibility were asked to talk about their disability and their experiences in relation to their disability, including the reactions of others and their feelings about others' reactions. Through an analysis of this experiential data, I sought to determine if there was a pattern. A social, rather than medical perspective, was taken. While a medical approach emphasizes the limitations and restrictions physically disabling injuries or conditions have on normal functioning (Altman, 1981; Ladieu, 1948; Langer et al, 1976; Rumsey, 1982), a social perspective recognizes both the limiting and liberating impact of definitions and evaluations that arise out of one's social interactions (Hahn, 1988; Phillips, 1985, Russell, 1989). My approach, then, is based on the theoretical principles of symbolic interactionism. I am assuming, like symbolic interactionists, that an individual *actively interprets* others' actions and this interpretation influences the individual's self-understanding.

My central source for procedures in analyzing qualitative material came from Glaser and Strauss' (1967) work The Discovery of Grounded Theory: Strategies for Qualitative Research and Strauss and Corbin's (1990) work Basics of Qualitative Research: Grounded Theory Procedures and Techniques. Glaser and Strauss' grounded theory, founded in symbolic interactionism, provided a strategy to my exploration. Data analysis began with writing notes and identifying categories during the first interview transcription. These first coding efforts quickly became overwhelming when the number of code words reached sixty-nine. Upon realizing that such detailed coding was unmanageable, more general codes were selected. Five general categories were used:

(1) Evaluations (cognitive) of Self
(2) Evaluations (cognitive) of Disability
(3) Reactions to Others
(4) Feelings (emotional) towards Self/Disability
(5) Experiences involving Others

Each interview was systematically coded using these five categories. The concept 'distancing', which is a central theme in the experience of having a disability 'sometimes' and will be explored at a later point in this work, became increasingly important as the analysis progressed. As I coded sections of interview data with the code word *feelings towards self/disability*, I began to see that the individuals distanced their disability from their self. This finding was an inherent part of the five generalized code words. That is, I found myself separating the individuals' evaluations of their self from their evaluations of their disability (See 1 and 2 above) as the individuals' themselves separated their evaluations of these two aspects in telling their story. 'Distancing' was also one of the categories identified in the original but abandoned coding attempt. As well, despite attempts to explore other themes in the individuals' experience, I kept returning to 'distancing' with each individual. After seeing that each of the individuals 'distanced' their disability from their self in some way, the twelve interviews were systematically read and coded for every instance of 'distancing'. These general sections of 'distancing' data were then selectively coded and refined into types, following which links began to emerge between 'distancing', the individuals' fluctuating visibility of their disabilities, and the changing responses of others. During the general coding of 'distancing', the category 'connecting' was also "discovered" (Glaser and Strauss, 1967), systematically coded and refined in a similar manner. As the analysis progressed, my strategy centered around re-reading, reflection and discussion with others.

Researcher's Role

Like many researchers before me, I am pursuing an investigation that has developed out of a personal experience. I am an individual with a disability exploring the experience of having a disability. Consequently, my "subjectivity is simultaneously enabling and disabling" (Peshkin, 1985, 278). As a result of my personal involvement, my research interests must be placed within their context, which is my disability and my experiences as an individual with a disability. While "the norms of scholarship do not require that researchers bare their souls, only their procedures" (Lofland and Lofland, 1984, 8), clarification of my own situation is necessary to achieve a complete understanding of this research.

My search began with many questions: Am I disabled or non-disabled? How can I be both? How do I feel about myself when I am one or the other? How do other individuals respond to me at these times? How do their responses make me feel about myself? Are my experiences unique? While these questions at first seem puzzling, they have been relevant to my experiences over an eight year period of time and continue to be relevant. My disability, a fused hip and partial sciatic nerve palsy that are the result of a car accident, leaves me with difficulties in walking, balance and an inability to sit for extended periods of time. To others, I have a disability . . . sometimes. My injury has fluctuated quite significantly in both severity and visibility over the past eight years and continues to do so today. It can shift from highly visible to largely invisible and the reverse. This shift can occur from one moment to the next, like when I change my gait to ascend a flight of stairs. While I currently limp only slightly as I walk, I am unable to climb stairs "normally": I must go up one stair at a time, and this often attracts the attention of others.

While I am not studying a group engaging in ongoing social interaction in which I can participate, I am an "insider" in that I have a disability 'sometimes'. My personal experience gives me a degree of sensitivity and insight into the experiences of others, which is otherwise unattainable. It is likely that approaching this investigation from one's own direct experience will yield an understanding of the subject matter that is wholly different than the analysis made by a researcher without the personal experience. Charmaz (1990) states that "an over-riding interest in one concept such as stigma, or, for that matter, in one specific chronic illness, fundamentally shapes the later analysis" (1165). While it may be the case, this need not be thought of as a negative evaluation of my personal involvement. Rather, as Douglass and Moustakas (1985) suggest, a passionate involvement in a topic or subject of study enriches one's "pursuit of essential meanings connected with everyday human experiences" (39). Glaser (1978) likewise highlights the positive value of a personal interest in a topic of study: "The most fun comes in studying a personal life-cycle interest. It is automatically consummatory, since the analyst's vitality is consumed by what he might find out that informs and helps him personally" (28). As my disability affects both the questions I ask and the interpretations I make, my role as a researcher cannot be separated from my disability.

Critics, however, find that "perspectives acquired as a consequence of demographic characteristics such as age, sex, ethnicity. . ." (Borman et al, 1986, 45) and, in this case, disability are impediments to inquiry. While it is clear that all researchers bring "baggage" with them into the research process, the inferential difficulties that come with personal experience with a research topic undoubtedly multiply as one's involvement deepens. For this investigation, I have asked the participants to reflect on their past experiences and to verbally or narratively take me through some of them. Following this, I analyzed their stories within my own system of meanings as a researcher and an individual with a disability. The reality that emerges from this analysis is undoubtedly a "product of an interaction between the researcher and the phenomena under study" (Turner, 1981, 228).

Everyday experiences and special interests have often inspired researchers to pursue qualitative investigations of a particular topic or subject. These researchers can be categorized based on one central dimension, that being their involvement. This involvement-distinction is not one of being involved or not involved. Instead, it is a distinction in the degree or extent of one's involvement. For many, their involvement is superficial. Davis' (1959) cab driving experiences do not continue to be an active part of him. Neither do Schmidt's (1979) travel agent 'adventures'. Davis' and Schmidt's experiences are not ongoing. Others find themselves exploring a subject that is more intimate. Roth (1974) used her hospitalization with tuberculosis as "an opportunity for on-the-spot observation of social interaction in an institutional setting" (347). Krieger's (1985) part in and study of a lesbian community stemmed from her personal involvement in the community. All of these experiences, however, lack a permanent visible, or at least permanently 'sometimes' visible, feature that affects one's reception in the social world.

This is the essential difference between the relationships of the above writers to their subject matters and my relationship with my research interests. This is true not only of my case, but also those of researchers that are so touched by a personal characteristic such as their gender or race that it leads them to further explore it. All of these, one's disability, gender, or race, are qualities of oneself that are *ongoing*, and often noticeable, throughout one's life time. In her work *From Disability to Handicap: An Inevitable Response to Social Constraints*, Russell's (1989) involvement is similar to my own. She examines individuals' adjustment within a restricting social and cultural context following their diagnosis with multiple sclerosis. While she does not expand on her own perceptions and experiences, Russell does illuminate her perspective by indicating that she herself has multiple sclerosis. However, her direct experience with the subject does not necessarily make her findings more valid than the findings made by one who is less involved: there are many "right" conclusions. It gives the reader a better understanding of how the writer arrived at both the questions and conclusions, which can add to the clarity of the findings, and, in turn, assists others in the continuing search for further understanding. Like myself and the other writers discussed above, Russell is an "opportunistic" (Riemer, 1977) researcher: one that has taken advantage of already being a participant in a subject worthy of study. Like gender and race, disability is not a role one may choose to step into. My position as an individual who has a disability 'sometimes' is one of the most direct-participatory experiences possible. Consequently, while some argue that a researcher's personal characteristics and convictions should not be declared, it would be a mistake to ignore my disability and what it reveals about my exploration. While this is only a fraction of who I am, it is the basis of my research interests.

Chapter Two

HAVING A DISABILITY 'SOMETIMES'[7]

The cultural way of speaking about disability does not include those who appear to *have a disability 'sometimes'*. Rather physical disabilities have customarily been separated into two categories - visible and invisible. This distinction seems clear, as does the distinction between being disabled and not being disabled. As Goffman (1963) identified in his work Stigma, some disabilities simply do not fit into this classification. Several of the notions he introduces in this work are helpful in identifying individuals that *have a disability 'sometimes'* and determining who they are.

Goffman devotes a large portion of his monograph Stigma to a discussion of the experiences of individuals who have a disability that falls between the two extremes "where no one knows about the stigma and where everyone knows" (73): individuals who can "pass" as either. Individuals who have a disability 'sometimes' also fall between these extremes and some "pass" as able-bodied at certain times during the course of their disability. Like Goffman's individuals who "pass", individuals who have a disability 'sometimes' may, but do not necessarily, have control over the changes in the visibility of their disabilities. They may, but do not necessarily, *intend* to pass as "normal". Goffman (1963) expands his notion of "passing" by outlining a "natural cycle of passing":

> The cycle may start with unwitting passing that the passer never learns he is engaging in; move from there to unintended passing that the surprised passer learns about in mid-passage; from there to passing "for fun"; passing during non-routine parts of the social round, such as vacations and travel; passing during routine daily occasions, such as at work or in service establishments; finally, *"disappearance" - complete*

> *passing over in all areas of life, the secret being known only to the passer himself* (79, emphasis added).

He adds that "some discreditable attributes preclude the final phases of the cycle" (80). This is the case for individuals who have a disability 'sometimes' for whom "complete passing" is not possible as their disability *will* reappear or change in visibility at some point. If an individual's disability becomes invisible to others, as with Goffman's person who completely passes, they do not have a disability 'sometimes'. Likewise, an individual no longer has a disability 'sometimes' if their disability remains visible and constant in how it is visible: these individuals have a disability 'always'. The experiences of those who have a disability 'sometimes', 'always' or 'never' in the eyes of others are not necessarily identical. Unlike individuals whose disability is unchanging in its visibility to others, individuals who have a disability 'sometimes' *lack consistency in the appearance of their disability.*

In addition to individuals who can "pass", individuals who are *unable* to "pass" as able-bodied may also have a disability 'sometimes'. Instead of finding that their disability changes from visible to entirely invisible or the reverse, these individuals find that their disability becomes less visible or more visible. For those who are not physically able to conceal their disabilities, they may "cover" (Goffman, 1963) their disabilities to "keep the stigma from looming large" (102) rather than pass. Nonetheless, individuals who have a disability 'sometimes' do not necessarily attempt to "cover" or "pass", nor are they necessarily able to do so. They are to some degree confined by the bounds of their disability.

More recently, Conrad (1987) explores "dimensions of illnesses" in his article *The Experience of Illness: Recent and New Directions* and refers to the continuum of visibility:

> Surely there are differences among illnesses as to how hidden or visible they are to others. Illnesses probably fall on some kind of continuum

> with completely visible illnesses such as a skin disease or severe cerebral palsy on one end through *partially visible* ones - MS and Bell's Palsy, for example - in the middle, to completely invisible ones such as epilepsy and hypertension on the other end (26, emphasis added).

Rather than "partially visible", the middle of the spectrum from visible to invisible would more appropriately seem to be "sometimes" visible and its counterpart "sometimes" invisible. Individuals with both of the illnesses that Conrad gives as examples of 'partially visible' - multiple sclerosis and bell's palsy - do find that the visibility of their disability changes with periods of exacerbation and remission. These disabilities are highly visible sometimes and less visible or invisible at other times. As a result, individuals with both of these types of disabilities may find that they have experiences comparable to others who also have a disability 'sometimes'.

While interest in the experience of having a disability is growing, exploration of the experience of having a disability 'sometimes' have been overlooked in the search to understand what it means to be disabled in our social world. Nonetheless, other writers have touched on aspects of this experience in their examination of a particular illness or within the general framework of disability. For example, one of Lonsdale's (1990) illustrations of the experiences of women with disabilities reveals women who have a disability 'sometimes':

> Some women felt that public attitudes towards them and the response they got from people improved if they were well-dressed or if they were sitting down...Debra, who generally had to move by using a wheelchair but who could still stand, said she felt other people's attitudes were completely different towards her when she was sitting than when she was standing (145).

Likewise, Corbin and Strauss (1987), in their investigation of managing chronic illness, refer to a fellow with parkinson's disease who indicates he has a disability that fluctuates in visibility. His "ability to function physically varied from day to day and *sometimes* quite drastically within a day" (263, emphasis added). Furthermore, Brooks and Matson (1987) even go so far as to suggest in their article *Managing*

Multiple Sclerosis that the "*special* difficulty of MS is that all concerned are required to reinterpret reality continually as symptoms unpredictably appear and disappear" (100, emphasis added). Not to minimize in any way the struggles one faces with having multiple sclerosis or any other illness or injury, individuals with a *variety* of kinds of disabilities must cope with fluctuations in the visibility, and possibly severity, of their disabilities.

Individuals that have a disability 'sometimes' find that their disability fluctuates between the extremes of visible and invisible. The fluctuation may be from visible to invisible, from highly visible to less visible or the reverse of either. The fluctuation may involve a change in the *degree of disability* (e.g. an individual's disability may go into remission with the disability becoming invisible), *circumstances* (e.g. an individual's disability may become less visible if they are sitting rather than standing) or *environment* (e.g. an individual's disability may become more visible in certain locations such as a recreation facility). The frequency and extent of changes in the visibility of one's disability are of course unique to every individual. As well, not all individuals with any particular injury or condition will have changes in the visibility of their disability. While some individuals with multiple sclerosis, for example, find that their disability fluctuates in visibility, not all individuals with multiple sclerosis necessarily will. In this regard, Conrad (1987) suggests that '[i]t is difficult to make sociological distinctions among chronic illnesses because so many illnesses have severe and mild forms or different stages or execerbations [sic] which would place them in different categories" (26). It is the experiences of just such a group that I am interested in - those who have a disability that fluctuates in visibility. The focus is on the common experiences of the individuals and on the changes in categories within which the individuals fall. Ultimately, the category *having a disability 'sometimes'* allows for meaningful comparisons across *many* kinds of disabilities, all of which *lack consistency in visibility*.

In the five brief vignettes that follow, we will further explore the nature of having a disability that changes in how visible it is - a disability 'sometimes'.

The Case of Donna

Donna, a woman in her late thirties who was diagnosed with multiple sclerosis seventeen years earlier, finds that "every day is different. Some days I feel a little bit more loose and relaxed and able to get around more, and other days I feel like...my whole body is hurting...Every day is different" (I: 655-664). As a result, she uses a number of different mobility aides depending on her need for assistance, including a wheelchair, arm crutches, walker and cane. While her disability varies in the way it is visible as she alternates the aide she is using, Donna also has times when her disability is invisible. She explains that as she is not "physically twisted up or crippled that you can see, people have a hard time believing it, if I had a cast they would even give me sympathy but they don't see it" (I: 169-172). She further illustrates her predicament of having a disability 'sometimes': "when I go to a parking lot at a shopping center and I park in the disability (stall), I stand up, get out of the car and everybody gets dirty looks and whatever you know because I'm young, what do I need a disability (stall for) cause I can stand and I should be wheeled in a chair or something" (I: 889-895).

The Case of Joann

Joann is a woman in her early thirties who was diagnosed with lupus a year and a half earlier. Her limping changes with fluctuations in her illness and includes "days when I don't have one kind of you know, where I don't have a visible limp" (I: 2051-2052). On the days when her lupus symptoms are diminished she is able to "pass" as able-bodied without any change in how noticeable her disability is for the particular individuals she encounters:

> I guess a positive experience I went out to the mall the other day and I was there for about six hours which is incredible for me...I had a

> *wonderful* day, I was really feeling good and I didn't feel sick so in all the stores that I went to and all of the clerks that I talked to, it was just as if I was healthy. (I: 2053-2061).

While they don't last, she cherishes these non-visible times in the course of her disability. The visibility of her disability also changes after she rises from a seated position. One example follows:

> You go in a nice restaurant and you're all dressed up and...I get up and go to the washroom, I feel like there are probably a few people who might be watching, staring, watching me limp to the bathroom and here I look like a fairly healthy young woman all dressed up in a nice restaurant and there I go limping off to the bathroom (I: 902-909).

Joann finds that her disability can entirely shift from invisible to visible.

The Case of Cheryl

Cheryl is a woman in her late-twenties who was born with a non-progressive form of muscular dystrophy. The most common type of change in visibility of Cheryl's disability occurs with a change in mobility aide between elbow crutches, which she has used since she was a child, or scooter. Her disability is more often visible than not due to these aides, as well as her small stature. Cheryl feels that her disability is always visible to others "unless (she is) sitting the whole time" (Q). In this regard, she has had several experiences with others in which her disability becomes visible after a period of being invisible. She recalls being out at a nightclub with friends when "somebody would ask me to dance or something and most of the time like I'd just say 'No thank you' but sometimes they're so *persistent*, just can't take no for an answer, so fine and I'd get up and then they're then they're *shocked* eh like you can actually see the look on their faces just the shock" (I: 251-257). She finds such "shock" on the part of others sufficiently unsettling that she has since made a point of putting her "crutches some place that's easily visible so that somebody isn't gonna mistake it or not know that I am disabled" (I: 473-475) preferring that her disability remain visible rather than risk sudden exposure.

The Case of Paul

Paul, a man in his fifties, began losing feeling in his legs five years earlier as a result of a tumor on his spine. For the past two years he has interchanged using a wheelchair and two canes. He explains that he tries to walk, rather than use his wheelchair for short distances, but he has "more mobility when I'm in my chair. I couldn't go very far with my canes, my physical endurance wouldn't allow me to do that." (I: 188-190). While he uses his canes less now than at the onset of his tumor, he continues to use both the wheelchair and canes. He recalls two specific types of experiences where the other individual did not realized he has a disability. He explains that strangers have on occasion been offended when he loses his balance and accidentally falls against them - until they see the canes:

> I'm still not very stable so I can fall against somebody and they sort of take offense to that, and I can understand why cause you don't want to touch other people, and so when that happens they sort of say 'What are you doing?' or look at you with a scowl and then they realize 'oh I'm sorry I didn't realize you're disabled' and are very apologetic about it (I: 804-808).

Similarly, he remembers standing in a crowd of people boarding a city transit bus, with other individuals' being highly impatient at his moving slowly onto the bus. Their impatience ceased though once they saw his canes. Paul's exchange of wheelchair for canes is at times visible to others, with there being "*absolute* dead silence" (I: 945) from a group of strangers on one occasion as he rose from his chair.

The Case of Ivy

Ivy, a woman in her late-twenties, has a form of muscular dystrophy that was diagnosed soon after birth. While this type of muscular dystrophy is often degenerative, she feels it has largely "stabilized" (I: 58). Ivy wore braces on both legs throughout her childhood until approximately four years ago. While she always tried to conceal them, her braces would become visible to others at times. At other times, she deliberately wore only one brace feeling that one was less stigmatizing than two:

> I'd just wear one brace, then it was ok because just one that just looked, see this is so stupid I can't believe I thought this, I just looked kinda cool because you probably just had an injury or something cause that's not so odd, I mean that's not so uncommon to just have one you know, but then two make you look like a real gimp <laugh> (I: 1417-1422).

Although she no longer wears braces, she still has a limp. She recalls that new acquaintances don't always notice her limping the first time they meet. For instance, with starting a new class in college, one of her new classmates did not recognize her disability the first time they met: "[I]in the second class this girl says 'Oh Ivy's limping. What did you do?'" (I: 271-272). In fact, as her disability has been less visible much of the time, Ivy reflects that friends would sometimes "forget" about her limitations. She remembers the times she was left behind at the top of a set of stairs: "If it's not an incredibly noticed disability like you're not in a wheelchair...people tend to just forget...just leave you behind and you are left standing there" (I: 259-265).

As illustrated in the preceding sketches, fluctuations in the visibility of one's disability take a number of forms. As was discussed previously, they may be a result of a change in the individual's *disability* or the *circumstances* or *environment* within which the individual finds themselves. It is important to see that these individuals can be identified further on two dimensions. First, there is the *degree* of fluctuation in visibility, as certain individual's disabilities will fluctuate in visibility to a greater or lesser extent than others. For example, individuals who are compelled to use a mobility aide at all times, but who can change the kind of aide (i.e., Cheryl, Donna and Paul), obviously have less fluctuation in the visibility of their disability than do those individuals who do not use an aide (i.e., Joann and Ivy). A second important distinction concerns the *frequency* of the fluctuations in the visibility of the individuals' disabilities. Fluctuations may occur from moment-to-moment, day-to-day, month-to-month and the like. There are of course limits outside of which an individual's disability does not fluctuate in visibility to any appreciable extent. For example, an individual whose disability changes in visibility only once every five years may have a number of experiences to do with this fluctuation for a relatively brief period of time following the change but this will not last for any substantial length of time. Their experience is largely that of one whose disability is unchanging in its visibility. Along with differences between individuals, any particular individual's disability may change in the degree and frequency of fluctuations in visibility. One final characteristic of the disabled individuals being investigated must be specified. The disability of focus is permanent rather than temporary. While a temporary disability may fluctuate in visibility, the impact of differential categorization and evaluation on the temporarily disabled is entirely different from that of the permanently disabled. Not only are their responses incomparable, but the temporarily disabled also behave differently than the permanently disabled. As Levitin (1975) notes: The temporarily disabled are "active, often aggressive, in making certain they are not given a label and role that has social consequences far more serious than those of a temporary stigma...[and] see that the normal has no opportunity even to contemplate such a label." (552).

Despite the variations between the individuals, all of the individuals in this investigation have had at least one experience in which the other individual did not realize they had a disability and then it became apparent. Each of their disabilities has entirely shifted from invisible to visible: they have all "passed", be it intentional or unintentional. Most importantly, they share the three following characteristics:

(1) The individual has a physical disability.

(2) The individual's disability fluctuates in its visibility, be it situationally-based, physically-based or aide-based.

(3) The individual's disability is permanent.

My focus is not based on there being a before- and after-disability. Of the five individuals who have a disability 'sometimes', two have had their disability since birth while the other three acquired a disability at a later point. This is not to say that there are not differences between these two groups. Certainly disabling injuries and illnesses that occur later in life necessitate a notable modification of one's self, while adjustment to disabilities that are present at birth, or soon there after, is more gradual (Buscaglia, 1983). The selection of interviewees was based upon the three central characteristics or criteria outlined above.

Chapter Three

SOCIAL CONTEXT OF HAVING A DISABILITY 'SOMETIMES'

As one moves about the social world on a daily basis, one encounters many individuals including strangers, acquaintances, and significant others. Each individual in this investigation told of differential responses to their disability from the others they encounter. One of the women explained that her "good friends...they're there right from the start, that's why it's really sad you know my friends and my family <choked up> you know your friends you can choose right, your family you're stuck with" (Donna, I: 708-710). While the nature of the relationship between individuals is often important to the impact of the others' feedback on one's self-understanding, in all relationships the others' responses are always mediated by one's *perceptions* of those responses. The impact of the feedback from others is therefore indirect. I am concerned only with the relationships and the 'other' as they are *perceived* by the disabled individuals. As we examine some of the five individuals' experiences with others during times of visibility, times of invisibility, and times of change in visibility, the complexity of having a disability 'sometimes' is clear.

Times of Visibility

All individuals who have a disability 'sometimes' have occasions when their disability is visible to others. Rejection underlies many of these experiences. Cheryl recalls several of these experiences as she reflects on others' responses to her and her disability. One memorable experience follows:

> In one situation...I was coming up the elevator and they were both two older ladies, and we got on at the same time and we pushed the buttons and everything, they were behind me and usually people let me get off first cause I can't hold the door open you know [reference to using two crutches], so they let me off first, *not* these two, they pushed by me and...as they went by this lady said 'Oh I didn't even realize that was a little cripple', and I thought...like *how rude* how how rude...That just that that really hurt, I guess the ignorance hurt like did they think I was deaf too (I: 1608-1623).

While this incident occurred several months previously, it remains vivid in Cheryl's memory and she finds herself "upset about it even now" (I: 1625). Several of the stories Paul relates are similarly disturbing:

> I went to Toronto the airport, my family was with me so I was traveling with somebody else, and when it came time to go through the metal scan thing and the wheelchair can bypass that, I wasn't with my canes but the attendant there turned to my wife and said 'Well can he stand up?', and so you know you feel rather bad about that cause why couldn't he ask me and then he said 'Well does he have a ticket?', you know we're all traveling together, sure we got tickets and I said you know like that is kind of humiliating, and that has happened a couple of times when we've gone to places and the airport was the most *obvious* one you know, it's a situation where people look at you because you're in a wheelchair, you have other disabilities as well, and you know that's unfortunate that happens but you feel a little bit put down and so you get resentful maybe of the person (I: 728-743).

> I go to restaurants sometimes and I don't take my chair because they can drop me off at the entrance, and then you can go from the entrance to sit down in the chair, well the fact is the chair that they want you to sit in is at the other side of the restaurant and like I *why* do you have to sit me at the other side of the restaurant? why can't it be why can't you sort of just make it convenient for sit me here, cause you go past a number of empty chairs -Sherry: Mm hm and you have your cane so they see?- oh ya so they see it and yet they sit you at the *far* end of the restaurant, and from that standpoint you're sort of saying well why can't are they sitting me back here, because of my disability? or are all these other chairs reserved? but I don't know, it doesn't say reserved on them so why do that? people are different I guess, they set you off in a location (I: 1255-1269).

On these two occasions, the feedback Paul received from other individuals to both his canes and wheelchair seem equally rejecting. This is not always the case as we will see in the following sections.

Times of Invisibility

While it would seem unlikely that times of invisibility would bring rejection from others, the circumstances or environment influenc_ the responses of others to the invisibility of an individual's disability. Donna, for example, uses some kind of aide at all times but still momentarily "passes". On a number of occasions, she has received a negative response from others for the moment before her aide becomes visible:

> ...when I go to a parking lot at a shopping center and I park in the disability (stall), I stand up, get out of the car and everybody gets dirty looks and whatever you know because I'm young, what do I need a disability (stall for) cause I can stand and I should be wheeled in a chair or something, and then I open up my back door, pull my chair out, then I take off and they 'huh?', they can't believe it you know (I: 889-896).

The circumstances - a parking stall for persons who have a disability - require that Donna's disability be visible to others in order to validate her use of it.

Change from Invisible to Visible

Several of the participants in this study recount experiences that involve a change in the visibility of their disability with it becoming visible after a period of being unnoticed. For Cheryl, the profound impact of receiving a negative response to such a change in the visibility of her disability is well-illustrated in the experience she relates. She explains that while out at a nightclub with friends,

> somebody would ask me to dance or something and most of the time like I'd just say 'No thank you' but sometimes they're so *persistent*, just can't take no for an answer, so fine and I'd get up and then they're then they're *shocked* eh like you can actually see the look on their faces just the shock...I don't know, it makes me mad in a way because I'm the same person as I was sitting down, but now all of a sudden they've got this whole different attitude, this whole different perspective of me (I: 251-268).

Goffman (1963) writes of just such a situation: "[H]e who passes [as able-bodied] leaves himself open to learning what others 'really' think of persons of his kind...when they start out not knowing but learn part way through the encounter and sharply veer to another course" (84). Although Cheryl sees herself as "the same person" (I: 265) with or without the disability, having a man get a "whole different attitude" (I: 266-267) after seeing that she had a disability was sufficiently unsettling that she has since made a point of putting her "crutches some place that's easily visible so that somebody isn't gonna mistake it or not know that I am disabled" (I: 473-475). Joann relates that she too has on occasion sensed a change in the other individuals' awareness of her disability as her disability becomes noticeable. One such experience, which took place at an intimate family get-together, follows:

> If I get up (from the dinner table) and I'm having a bad day and I have to limp to the bathroom, it's almost this imperceptible thing (or) communication going around, and even if I've told them I'm having a bad day, they're all of a sudden faced with it, it's one thing for me to be sitting across the table and look fairly healthy and fairly active, and then it's another for me to get up and start limping or that kind of thing where it's a more visible thing, and then it kind of hits them in the face 'Oh ya she is sick'" (I: 930-939).

She reflects that her "self-esteem goes down a little bit...really being self-conscious about how I look or even a little sorry for myself" (I: 1744-1746) following a change in the visibility of her disability from invisible to visible. Like Cheryl and Joann, Ivy is acutely aware of a difference in others' behavior that corresponds with changes in the visibility of her disability: "You do notice the difference with the braces with the visual thing and without...strangers I think are more apt to come up approach you or not shy away from you...I think people tend to not [approach] somebody who's got a real visible thing like that" (I: 488-500). At times when her braces would become visible after being hidden, Ivy recalls feeling "so *incredibly* self-conscious" (I: 876-877) as the other person would stare.

Change in the Kind of Visibility

Three of the participants' experiences with having a disability 'sometimes' involve a change in the *kind* of visibility of their disability as they vary the side they are using. Cheryl finds that there is not the same "negative connotation" (I: 1689-1690) attached to the scooter as there is to the crutches:

> I think like a scooter to other people is almost a toy like it almost like it doesn't have the same *stigma* attached as say a power wheelchair or a manual wheelchair, like I get a lot of comments from people...they'll ask how far does that go? or how fast can it go? or isn't that you know makes it easy to get around or I wish I had one. Don't ever hear someone say...'I wish I had crutches' <laugh> (I: 607-618).

To Cheryl, others' sociability is clearly tempered at times when she uses crutches. As with Cheryl, many of Paul's experiences involve a change in the kind of visibility of his disability as he is compelled to use either a wheelchair or canes. He has found that the responses of others often differ when he uses the canes compared to the wheelchair, with him being "somewhat less in their eyes than I would be if I was standing tall" (I: 279-280). He reflects that unlike the wheelchair, "canes seem to be quite common...when you're in a chair, it's I think they feel that you're more debilitat(ed) than when you're upright" (I: 342-343). He further explains that acceptance into a group does not happen to the same extent if you are not "standing tall":

> [C]anes are not as pronounced because your stature your line of site is higher, when you're in a wheelchair the thing that happens lots of times, people do not see you in their line of sight and...when you go through go to go through a crowd you're constantly saying 'excuse me you know can I get by?' and they sort of look at you as if ya ok if you're just passing by it's not something that's '*Oh hi* Paul, how are you doing?', but other people can walk up to them who have the same line of sight when they're standing and even though they don't know them, they are more readily accepted into the group (I: 889-899).

Like Paul who relates that "there's something *quite* different about a wheelchair than there is about canes" (I: 1325-1326) for others, Donna observes that others "notice [her walker] more than the cane and not as much as the wheelchair" (I: 1496-1508).

While it may or may not be what others intend, and while the feedback from others varies for each individual, these five participants' narratives reveal experiences of rejection, which come in the form of scrutiny, apprehension, exclusion and insults on the part of others. In her investigation of the experiences of twenty-four individuals with a physical disability, Coleman (1989) reports that "the stories they [the disabled individuals] relate about encounters with others do not reveal many supportive, accepting or nurturing responses" (69). Rather she heard stories of "rejection". The impact of rejecting feedback can be great. Cheryl, for example, explains:

> if people made more of an effort to make eye contact or to say good morning or whatever, like I'm talking about strangers, people that don't know me, then I suppose that would make me feel better about myself, but when you look at somebody and they look away right away, well that doesn't leave you with a very good impression (I: 684-691).

Other individuals unquestionably play a role in the individuals' acceptance or lack of acceptance of their disabilities as a part of their self. Nonetheless, the participants in this investigation do describe others as supportive and understanding at times. One of the women, for example, relates the response of individuals at her church to her changing the aide she was using:

> *Donna:* I think I must of got a few comments about me using the walker now or whatever, but I can't really remember cause the people that do talk to me there [at her church] like they know my condition or whatever and they're not so abrupt as to mention any minor change or whatever so they just...
>
> *Sherry:* Abrupt like who?
>
> *Donna:* Like some people like they don't have to tell me everything they notice, they'll say something positive you know or they just say oh you know they're glad you could come or whatever but they don't say anything like derogatory (I: 1686-1696).

Donna's experience is not always that of rejection, and each of the other four individuals have such stories to tell. Joann, for instance, cherishes others' lack of awareness when she is able to "pass" as able-bodied, and the feedback from others is that of indifference. She explains:

> [T]here are days when I don't have one kind of you know, where I don't have a visible limp...I guess a positive experience I went out to the mall the other day and I was there for about six hours which is incredible for me...I had a *wonderful* day, I was really feeling good and I didn't feel sick so in all the stores that I went to and all of the clerks that I talked to, it was just as if I was healthy...I it's like I don't expect I'm not waiting for that shoe to drop, I'm not waiting for that 'Oh sprained your ankle?' you know that kind of innocent remark that they kind of make about why you're limping or those kind of things, so

> there's not gonna be a remark like that cause I'm not limping you know, so I don't wait for that extra little remark or little stare out of the corner of the eye, I don't look for it, I don't expect it (I: 2051-2071).

She finds such experiences rejuvenating. The responses these individuals receive from others are in fact ever-changing: at times rejecting, at times embracing and at other times indifferent. As Goffman so fittingly states "acceptance is conditional" (Goffman, 1963, 120). Nonetheless, this is the case for all of us with and without a disability: we all receive a variety of reactions from those around us, possibly including some of the ones described herein.

It is the very fact that individuals who have a disability 'sometimes' *lack consistency in the appearance of their disability* that makes having a disability 'sometimes' unique and makes the ever-changing responses of others perplexing. Having a disability that is unwavering in how it appears to others gives one some degree of continuity in their experiences and enables one to anticipate others' responses to a greater extent than one who lacks this continuity. As we all search for consistency in our social experiences, individuals who have a disability 'sometimes' must struggle all the more. *Uncertainty* is an inherent quality of their experiences, and as we have seen, it is a major factor in the social experiences of individuals who have a disability 'sometimes'. While this concept is not new to the exploration of having a disability (See Brooks & Matson, 1987; Bury, 1982; Conrad, 1987; Lubkin, 1986; Strauss et al, 1984; Webster, 1989; Wiener, 1975), the breadth of its meaning expands with reference to having a disability 'sometimes'. Not only are individuals who have a disability 'sometimes' *unsure* of how they will be received by others, as are all individuals with a disability (Goffman, 1963, 13-14; Lubkin, 1986, 67), their uncertainty is compounded by changes in the visibility of their disabilities and corresponding changes in the appraisals of others. To further understand the impact of others' ever-changing responses, as well as the impact of having a disability that fluctuates in visibility, we must look into the disability-self dynamics reflected in the individuals' experience and the issue of acceptance.

Chapter Four

'CONNECTING' AND 'DISTANCING' AND THE ISSUE OF ACCEPTANCE

There is considerable agreement between writers that one's self is constantly changing throughout one's life (Markus and Kunda, 1986; Markus and Wurf, 1987; Mead, 1934; Swann and Hill, 1982). Buscaglia (1983) concisely explains the essence of, and evolution of, one's self:

> Every individual has a perception of self. This self picture is made up of the vast amount of personal characteristics which comprise the person's identity. This identity concerns notions one has about one's body, mind, abilities and *disabilities*, likes and dislikes, together with a limitless number of personality characteristics one has learned, such as being loving, demanding, accepting or rejecting...One learns who one is from individual firsthand experience, from shared experiences with others, or through implied actions and covert feelings. One is continually amalgamating new learning with old knowledge and forever integrating it into an ever changing concept of self (172, emphasis added).

While an individual with a permanent disability must relate to their disabling injury or illness in some way, investigation into the link between one's disability and one's self has begun only recently and remains exploratory in nature (Charmaz, 1987; Conrad, 1987). Two central questions have emerged out of the stories told by the five participants in this investigation: what are the disability-self dynamics for an individual with a physical disability that fluctuates in how visible it is to others? how do these dynamics relate to acceptance-nonacceptance of one's disability?

As they talk about their disabilities, each of the five individuals interviewed 'connects' and 'distances' their disability in relation to self. These patterns may be seen as points along a continuum with 'distancing' at one end, 'becoming' at the other end and 'connecting' somewhere between. Although none of the individuals in this investigation were found to have 'become' their disability with their disability being fused with their self, each of them does 'connect' their disability to themselves in some way. They each regard it as a *part* of self: "part of the total package" (Cheryl, I: 894); "part of me now" (Donna, I: 397); "it's a part of yourself, it's a part of part of who you are" (Ivy, I: 1373-4); and "part of who I am" (Joann, I: 1208-9). In this respect, Yoshida (1993) in her "pendular reconstruction of self" identifies an outcome she calls "disabled identity as part of the total self", which parallels 'connecting' one's disability and self. She explains that the disabled identity is seen as "one aspect of the person, as opposed to encompassing or nearly encompassing the total self" (227-28). Several of the interviewees further indicate that their disability is *only* a part of them. They are not suggesting that they are not disabled, rather that in addition to the disability they remain themselves. Donna, for example, explains that "I'm still the same person" (I: 1610-1611) and Paul reflects that "even though I have some inabilities, I'm still a fantastic type person" (I: 853-854). While their disability is a part of them, they have not 'become' their disability. Cheryl is the most articulate in this regard: "having a disability is only one part of me, there's a lot more, and it bothers me when that's *all* that people look at to make up their mind about what kind of person I am" (I: 780-783).

Although each of the individuals in this investigation 'connects' their disability to themselves to some degree, each of them 'distances' their disability from themselves to a much greater extent. Ways of 'distancing' one's disability are many and varied: (1) attempting to hide one's disability, (2) not 'noticing' others' reactions to one's disability, (3) not telling others the true nature of one's disability, (4) telling others about disability to 'get past it', (5) disregarding one's disability as part of one's self, (6) longing to be 'normal' and 'blend in', (7) despising one's own reflection, (8) blaming one's disability, (9) emphasizing recovery, (10) rejecting one's own group, (11) other 'distancing' statements. A description of each of these follows:

1. Attempting to Hide One's Disability

Two of those interviewed 'distance' their disabilities from themselves by hiding, or attempting to hide, their disabilities from others. For the most part, Ivy and Joann are the only ones who are in a position to hide their disabilities, as Cheryl, Paul and Donna are compelled to use a mobility aide of some kind at all times. Joann and Ivy have in fact been intent upon hiding their disabilities from others throughout much of their time with a disability. Joann explains that she has "little techniques to try to cover it up so that people wouldn't notice" (I: 820-822). For example, to avoid limping after sitting for an extended period of time at a restaurant, she tries to "look like I'm adjusting my clothes or putting on a sweater, and what I'm really doing is stretching my legs, testing them out and seeing how strong they are so that I don't limp" (I: 269-272), or at a movie theater, she waits "until everybody else files out and I can file out at the end crippled and limping" (I: 1026-1028). Trying to 'distance' herself from her disability comes from a fear of rejection from others:

> I hate the idea of people looking at me and thinking of me as a young healthy woman, and then seeing me limp down the hallway or limp to the washroom or limp out of the restaurant, and then 'Oh that poor girl. What's wrong with her?' you know, I don't I don't I don't want that pity, I don't want people saying 'Oh that poor girl', I do still hide it, I've got my ways of kinda getting around it (I: 273-279).

She believes that others will " have this second opinion or have to re-think or re-evaluate what they think" (I: 1162-1164) about her once they know of her disability. As a result, Joann refuses to use any mobility aides even though she admits to needing assistance at times. She prefers "not to make [her] disability visible" (Q):

> I've always I've refused to use a cane, when I thought in the back of my mind I think well I really probably could've got around a lot better if I'd had a cane for some of those bad days, but I just I couldn't do that, I wanted to make it as least obvious as possible, that the less I could rely on an external kind of crutch or facilitator (I: 1152-1158).

Joann further reflects that her refusal to use an aide is "[be]cause it's visible, ya ya I think I'd have to be pretty sick to even think about getting a [disability] sticker or parking in a [disability] stall" (I: 1715-1716). Coleman (1989) in her investigation of the experiences of twenty-four individuals with multiple sclerosis similarly found that some of the individuals made an "active effort to deny the existence of MS" (36) by resisting the use of a mobility aide. Coleman cites one woman: "The cane reminds me about the disease - so I shove it under my desk where I won't see it". (36) Goffman (1963) likewise explains that "since the physical equipment employed to mitigate the 'primary' impairment of some handicaps understandably becomes a stigma symbol, there will be a desire to reject using it" (92).

Although Joann's desire to conceal her disability is for some writers part of the "initial stage of adjustment" (Wright, 1983, 117) as she was diagnosed less than two years earlier, Ivy, who has had a disability since birth, has maintained an obsession with hiding her disability from others since she was a child. While Ivy no longer wears leg braces, she was compelled to wear plastic ankle-to-knee braces from childhood until her mid-twenties. For over two decades, then, she struggled to hide them from others' sight. She would "wear a pair of socks over top of them [so that] people couldn't tell, you know you couldn't see...I'd always make sure my jeans were long enough so that when you sat down because people would stare, it was *so* obvious...and as soon as you sit down, people look, and they notice right away" (I: 300-316). As well, she never wore dresses or shorts as they would make her braces visible: "I wouldn't hike in shorts cause I wouldn't show my braces with the shorts, and it's a drag, it's like thirty above out and your wearing *jeans*" (I: 366-368). If she did go to the beach in a swimsuit, it was without her braces:

> [G]oing swimming [or to] the beach, it was really hard to do that because I couldn't walk well...it just wasn't fun because I didn't have my braces on you know, and you go to the beach and you're in your bathing suit or shorts, I just couldn't walk and it was just such an effort to, it was easier not to go (I: 369-376).

Ivy responds with intense distaste to the following question: "If you had to wear your braces now, would you be really concerned about people seeing them?" (I: 327-329). She unconditionally rejects her braces in her response:

> Oh wow I that would be really awful, that would be *really awful*, ya isn't that funny cause I was thinking about that the other day for some reason well and probably because if I'm having trouble walking or something...one person would always say 'Well maybe you should did you ever think about wearing your braces?', *'I'm not going to do that'*, and I mean it's just such a force like whenever I react like that to something somebody says *'That's a stupid idea,'* I know that's pushing some button in me like and that would ya I I I can't even comprehend that thought now, it gave me such a *incredible* sense, I hate to say it changed my life, but it really did (I: 330-342).

In this regard, Brooks and Matson (1987) identify acceptance of an mobility aide as "a clear indication to self and others that physical limitation has become a *significant part of one's life* " (92, emphasis added). By separating themselves from visible mobility aides, both Ivy and Joann are 'distancing' themselves from their disabled-identification and thus their disabilities.

As well as being a form of "stigma management" (Goffman, 1963) and a "normalizing tactic" (Davis, 1961; Strauss, 1975), hiding one's disability may also be an attempt to physically 'distance' oneself from the negative feedback of others towards one's disability. While she is no longer compelled to wear leg braces, Ivy continues to avoid participating in activities, such as skiing, that make her disability more noticeable:

> I notice I don't like to do things that where I feel that make my disability more pronounced, things like I just sort of learned how to cross-country ski and I'm obviously not very good at it...and I'm never going to be an Olympic champion <laugh> you know, but I just would like to get to the point where I can just stand up and I was, but next weekend we're supposed to this friend of mine is getting all these other friends together to go away for this ski weekend or whatever you want to do right, and like I want to go, but part of me is very hesitant because it's *such a visible thing* then, and like I'll I feel like I'll be not on display but it's different doing it with one or two friends who know that if I fall down, it's not just a matter of well get up you know or like it will just be so much more pronounced, like I'm not sure I even want to try that in front of all those people (I: 905-921).

Even without her braces and with the "incredible sense of freedom and confidence" (I: 344-345) that came with the elimination of her braces, Ivy continues to 'distance' her disability and the response of others to her disability. Nonetheless, she also finds herself somewhat relieved once others have "noticed, then I don't have to hide it or I don't have to try to hide it or what's the use of trying to hide it" (I: 1142-1143). While Conrad (1987) maintains that "although [passing] may insulate the self from the reactions of others, it cannot protect the self from one's own doubts of competence and identity" (12), it would seem that insulating oneself from the harsh reactions of others may do just that. It may insulate one from some of the "reality" of one's disability. Nonetheless, for individuals who have a disability 'sometimes' the effort of hiding one's disability is futile because these individuals' disabilities will become visible again: this is the nature of having a disability 'sometimes'.

2. Not 'Noticing' Others' Reactions to One's Disability

As we saw previously, an individual with a visible physical disability will invariably receive negative responses from others. As Cheryl reflects on the negative feedback she has received from others towards her disability, she repeatedly comments that she does not "notice people's reactions [or] even pay attention" (I: 114-116). Nonetheless, she is able to go on at length about specific negative responses. For example, at one point in the interview, Cheryl states that she "ignores" other people's reactions to her disability yet she continues on to explain the intricacies of others' avoiding eye contact with her:

> *Cheryl:* [A] lot of times I don't make eye contact with people in the hallways, like say we've got a long way to walk from my office to where the washrooms are and I'm always walking to and fro//
>
> *Sherry:* This is at work?
>
> *Cheryl:* Yup and I would say I would say that when I make eye contact with people they are usually women and they either they smile first...and you know that's fine, and I find most of the men don't

> want to make eye contact or they look away as soon as I meet their eyes, they look away (I: 654-666).

While Lubkin (1986) argues that "[w]ell-adjusted individuals who feel comfortable with their identity, have dealt with stigma for a long time, and choose not to invest much effort in responding to the reaction (of others) may disregard it" (68), by not 'noticing' others, Cheryl is shielding herself from other's response and thus 'distancing' her disability from herself. While Cheryl permits herself not to think about others' negative response by not 'noticing', Joann "purposely" (I: 978) tries not to notice the reactions of others. She explains: "If I get up and go to that washroom, I won't look at anybody else. I'm afraid of finding people staring at me <choked up> so that's why I rarely notice because I don't want to notice if people are staring <very choked up>" (I: 978-982). Joann deliberately tries to protect herself from others' staring, further 'distancing' herself from her disability. By shielding themselves from others' responses, Cheryl and Joann can shield themselves from the presence of their disability.

3. Not Telling Others the True Nature of One's Disability

As two of the individuals describe their experiences, they reveal another form of 'distancing': not telling others the true nature of one's disability. In both these cases, the women are disowning their disabilities. Joann explains:

> [T]he first year or so I couldn't even say the word lupus, I had I would make up 'Oh I have a form of arthritis', cause people might understand that. I didn't want to go into all the other symptoms cause there are just so many and it's so internalized you know, it's not like a broken leg that people can kind of relate to, arthritis some of them can relate to, so I tended to use that as an excuse, call it a form of arthritis (I: 1183-1190).

She reflects that she thought telling them I have lupus "would somehow change their view of me" (I: 485-486). While she understands that her inability to tell others the true nature of her illness is unhealthy (I: 225-229), Joann relates that she still has difficulties with this at times: "I still sometimes get embarrassed if I'm limping and 'Oh did you sprain your ankle?', no I have arthritis, sometimes I even fall back into that instead of saying no I have a disease called lupus" (I: 684-687). Likewise, Ivy has often avoided revealing the true nature of her disability to others. For much of her life, rather than say she has muscular dystrophy, she would tell others "'Oh I hurt my knee'" (I: 274-75). She "just couldn't handle the fact of telling people I had muscular dystrophy" (I: 285-286). Overall, the information these individuals choose to conceal about themselves and their disabilities depends on their relationship with the other person. Joann, for example, strives to conceal her illness "mostly with people that I don't know or I'm just kinda starting off with almost where I think I'll never see them again. People that I want to have that I think I'll have a relationship with or want to get to know or are gonna be part of my life for sometime, I guess want them to know about it" (I: 1215-1220).

4. Telling Others About the Disability to 'Get Past It'

Joann deliberately omitted telling others the truth for a period of time after the diagnosis of her disability and remains unable to at times today. She also 'distances' herself from her disability by taking the opposite strategy: telling others about her disability to "get past" (I: 575) it. She explains:

> I've met these people for the first time, I'm going for dinner, I'm not afraid to tell them more or less my whole medical history because I want them to understand that that's just my medical history, that I'm positive about where I'm at and who I am and those kinds of things, so they can get past the disability. (I: 571-576).

Joann's "voluntary" (Goffman, 1963, 100) and deliberate disclosure allows her to 'get past' her disability rather than putting herself under the pressure of having to hide it. She relates being able to speak about the nature of her disability with acceptance: "until I was able to say verbalize what I had, I wasn't owning up to it <choked up> and I found once I was able to do that, there was a big change as well, cause all of a sudden I could talk about it and I came to accept it and that was a big turning point for me" (I:

225-229). In this regard, Goffman (1963) further explains that the individual "can come to feel that he should be above passing, that if he accepts himself and respects himself he will feel no need to conceal his failing" (101). In his work *Deviance Disavowal: The Management of Strained Interaction by the Visibly Handicapped*, Davis (1961) identifies a behavior by which the disabled individual tries to "encourage the normal to identify with him...in terms other than those associated with imputations of deviance" (127). He calls their effort to make their disability a less important factor "breaking through" or "normalizing". While Joann's telling others about her disability to "get past it" may serve as a coping mechanism such as Davis describes, together with the other 'distancing' strategies Joann engages in, telling others about her disability to "get past it" allows her to further separate or push her disability from herself.

5. Disregarding One's Disability as Part of One's Self

As two of the individuals articulate their situations, they disregard their disability as part of their self. Joann separates herself from her illness in this way several times. For example, she relates that with meeting new people, "it's like starting on fresh ground and they just accept me for who I am without knowing anything about my past [meaning her illness]" (I: 349-351). She again 'distances' her disability from herself as she tells about her anger at being ill. She clearly expresses the division: "I don't think it's [angry] at myself, I think it's [at] this stupid lupus" (I: 839-840). This boundary between one's disability and self is likewise clear for Cheryl. While others admire Cheryl for her strength in dealing with her disability, Cheryl would rather they admire her for one of her "personal qualit[ies]", of which her disability is not included. Furthermore, although she is employed working with individuals who also have a disability, she 'distances' her disability in her reflection that she "never particularly wanted to work only with people with disabilities or to be not really well known as somebody with a disability" (I: 771-779).

6. Longing to be 'Normal' and 'Blend In'

For several of the participants, longing to be "normal" is a component of 'distancing' their disability from their self. This aspect of distancing is evident in Paul's moving from his wheelchair to a 'regular' chair in his office. While he maintains that he moves to an office chair for "exercise" and "relief", Paul is aware of the message his conduct sends to others:

> I suspect and I only you know as much as I said they didn't seem to treat me any different, but I sort of suspect that when they see you in a normal chair, they don't have the same fear, there seems to be a fear about chairs like people don't want to I don't know whether close is the word but you know there's sort of a barrier around a chair like it's something that tells them that there's something wrong, whereas a normal chair certainly 'Well at least he can get out of his chair' you know like I sort of sense that, and I don't know nobody's ever said anything but you can really sense that in people's mannerisms (I: 1706-1716).

Paul's desire to show others that he has "normal" abilities is again evident as he tells of opening doors himself rather than using electric doors: "it's kind of an kind of an ego thing for me to say 'Hey like I *can* open the doors, I *can* do this, I don't need the electric doors'" (I: 1616-1618). Paul in fact downplays his disability while emphasizing his previous athletic abilities at many points as he tells about his experiences. He repeatedly refers to his disability as merely an "inconvenience" (I: 143, 297-298, 573, 630) while interjecting throughout the interviews that he was "quite athletic" (I: 14, 28, 593, 615-623) prior to the onset of his symptoms. Joann likewise longs to be "normal". She relates that when she is out with her boyfriend she is especially conscious of not wanting to "stick out":

> I guess I don't want people thinking even feeling sorry for him 'Oh that poor man got saddled with that woman and she's *so sick* and all he has to do is look after her and he can't do anything' and you know that kind of stuff, I'm afraid of that happening, people thinking that or so when I'm with him, it's different, that I'd like to appear more normal...or not disabled (I: 757-764).

She also finds solace at social functions with other individuals with disabilities where she "blends right in" and feels she has "less wrong" with her (Joann, I: 1537; 1479;

1012; 2049), and at functions with older individuals where she sticks out "cause I didn't have gray hair <laugh> I didn't stick out because of my physical disability" (I: 1480-1481).

7. Despising One's Own Reflection

Another form of 'distancing' one's disability can be found in Ivy's passionate refusal or inability to watch herself on videotape:

> I saw this videotape afterwards and you know I saw about I bet I watched thirty seconds of it and I just it was like I was so repulsed like I I you know it was such a *strong* emotion like I just I like I can't even watch this, I just left I mean I couldn't watch it, I couldn't bear to see myself walk and I was so embarrassed that other people were watching this, and obviously they were watching me walk too (I: 1056-1064).

As she explains her difficulty with her own appearance and the visibility of her disability when it is reflected back to her, Ivy further separates herself from her disability.

8. Blaming One's Disability

Cheryl further separates her disability from her self as she places "blame" (I: 357-370) on her disability for the fact that she has never had a boyfriend. After asking Cheryl to describe how she feels about herself, she explained:

> That's a hard question. I know that I'm a good person, I've got good qualities, I'm positive try to be as positive as I'm a lot more positive than a lot of people, I like the fact that I'm concerned about other people, I try to help other people, caring, honest and have good values, I guess that the only area I I've never had a boyfriend and that's something that bothers me, and I don't know if that's because of the disability if you need to blame my disability and yet I can't think of any other reason why I *don't*, because I am a carrying person and I think I have a lot of qualities that somebody would be looking for in a mate (I: 357-370).

Ivy similarly implicates her disability for her lack of a partner as she poses the question "who's going to want to go out with a little crippled girl?" (I: 667). After being asked what she thinks this says about her, Ivy reflects that it shows she is "*very very* *insecure*" (I: 674). Phillips (1990) relates similar stories and passages in her article *Damaged Goods: Oral Narratives of the Experience of Disability in American Culture* to illustrate her informants' perceptions of being "damaged goods". In their accounts, both Cheryl and Ivy regard themselves as defective or "damaged".

9. Emphasizing Recovery

Joann's emphasis on future recovery is another way she 'distances' her disability from her self. In her article *Struggling for a Self: Identity Levels of the Chronically Ill*, Charmaz (1987) identifies as emphasis on recovery as a "restored self" identity in which the individual expects that "*recovery* should be the *sequel* to illness" (301). Although it may be suggested in Joann's case that her emphasis on recovery is an artifact of her diagnosis being fairly recent, this dimension is intimately tied to some of those who have a disability 'sometimes'. Joann explains:

> I'm looking forward to going into remission and that's I guess the one thing with this disease, there's a good chance that I could go into remission where I can be very healthy or fairly healthy and not have as many symptoms, and so to me the future is only getting better (I: 1109-1113).

Like many others, Joann has had periods of remission in the course of her illness, which encourages her to consider recovery her goal.

10. Rejecting One's Own Group

Each of the participants 'distances' themselves from their disability by rejecting their own group - other individuals with disabilities. For several of them, this strategy was found in the form of rejection of specific others who also have a disability. For example, Cheryl distances or alienates herself from her disability by finding that men with disabilities are unsuitable dates:

> I've thought about this and that and talked to other people about whether disabled people should go out with other disabled people and I've always said 'No there's no way', and I think *that* says a lot about how *I* view disabled people because I'm not like to me it's like 'why should I

> have to settle for someone whose disabled?', like cause that was my attitude and sometimes it still it's I sometime go back and forth (I: 382-391).

She later adds that she has "been socialized in this world too" (I: 1786) meaning that she has many of the same negative attitudes towards individuals with disabilities as do the non-disabled. Ivy similarly rejects a coworker who also has a disability:

> *Ivy:* This fellow at work that I was saying that with the disability and the brace and stuff, he's the nicest guy and he's a real big sports fan, I don't have a lot of none of my girlfriends like sports so you just can't talk sports with them <laugh>, and I I would never I would shy away from going places or walking with him, because I think that people would my disability would be so much more noticeable, which is really I I *don't like* feeling that way, I mean I think it's wrong.
>
> *Sherry:* But still?
>
> *Ivy:* Um ya I still think of it but I don't shy away from him or I don't I mean I'm getting over it cause I really realize like that's really that's a silly way to think and it's bad and it's not it's not a good thing, it's not a nice emotion you know it's not, and I mean that's what people would do to me in school kinda you know guilt by association or whatever, like you're going to catch it type of thing.
>
> *Sherry:* And what do you think feeling like that says about how you feel about the visibility?
>
> *Ivy:* Obviously that it's something to be ashamed of, which and it's not and there's some things you can say in your head you can tell your like in your head you know this like you know, but that reaction says something else and things like that are *so so* hard to change and you just have to work so hard at changing them, but you know something like that I mean I have to change that (I: 1423-1450).

Goffman (1963) explains that "the sight [of another with a stigmatizing feature] may repel him, since after all he supports the norms of the wider society, but his social and psychological identification with these offenders holds him to what repels him, transforming repulsion into shame, and then transforming ashamedness itself into something of which he is ashamed. In brief, he can neither embrace his group nor let it go" (108).

Downward social comparison is another dimension of rejecting one's group. In this regard, Joana repeatedly comments that other individuals with lupus that she knows have been "through a lot worse than I have" (I: 602) and "have it a lot worse off than I do" (I: 855). She explains how this helps to reassure her:

> I'm usually again either in the middle or you know at the top end of being more well right, I have less wrong with me almost and so then I feel less sorry for myself, there's less self-pity involved, it's like look what have I got to feel sorry for you know, I could be a lot worse off, this girl's got her toes cut off and she can only get around on crutches or you know this guy's gonna be in a wheelchair all his life, those kinds of things so then you phew quit get off the bandwagon and start getting on with my life, it's a better feeling too I guess. So I don't really ya being with other disabled people it's kinda a reality check (I: 1547-1557).

Ivy also boosts herself by derogating other individuals with disabilities, albeit a disability that is different from her own. As she explains that other individuals sometimes confuse muscular dystrophy with multiple sclerosis, she states that "multiple sclerosis is *much worse* in...some ways" (I: 949-950). Likewise, Donna and Paul downwardly compare themselves with others as they acclaim their "luck" with their disabilities. Donna reflects that she is

> one of the lucky ones because I can still walk, I can even take a little bit of steps with nothing. I'm lucky also that I don't have constant pain, I've never had constant pain like some people do, just when I walk and push myself too hard, then I have pain and I know what it's like, at least I can sit down, put my feet up, relax and I'm out of pain, so I don't have to live constantly with it. I take no medication unless like I get a headache or something (I: 125-162).

Paul similarly downwardly compares himself with others as he explains that he has handled his disability better than others:

> I think the most important thing that I have been very strong willed. I have sort of psychologically trained myself, whether this is true or not, the doctors tell me this that I should be a. a higher pain area than I'm at, and yet I've had no pain from day one even in the operation, I had no pain, I had no medication, I'm not on medication, I don't take any medication, I don't want any medication and as a result of that I have said that you know just because of my strength then I will cope with this in the best way I can...I will try and carry on even though I have some inconvenience, so that's I mean that's an important factor because [I] know a lot of people that have had a problem and they've sort of given up (I: 614-632).

In addition to boosting one's feelings about one's situation (Taylor, 1983, 27), downward social comparison also further 'distances' one from their disability, other individuals with a particular injury or illness and individuals who have a disability as a whole. Gibbons (1986) explains: "By derogating others like themselves, stigmatized people are derogating the stigma and, to some extent, accepting the societal perception of it" (137). Rejection of one's group is rejection of one's self (Rosenberg, 1979).

11. <u>Other 'Distancing' Statements</u>

The individuals in this investigation make a number of other statements as they describe their experiences that 'distance' their disabilities from themselves. These statements are not as easily categorized as the others, so I include them as further illustration of the 'distancing' strategy: Donna reflects that her disability is the "biggest disappointment in life" (I: 1158); Ivy relates that "it really bothers me to even say that that I limp" (I: 1705-1706); Paul resists using his wheelchair around particular friends as he does not "want to put any more burden on them" (I: 593); After being asked "how much do you think your disability affects what you think about yourself?", Cheryl comments: "Mm I'm sure it has a lot of affect because like I just said having a disability is not generally a good characteristic in the eyes of the public. When you know that people are you know feel that people are looking down on you..." (I: 306-310). Cheryl leaves her sentence unfinished, but its meaning is clear.

In their article *Accompaniments of Chronic Illness: Changes in Body, Self, Biography, and Biographical Time*, Corbin and Strauss (1987) identify the range of integration that exists between 'connecting' with one's disability and 'distancing' one's disability within their concept "contextualization" :

> Illness is only one of many life events, albeit a major one, that can occur, in a person's life. Like other events and their accompanying trajectories, it must be incorporated in [one's] biography...Contextualization is that incorporation. The degree of contextualization of an illness trajectory can vary from 0 to 100 percent. The 0 represents a state of nonintegration: the trajectory exists but is discounted, kept separate from the rest of a biography, it is not 'part of me' [*distancing*]. The 100 represents a state of fusion, the trajectory 'is me' [*becoming*]...For the most part, integration lies somewhere

> between, somewhat part of biography yet not fused with it [*connecting*]. To paraphrase many of our interviewees...: "I have a chronic illness, it is part of me, there is now an ill aspect of self to be added to the others but there is more of me than it" (265).

'Connecting' represents integration, 'distancing' represents some degree of separation and 'becoming' represents amalgamation. While exploration of 'connecting' or integrating one's disability with one's self is fairly extensive, in depth examination of 'distancing' is limited. To further understand the impact of 'distancing' on an individual and the relationship between 'connecting' and 'distancing', we must explore the issue of acceptance.

The Issue of Acceptance

Individuals' assessments of self are influenced by the *perceived* evaluations of others. Despite Swann's (1987) argument that "people rarely develop self-views that are generally negative because their social worlds rarely provide them with feedback that would sustain such views" (1046), both of these factors have been found in the individuals' descriptions of their experiences with others. We have seen that negative feedback is directed towards those with a visibly disabling injury or condition, and we have found that each of the individuals 'distance' their disability from themselves in some way, a less than positive response to an aspect of oneself. In this regard, Hanks and Poplin (1981) suggest that devaluing "reactions [towards individuals with disabilities] may come into play against disabled individuals to distort their conceptualization of self and social reality" (316). Nonetheless, in their understanding of themselves, individuals are not wholly at the mercy of the social world. Swann (1983) explains: "[I]t is grossly misleading to characterize people as passive creatures who watch in wonderment as their self-conceptions are tossed about willy-nilly by the situational pressures that swirl about them" (60). One's understanding of self at any point in time is, in fact, a balance between one's beliefs and assessments of self and the perceived responses of others towards oneself.

As a result of these combined forces, disabled individuals' *acceptance* of their disabilities is a complex issue. For individuals who have a disability 'sometimes', acceptance is further complicated by variation in the visibility of their disabilities and in the feedback from others. A number of writers have concluded that individuals who have "accepted" their disability regard it as one of their many qualities (Brooks & Matson, 1987; Kerr, 1977; Levitin, 1975) as do the individuals in this investigation (i.e., 'connecting'). This raises an important question: Have the individuals in this investigation accepted their disability?

As was explored in this thesis, each of the individuals both 'distances' their disability from their self and 'connects' the two as they relate their experiences. This duality is unmistakable in the second interview with Ivy as she reflects on having given her braces away for research:

> *Ivy*: I took pictures of them...it was really really hard to let that stuff go, like it was *really* hard to to get that away like I almost you know I just almost like no I don't want to do this.
>
> *Sherry*: Why?
>
> *Ivy*: I don't know like I don't know why it was hard...it's a part of your history I guess, maybe it reminded me of in a sense some good times at home when I was young...I think that reminded me of a really nice time, I was really you know I was the baby of the family and quite spoiled, you got a lot of attention, I mean in a way having a disability growing up you got a lot of attention...so maybe that's why maybe they held a lot of good memories for me and it's a part of yourself, it's a part of who you are...
>
> *Sherry*: What did you think of people taking pictures of you with your braces on?
>
> *Ivy*: *Oh God* you don't know -S: Mm?- no no you didn't didn't do that (I: 1357-1381).

At one moment she fondly remembers her braces: her memories of them and of having a disability are part of her. At the next moment, she is repulsed at the thought of having photographs taken of her wearing them. Yoshida (1993) incorporates such a dynamic process into her model based on the experiences of individuals following spinal cord injury. She explains the nature of the pendulum of reconstruction of one's self:

> The [identity transformation] model is constantly in motion as respondents interpret and take action in their world. The fluidity of the model suggest movement between identity views is over a period of time. However movement can conceivable be from moment to moment, situation to situation, or day by day...identity reconstruction is a continuous, evolving dual-directional process" (241).

Webster (1989) also succinctly describes the nature of acceptance: "What I see as the crucial point about acceptance, and the most misunderstood [is that]...acceptance is a process and, in no sense, an event. What acceptance means in daily life is a constantly changing, evolving, and sometimes messy reality...There is no end, no point at which one can say, 'Aha! I have accepted. On to the next task'" (92). Furthermore, Corbin and Strauss (1987) add that fluctuations in one's acceptance may come with changes in the visibility of one's disability, as they do for those who have a disability 'sometimes': "It is also possible, having come to terms with one set of limitations, to return to a state of nonacceptance. This can happen if another trajectory follows, or limitations increase, or a biographical condition changes so that the limitations become more noticeable" (270). As we have seen with each individual in this investigation, the degree of acceptance does vary. While the message given to disabled individuals is that they *must* accept their disability, and acceptance may be the desired outcome for many, it is by no means an end state. For the five individuals studied in this investigation, shifts in acceptance take the form of 'distancing' themselves from, yet 'connecting' themselves with, their disabilities. Although Charmaz's (1983) focus is to a large extent on 'concrete' struggles such as social isolation, living a restricted life, and becoming a burden to others, she finds that "experiencing debilitating illness poses questions about, if not a *direct assault* upon, the self" (172, emphasis added). Likewise, 'distancing' one's disability from oneself is an attack or assault on one's disability and thus on a part of one's self. Although each of the individuals in this investigation 'connects' to their disability to some degree, each of them 'distances' their disability to a much greater extent.

Of the five individuals, Joann clearly exhibits the greatest variety and number of 'distancing' strategies (n=8) (See Table 4.0 for an overview). Paul (n=2) and Donna (n=1), on the other hand, display the least number, with Cheryl (n=4) and Ivy (n=5) falling midway. The variation among the individuals is considerable. It seems that certain 'distancing' strategies allow one to distance their disability from their self to a *greater* extent than other strategies. Likewise, it seems that the level of 'distancing' increases as the number of 'distancing' strategies one engages in increases. It is difficult however to establish a scale or continuum of 'distancing' types to examine either of these propositions. As well, there are a number of possible reasons for the variation in 'distancing' strategies that the individuals display. Firstly, individuals may have a number of idiosyncratic characteristics that lead to this variation, like their coping skills, mood or ability to articulate their story. For example, Paul talked less about his emotions and feelings, and this may have influenced the number of 'distancing' strategies he related as he told his story. While it appeared that he was less able to express these aspects of his experiences than the women participants, the more

Table 4.0 Outline of Individuals' 'Distancing' Types

TYPES OF DISTANCING	PARTICIPANTS				
	DONNA	JOANN	CHERYL	PAUL	IVY
1. Attempting to Hide One's Disability		√			√
2. Not 'Noticing' Others' Reactions to One's Disability		√	√		
3. Not Telling Others the True Nature of One's Disability		√			√
4. Telling Others about the Disability to 'Get Past It'		√			
5. Disregarding One's Disability as Part of One's Self		√	√		
6. Longing to be 'Normal' and 'Blend in'		√		√	
7. Despising One's Own Reflection					√
8. Blaming One's Disability			√		√
9. Emphasizing Recovery		√			
10. Rejecting One's Own Group	√	√	√	√	√

formal nature of the interview setting (his office) may have influenced his openness about his feelings and emotions. Although it does not appear that the variation in 'distancing' strategies relates to the onset of the individuals' disabilities, as both Joann (onset=one and a half years earlier) and Ivy (onset=since birth) demonstrate a high number of 'distancing' strategies and are very different in the onset of their disability, the length of time one has had a disability and possibly the time since the onset of the condition or injury may also influence how one deals with changes in the visibility of their disability and in the responses of others. The individuals' disabilities themselves may also have an affect on the extent to which they go into detail about their experiences, such as with Donna who informed me at the beginning of the first interview that she tired easily and the interview would have to be kept fairly short. As a result of her fatigue, she may have left out some of the details in her descriptions. As well, the individuals' stories may have been influenced by the individuals' intellect, as individuals vary in their ability to know and think and to express their thoughts. Finally, underlying all of the interviews is the individuals' self-presentation; that is, each individual controls what they express about themselves, which may include 'distancing' their disability from their self to a lesser extent than another individual. Thus, examining the variation among individuals did not offer any addition information to clarify the 'distancing' strategy. Overall it is less important to know who 'distances' their disability the most or the least than it is to know generally about strategies of 'distancing' and the relation between 'distancing', 'connecting' and acceptance.

Chapter Five
SUMMARY

While physical disabilities are often divided into those that are visible and those that are invisible, some individuals' disabilities fluctuate between the two extremes. The fluctuation may be from visible to invisible, from highly visible to less visible or the reverse of either. It involves a change in the *degree of disability* (e.g. an individual's disability may go into remission with the disability becoming invisible), *circumstances* (e.g. an individual's disability may become less visible if they are sitting rather than standing) or *environment* (e.g. an individual's disability may become more visible in certain locations such as a recreation facility). Five individuals who have a disability that fluctuates in visibility - *a disability 'sometimes'* - were located through a variety of organizations, facilities and newspaper advertisements to be interviewed about their experience with having a disability. The individuals share three central physical characteristics: each of the individuals has a physical disability; their disability fluctuates in its visibility, be it situationally-based, physically-based or aide-based; and their disability is permanent. The individuals' disabilities include muscular dystrophy, multiple sclerosis, tumor on spine, and lupus.

Over an eight month period, each individual was interviewed at least twice. Each was asked to tell about their experiences with others in relation to their disabilities and about their own feelings about their disability. They told of a variety of experiences with others at times when their disability was visible, invisible, changed from invisible to visible and changed in the way it was visible. While it may or may not be what others intend, and while the feedback from others varies for each individual, these five participants' revealed experiences of rejection, which come in the form of scrutiny, apprehension, exclusion and insults on the part of others - sometimes. The feedback of others that these individuals recalled was in fact ever-changing: at times rejecting, at times embracing and at other times indifferent. The individuals' *uncertainty* with having a disability that changes in visibility is thus compounded by being unsure of how they will be received by others.

As they talked about their disabilities, each of the five individuals 'connected' their disability to their self. To a considerably greater extent, however, each of the individuals 'distanced' their disability from their self, with 'distancing' being an attack on one's disability and thus on a part of one's self. It became apparent as the individuals' experiences were examined that having a disability 'sometimes' encourages one to 'distance' their disability. More specifically, the rejection from others at times of high visibility invites one to *physically* (i.e., attempting to hide one's disability), *intellectually* (i.e., disregarding one's disability as part of one's self, not 'noticing' others' reactions to one's disability, disregarding one's disability as part of one's self, longing to be 'normal' and 'blend in', despising one's own reflection, blaming one's disability, emphasizing recovery, and rejecting one's own group) and *verbally* (i.e., not telling others the true nature of one's disability and telling others about disability to 'get past it') 'distance' their disabilities. While there was considerable variation in the strategies used by the individuals, each of the individuals who has a disability 'sometimes' 'distanced' their disability from their self as they spoke about their experiences with others.

Three central features of the experience of appearing to have a disability 'sometimes' emerged from the individuals' detailed accounts of their experiences: the individuals' disabilities fluctuate in visibility; the feedback the disabled individuals' receive from other individuals fluctuates; and the disabled individuals' self-understanding fluctuates. That these three are related is unmistakable. While I had intended to closely examine the correspondence between the fluctuations in the visibility of one's disability, in the responses of others and in self-understanding (See Appendix D), unraveling the connections between these elements is not within the scope of this thesis. Nonetheless, we are able to conclude from the five individuals' experiences that the fluctuations in the visibility of their disabilities, the fluctuations in feedback from others, and the twofold 'distancing-connecting' of their disability with their self, amplifies the *uncertainty* of having a disability.

While a limitation of this investigation is the small number of participants and disability types from which these conclusions have been drawn, the intention of the project has been accomplished. That was to identify and explore the experience of having a disability that fluctuates in visibility to others. Although many of the conditions and injuries included in the category *having a disability 'sometimes'* have been individually explored, this group as a whole has been overlooked in the search to understand the experience of having a disability. For those striving to assist disabled individuals in their healing and to help others understand the experience of having a disability, further exploration of the uniquely *uncertain* aspects of having a disability 'sometimes' is necessary. 'Having a disability sometimes' is a highly meaningful category of study.

Reflections Back on my Role

As this work progressed, I became increasingly aware of the importance of my having a disability 'sometimes'. The findings of this exploration are very much a blending of my experiences and the experiences of those I spoke with. Throughout, I have analyzed their stories within my own system of meanings as a researcher and as an individual with a disability that fluctuates in visibility. My personal experience with having a disability has inspired, rather than impeded, this exploration. Davis (1973) explains: "to see the world with pure eyes unsullied by prior experience or assumption is, in other words, to see nothing at all, simply because without prior experience we don't know what to look for or what we see" (339). My disability has given me a sensitivity towards the experiences of other disabled individuals and an enduring interest in the pursuit of understanding the experiences of those who have a disability.

The Issue of Trustworthiness

This investigation has both strengths and limitations by which one may evaluate the "trustworthiness" (Lincoln and Guba, 1985) of the inquiry, with the central question for evaluation being 'Can one trust the findings of the study?'. Many aspects of this exploration attest to the dependability of the findings: the researcher's preconceptions were clarified at the outset of the study; procedures by which participants were located and selected, and how the study was conducted (i.e., interview questions) are well-documented; two or more interviews were conducted with each participant; a journal of analysis decisions, questions and impressions was maintained throughout; decisions in the analysis process were discussed with colleagues; negative instances of the central category were searched for, which resulted in the category 'connecting'; confirmation of the meaningfulness of the findings was received from an individual who also has a disability 'sometimes' but did not participate in the study; and indications of the findings were found in other disability-related literature. All of these aspects contribute to the trustworthiness of the results. Nonetheless, there are several limitations: the findings were not checked with the participants of the study; there was minimal "triangulation" (Guba and Lincoln, 1983, 106) (i.e., use of other data sources); and while the categories discussed in this work (i.e., 'distancing' and 'connecting') are fairly well developed, they lack depth. The first two of these are problems with the original study design, while the third reflects the exploratory nature of the investigation.

Other Questions for this Data

Many of the individuals' stories and reflections have not been included in this work. In addition to contextual or background material that was essential to understanding the individuals' experiences and framing their experiences in such a way as to help others understand, there lies clues to unanswered questions about the experience of having a disability 'sometimes'. These questions include: What else is there about the experience of having a disability 'sometimes' that is distinct from the experience of those who have a disability that does not fluctuate in visibility?; Are there gender differences in the experience of having a disability 'sometimes'?; Under what circumstances is one more likely to engage in a particular type of 'distancing' than another?; and How are the various 'distancing' strategies used in one's dealings with friends, strangers and others?.

Future Research

In addition to interviewing individuals with disabilities, there are three other possible sources of data which may help us to understand the experience of having a disability 'sometimes'. The first involves speaking to significant others that surround the disabled individual, such as family, friends or coworkers, about their perceptions and thoughts on the disabled individual's disability changing in visibility. The second, observing interactions between a disabled individual and an other followed by speaking with the individuals involved about their perceptions, feelings and intentions, would also provide another source of data. Finally, a third source, which is supplemental in nature, includes data which may be provided by the disabled individuals in the form of photographs, videotapes, diaries or other such materials. One or all of these three forms of data may extend and enrich our understanding of the individuals' experiences and add another dimension to understanding interactions between disabled individuals and others. These forms of data, as well as further in-depth interviewing of individuals who have a disability 'sometimes', may be used in future research to explore a variety of questions about the experience of having a disability 'sometimes':

- Does having a disability 'sometimes' have an impact on an individual's relationships with loved ones, coworkers, new acquaintances and others?
- Does having a disability 'sometimes' affect relationships with those who have a disability 'always', 'never' or 'sometimes'?
- Does having a disability 'sometimes' have an effect on able-bodied and disabled individuals' views of these individuals as "legitimate" or "illegitimate" disabled persons?
- Does having a disability 'sometimes' have an effect on the individual's view of themselves as a "legitimate" or "illegitimate" disabled person?
- For individuals who have a disability 'sometimes, does their identification with able-bodied and disabled individuals change with fluctuations in the visibility of their disability?
- Does having a disability 'sometimes' have an impact on these individuals role in the disability rights movement or on their making use of specific forms of disability assistance (i.e., self-help groups for individuals with disabilities)?
- Are there developmental stages in the coping history of individuals who have a disability 'sometimes'?
- Are there other 'distancing' types?

In addition to these questions, there is a great deal more we need to learn about the experience of having a disability 'sometimes' and how it affects one's journey in our social world.

FOOTNOTES

[1] While there has been, and continues to be, much debate over the 'correct' language to use with reference to an individual with a disabling injury or condition, and the preference of many is to use the phrase "individual (or person) with a disability" rather than "disabled individual", the former becomes verbose with repetition. In using the latter phrase I am in no way suggesting that the disability comes first and the person second. (See *Dialog*, Spring 1993, Vol. VII, No. 1, pp. 24-25).

[2] For much of the selection, individuals with a sight or hearing impairment in addition to another physical disability were not included. It was felt that such an impairment would influence perceptions: the way that a sensory impaired individual experiences their social world is likely to be different from that of someone without such an impairment. In one case, I found it necessary to relax this criteria. One individual with a partial hearing impairment is included in this study.

[3] 34 returned - one respondent did not want to be interviewed at a later time.

[4] While this individual responded that her disability is "never" visible, it is apparent by her other answers (i.e. that she currently uses a manual wheelchair, cane(s) or walker) that her disability is visible at least sometimes. As she uses a number of different aides, then, she may have a disability 'sometimes'.

[5] This individual was not found to have a disability 'sometimes' due to the nature of his disability as described in questions 6 and 7 (depressive disorder).

[6] Each of the individuals' reflections reported in this thesis is identified as being from their interviews (I) or questionnaire (Q). The numbers which follow indicate the line numbers of the transcription where the passage can be found. Each line was numbered consecutively across interviews beginning with number one for each participant.

[7] A version of this chapter has been published: *Canadian Woman Studies*, Summer 1993, Volume 13, Number 4, pp. 26-27.

BIBLIOGRAPHY

Altman, B. M. (1981). Studies of Attitudes Toward the Handicapped: The Need for a New Direction. Journal of Social Problems, 28(3), 321-337.

Borman, K., LeCompte, M. and Goetz J. P. (1986). Ethnographic and Qualitative Research Design and Why it Doesn't Work. American Behavioral Scientist, 30(1), 42-57.

Brooks, N. A. and Matson, R. R. (1987). Managing Multiple Sclerosis. Research in the Sociology of Health Care, 6, 73-106.

Bury, M. (1982). Chronic Illness as Biographical Disruption. Sociology of Health and Illness, 4(2), 167-182.

Buscaglia, L. (1983). The Disabled and Their Parents: A Counseling Challenge. Toronto: Holt, Rinehart and Winston.

Charmaz, K. (1983). Loss of Self: A Fundamental Form of Suffering in the Chronically Ill. Sociology of Health and Illness, 5(2), 168-193.

Charmaz, K. (1990). Struggling for a Self: Identity Levels of the Chronically Ill. Research in the Sociology of Health Care, 6, 283-321.

Charmaz, K. (1990). 'Discovering' Chronic Illness: Using Grounded Theory. Journal of Social Science and Medicine, 30(11), 1161-1172.

Coleman, P. A. (1989). The Management of Chronic Illness: An Interactionist Investigation of Experiences with Multiple Sclerosis. Ph.D. Thesis. Bryn Mawr College.

Conrad, P. (1987). The Experience of Illness: Recent and New Directions. Research in the Sociology of Health Care, 6, 1-31.

Corbin, J. and Strauss, A. L. (1987). Accompaniments of Chronic Illness: Changes in Body, Self, Biography, and Biographical Time. Research in the Sociology of Health Care, 6, 249-281.

Davis, F. (1959). The Cabdriver and his Fare: Facets of a Fleeting Relationship. American Journal of Sociology, 65, 158-165.

Davis, F. (1961). Deviance Disavowal: The Management of Strained Interaction by the Visibly Handicapped. Social Problems, 9(2), 120-132.

Davis, F. (1973). The Martian and the Convert: Ontological Polarities in Social Research. Urban Life and Culture, 2(3), 333-343.

Douglass, B. G. and Moustakas, C. (1985). Heuristic Inquiry: The Internal Search to Know. Journal of Humanistic Psychology, 25(3), 39-55.

Gibbons, F. X. (1986). Stigma and Interpersonal Relationships. In Ainlay, Stephen C. et al (Eds.). The Dilemma of Difference: A Multidisciplinary View of Stigma. New York: Plenum Press, 123-144.

Glaser, B. G. and Strauss, A. L. (1967). The Discovery of Grounded Theory: Strategies for Qualitative Research. New York: Aldine.

Glaser, B. G. (1978). Theoretical Sensitivity: Advances in the Methodology of Grounded Theory. San Francisco: University of California.

Goffman, E. (1963). Stigma: Notes on the Management of Spoiled Identity. Englewood Cliffs, N.J.: Prentice-Hall.

Hahn, H. (1988). The Politics of Physical Differences: Disability and Discrimination. Journal of Social Issues, 44(1), 39-47.

Guba, E. G. and Lincoln, Y. S. (1983). Effective Evaluation. San Fransisco, California: Jossey-Bass.

Hanks, M and Poplin D. (1981). The Sociology of Physical Disability: A Review of Literature and Some Conceptual Perspectives. Journal of Deviant Behavior, 2(4), 309-328.

Kerr, N. (1977). Understanding the Process of Adjustment to Disability. In Stubbins, J. (Ed.). Social and Psychological Aspects of Disability. Baltimore: University Park Press, 317-324.

Krieger, S. (1985). Beyond 'Sensitivity': The Use of the Self in Social Science. Qualitative Sociology, 8(4), 309-324.

Ladieu, G., Adler, D. L., and Dembo, T. (1948). Studies in Adjustment to Visible Injuries: Social Acceptance of the Injured. Journal of Social Issues, 4(4), 55-61.

Langer, E. J., Fiske, S., Taylor, S., and Chanowitz, B. (1976). Stigma, Staring, and Discomfort: A Novel-Stimulus Hypothesis. Journal of Experimental Social Psychology, 12(5), 451-463.

Levitin, T. E. (1975). Deviants as Active Participants in the Labeling Process: The Visibly Handicapped. Social Problems, 22(4), 548-557.

Lincoln, Y. S. and Guba, E. G. (1985) Naturalistic Inquiry. Beverly Hills, California: Sage.

Lofland, J. and Lofland L. H. (1984). Analyzing Social Settings: A Guide to Qualitative Observation and Analysis. California: Wadsworth.

Lonsdale, S. (1990). Women and Disability: The Experience of Physical Disability among Women. London: Macmillan Education Ltd.

Lubkin, I. M. (1986). Chronic Illness: Impact and Interventions. Boston: Jones and Bartlett Publishers.

Markus, H., and Kunda, Z. (1986). Stability and Malleability of the Self-Concept. Journal of Personality and Social Psychology, 51, 858-866.

Markus, H., and Wurf, E. (1987). The Dynamic Self-Concept: A Social Psychological Perspective. Annual Review of Psychology, 38, 299-337.

Mead, G. H. (1934). Mind, Self and Society from the Standpoint of a Social Behaviorist. Chicago: University of Chicago Press.

Peshkin, A. (1985) Virtuous Subjectivity: In the Participant-Observer's I's. In Berg, D. N. and Smith, K. K. (Eds.). Exploring Clinical Methods for Social Research. Beverly Hills: Sage.

Phillips, M. J. (1985). 'Try Harder': The Experience of Disability and the Dilemma of Normalization. The Social Science Journal, 22(4), 45-57.

Phillips, M. J. (1990). Damaged Goods: Oral Narratives of the Experience of Disability in American Culture. Journal of Social Science and Medicine, 30(8), 849-857.

Riemer, J. W. (1977). Varieties of Opportunistic Research. Journal of Urban Life, 5(4), 467-477.

Riessman, C. K. (1990). Strategic Uses of Narrative in the Presentation of Self and Illness: A Research Note. Journal of Social Science Medicine, 30(11), 1195-1200.

Robinson, I. (1990). Personal Narratives, Social Careers and Medical Courses: Analyzing Life Trajectories in Autobiographies of People With Multiple Sclerosis. Journal of Social Science Medicine, 30(11), 1173-1186.

Rosenberg, M., (1979). Conceiving the Self. New York: Basic Books, Inc.

Roth, J. A. (1974). Turning Adversity to Account. Journal of Urban Life and Culture, 3(3), 347-361.

Rumsey, N., Bull, R., and Gahagan, D. (1982). The Effect of Facial Disfigurement on the Proxemic Behavior of the General Public. Journal of Applied Social Psychology, 12(2), 137-150.

Russell, S. (1989). From Disability to Handicap: An Inevitable Response to Social Constraints. Canadian Review of Sociology and Anthropology, 26(1), 276-293.

Schmidt, C. J. (1979). The Guided Tour: Insulated Adventure. Journal of Urban Life, 7(4), 441-467.

Strauss, A. L. (1975). Chronic Illness and the Quality of Life. Saint Louis: C.V. Mosby Co.

Strauss, A. L., Corbin, J, Fagerhaugh, S., Glaser, B., Maines, D., Suczek, B. and Weiner, C., (1984). Chronic Illness and the Quality of Life. St. Louis, C.V. Mosby Co.

Strauss, A. L. and Corbin, J. (1990). Basics of Qualitative Research: Grounded Theory Procedures and Techniques. Newbury Park, Sage Publications.

Swann, Jr., W. B. (1983). Self-Verification: Bringing Social Reality into Harmony with the Self. In Suls, Jerry (Ed.). Psychological Perspectives on the Self, Vol 2, 33-66.

Swann, Jr., W. B. (1987). Identity Negotiation: Where Two Roads Meet. Journal of Personality and Social Psychology, 53, 1038-1051.

Swann, Jr., W. B. and Hill, C. A. (1982). When Our Identities are Mistaken: Reaffirming Self-Conceptions Through Social Interaction. Journal of Personality and Social Psychology, 43(1), 59-66.

Taylor, S. E., Wood, Joanne V., and Lichtman, R. R. (1983). It Could be Worse: Selective Evaluation as a Response to Victimization. Journal of Social Issues, 39(2), 19-40.

Turner, B. A. (1981). Some Practical Aspects of Qualitative Data Analysis: One Way of Organizing the Cognitive Processes Associated with the Generation of Grounded Theory. Quality and Quantity, 15, 225-247.

Webster, B. D. (1989). All of a Piece: A Life with Multiple Sclerosis. Baltimore: The Johns Hopkins University Press.

Whyte, W.F. (1982). Interviewing in Field Research. In Burgess, R.G. (Ed.) Field Research: A Sourcebook and Field Manual. London: Allen and Unwin, pp. 112-122.

Wiener, C. L. (1975). The Burden of Rheumatoid Arthritis: Tolerating the Uncertainty. Social Science and Medicine, 9, 97-104.

Williams, G. (1984). The Genesis of Chronic Illness: Narrative Re-Construction. Sociology of Health and Illness, 6(2), 175-200.

Wright, B. A. (1983). Physical Disability: A Psychosocial Approach. New York: Harper and Row.

Yoshida, K. K. (1993). Reshaping of Self: A Pendular Reconstruction of Self and Identity among Adults with Traumatic Spinal Cord Injury. Sociology of Health and Illness, 15(2), 217-245.

Appendix A

CHARACTERISTICS OF QUESTIONNAIRE RESPONDENTS

PARTICIPANTS	SEX question 1	AGE question 2	GENERAL HEALTH (Excellent, Good, Fair, Poor) question 5	DESCRIPTION AND\ OR CAUSE OF DISABILITY question 6 & 7	ONSET OF INJURY OR CONDITION question 8
1	Female	60-69	Poor	Leukemia Necrosis of Hip Joints	Unknown 3 years
2	Female	40-49	Fair/Poor	Failed Back Surgery Syndrome	8 years
3	Female	70 +	Excellent	Leg Amputee (both)	3 years
4	Female	30-39	Fair/Poor	Lupus	2 years
5	Male	19-29	Good	Muscular Dystrophy	18 years
6	Female	-	Good	Spina Bifida	Since birth
7	Female	19-29	Excellent	Muscular Dystrophy	Since birth
8	Male	60-69	Good	Multiple Sclerosis	24 years
9	Male	40-49	Excellent	Polio	Since infancy
10	Female	19-29	Excellent/Good	Muscular Dystrophy	Since birth
11	Female	60-69	Good	Whip Lash	4 years
12	Female	30-39	Good	Muscular Dystrophy	Since birth
13	Male	40-49	Excellent	Cerebral Palsy	Since birth
14	Male	40-49	Good	Polio	40 years
15	Male	19-29	Excellent	Poor memory & loss of coordination due to MVA	11 years
16	Female	19-29	Good	Multiple Sclerosis	3 years
17	Male	-	Good	Multiple Sclerosis	1 year
18	Male	40-49	Excellent/Good	Multiple Sclerosis	5 years
19	Male	50-59	Excellent	Multiple Sclerosis	1 year
20	Female	40-49	Good	Multiple Sclerosis	18 years
21	Male	60-69	Fair	Multiple Sclerosis	29 years
22	Male	30-39	Excellent	Head Injury due to MVA	13 years
23	Female	40-49	Excellent	Multiple Sclerosis	9 years
24	Male	19-29	Good	Chronic Depressive Disorder	12 years
25	Male	50-59	Good	Tumor on Spine	3 years
26	Male	40-49	Good	Muscular Dystrophy	Since birth
27	Male	19-29	Good	Amyotropic Lateral Sclerosis	3 years
28	Male	50-59	Good/Fair	Muscular Dystrophy	45 years
29	Female	40-49	Good	Muscle pain and weakness (cause unknown)	10 years
30	Female	30-39	Good	Multiple Sclerosis	6 months
31	Female	40-49	Excellent/Good	Neuro Muscular Disorder	41 years
32	Female	50-59	Fair/Poor	Rheumatoid Arthritis, Spinal Cord Tumor	36 years 8 years
33	Female	30-39	Poor	Multiple Sclerosis	20 years

- No answer given

Appendix B

RESPONDENTS' ANSWERS TO QUESTIONNAIRE STATEMENTS

Even though the statements (question 13: a-e) were not used in the selection of participants as they were intended, it would seem to be a useful device in determining some degree of difference or similarity across individuals' experiences. As can be seen below, there was a great deal of variety across responses. Nonetheless, the questions were found to be quite useful in opening up some additional areas of discussion during the interviews. The question posed to the interviewee went as follows: "I was wondering if you could tell me some more about a few of your answers on the questionnaire? There were a number of statements that I asked you to indicate how often you would agree. The first was *'I feel sad about how other people treat me'* (a) and you put *'sometimes'*. Could you tell me what you were thinking about when you put that?".

PARTICIPANTS	STATEMENTS FROM QUESTIONNAIRE				
	I feel sad about how other people treat me.	Other people make me feel good about myself and my disability.	It angers me when other people stare.	I notice other people's reactions to my disability.	My disability puts me in amusing situations.
1	Often	Rarely	Never	Often	Never
2	Sometimes	Often	Never	Sometimes	Sometimes
3	Never	Always	Never	Never	Sometimes
4	Rarely	Rarely	Sometimes	Rarely	Rarely
5	Rarely	Often	Rarely	Rarely	Sometimes
6	-	-	Often	Often	Sometimes
7	Sometimes	Rarely	Sometimes	Sometimes	Rarely
8	Never	Often	Never	Sometimes	Rarely
9	Rarely	Rarely	Sometimes	Sometimes	Rarely
10	Rarely	Often	Sometimes	Often	Sometimes
11	Sometimes	Sometimes	Rarely	Sometimes	Sometimes
12	Sometimes	Always	Rarely	Sometimes	Sometimes
13	Sometimes	Sometimes	Rarely	Always	Sometimes
14	Often	Rarely	Often	Always	Never
15	Sometimes	Always	Always	Always	Always
16	Sometimes	Often	Often	Rarely	Never
17	Sometimes	Rarely	Often	Often	Sometimes
18	Never	Sometimes	Never	Sometimes	Sometimes
19	Never	Always	Never	Never	Sometimes
20	Sometimes	Always	Never	Sometimes	-
21	Never	Often	Never	Sometimes	Often
22	Never	Sometimes	Never	Often	Often
23	Never	Always	Never	Never	Rarely
24	Sometimes	Sometimes	Rarely	Rarely	Never
25	Never	Often	Never	Often	Sometimes
26	Sometimes	Often	Sometimes	Often	Sometimes
27	Sometimes	-	Never	Always	Sometimes
28	Sometimes	Rarely	Rarely	Often	Rarely
29	Sometimes	Rarely	Never	Sometimes	Never
30	Rarely	Sometimes	Rarely	Rarely	Never
31	Rarely	Sometimes/Often	Rarely	Rarely/Sometimes	Sometimes
32	Sometimes	Sometimes	Never	Rarely	Rarely
33	Sometimes	Sometimes	Often	Often	Sometimes

CHOICES: Never, Rarely, Sometimes, Often, Always.

Appendix C

INTERVIEW GUIDE

(1) Introductory Comments: These remarks took place off the record and were used to lead into the interview.

(a) Discuss Use of Tape Recorder

(b) Discuss Confidentiality

(c) Discuss Interview Style: When a person is interviewed for say the census, the answers they give are normally quite short, as are the questions. For example, for the question "how many people live in this house?", you might answer "two". Rather than having a short question-answer discussion like this, I would like to hear about your experiences. Please understand that I am not looking for short answers.

(2) Interview Questions:

Question 1: On the questionnaire you mailed back to me, you wrote about your disability (read off what the individual wrote). Could you tell me more about your disability. Please start from when you were first injured/ your illness was diagnosed.

Question 2: Could you think back to the time when you were first injured/having symptoms and tell me about your experiences with other people?

Question 3: Do other people notice your disability? How do you know? How does this make you feel?

Question 4: We all have experiences that make us feel sad, happy or angry. I was wondering if you could take me through some of these experiences. These are only examples. There are many others that you might think of that I haven't.

Question 5: I would like to know how people respond to your disability throughout a regular day for you. Could you describe to me what you do on any "normal" day.

Question 6: I would like to know about the people you meet in various locations: like work, school, home, recreation, shopping malls and any other place you can think of.

Question 7: Have you ever been in a situation where the others or the other individual doesn't realize you have a disability and at some point they realize?

Question 8: Are there places where you feel *less* disabled or *more* disabled than others because of how people treat you? or specific experiences where you feel less or more disabled?

Question 9: Are you concerned about what other people think about your having a disability?

Question 10: Could you tell me some more about a few of your answers on the questionnaire? (See Figure 1.2, Question 13)

Appendix D
MY FALSE START

The "Response Systems Model of Disabled Individuals in Transition" that follows was developed to illuminate the fluctuations in one's understanding of self, which are the result of the perceived self-discrepant and self-congruent evaluations made by others. Both the individual's possible self- and perceived other-definitions, along with the individual's potential responses to perceived other-definitions will be examined. While the model was a false start, I still see much of my own experience in it. The model remains useful in this regard, as well as encompassing and formalizing many of my preconceptions.

Possible Definitions-of-Self: Self and Perceived Other

Individuals can be grouped by their definition-of-self and by their perceived other definition-of-self. Logically, there are four possibilities. The three which are relevant to the proposed study are:

> Non-Disabled: The disability and its related restrictions are not recognized as a negative quality. These aspects are secondary in focus to other characteristics of self.
>
> Positively Evaluated as Disabled: The disability and its related limitations are not recognized as a negative quality. These aspects are foremost in one's definition-of-self however.
>
> Negatively Evaluated as Disabled: The disability and its related restrictions are regarded as a negative quality of self. These aspects are foremost in one's definition-of-self. The negative quality assigned to one's disability-related limitations enters into the evaluation of other personal qualities. This negativity, in fact, may overwhelm one's awareness of other qualities and render one unable to accurately evaluate other qualities of self.

One possibility has been excluded: Neutral Evaluation of Self or Other as Disabled. While one might propose that one's air of indifference towards, or unawareness of, another's disability is an indicator of neutrality, we perceive this as a lack of evaluation.

Orientations to Self and World

Individuals' responses to other individuals' categorizations and evaluations are, of course, variable. Nonetheless, based on the definitions-of-self and perceived other definitions-of-self outlined earlier, the disabled individual's anticipated responses to discrepant or congruent situations can be combined to produce nine separate orientations to self and the world. The definitions, self and perceived other, have been logically combined to produce a three-by-three table. The descriptors that seem to capture the essence of each of the nine alternatives are in the cells below (See Figure D.1):

Figure D.1 Derived Orientations to Self and World

		PERCEIVED OTHER DEFINITION-OF-SELF		
		Non-disabled	Positive Disabled	Negative Disabled
SELF-DEFINITION	Non-disabled	(1) Excel	(2) Ignore	(3) Reject
	Positive Disabled	(4) Examine	(5) Search	(6) Question
	Negative Disabled	(7) Dismiss	(8) Struggle	(9) Surrender

Each of the derived orientations or responses can, then, be described as follows:

(1) EXCEL - An individual who defines self as non-disabled and perceives that the other also defines one as non-disabled is "excelling" to his or her most positive understanding of self, which allows for maximum build or growth in all aspects of self together and apart from one's disability.

(2) IGNORE - An individual who defines self as non-disabled and perceives that the other favorably evaluates one as disabled is likely to "ignore" the other's categorization and evaluation. This individual has a stable understanding of self as non-disabled, which does not include putting their disability in the forefront of their understanding as the other does.

(3) REJECT - An individual who defines self as non-disabled and perceives that the other unfavorably evaluates one as disabled is likely to "reject" the other's categorization and evaluation. This individual has a stable understanding of self allowing him or her to discard or selectively interpret other's differential categorization and evaluation.

(4) EXAMINE - An individual who favorably evaluates self as disabled and perceives that the other defines one as non-disabled is inclined to "examine" the importance of one's disability in one's overall understanding of self. While still of consequence, the magnitude of this discrepancy is smaller than in either the question or struggle states.

(5) SEARCH - While an individual who favorably evaluates self as disabled and perceives that the other also favorably evaluates one's self as disabled is in a state of consensus, the individual "searches" for some missing quality; that being the ability to place one's disability and related restrictions in secondary focus to other characteristics of self. This individual is limited to a certain level of understanding.

(6) QUESTION - An individual who positively evaluates self as disabled and perceives that the other negatively evaluates one as disabled "questions" one's positive understanding of self as a disabled person. This state is less intense than the struggle state.

(7) DISMISS - An individual who unfavorably evaluates self as disabled while perceiving that the other defines one as non-disabled is inclined to "dismiss" the other's positive categorizations and evaluations.

(8) STRUGGLE - An individual who unfavorably evaluates self as disabled while perceiving that the other favorably evaluates one as disabled is likely to "struggle" with the incompatibility of the definitions.

(9) SURRENDER - An individual who unfavorably evaluates self as disabled and perceives that the other also unfavorably defines one as disabled is likely to "surrender" to this conception. This individual has reached the most negative understanding of self. Acceptance of this state results in one self-handicapping oneself.

The Response Systems Model of Disabled Individuals in Transition which follows places the derived orientations or responses into the context of a social situation and develops the logical alternatives.

The interplay between a disabled individual's perceptions of others' evaluations and categorizations and his or her understanding of self is illustrated in the following model (See Figure D.2). This model represents one social situation from which a disabled individual enters and exits. Each of the nine responses to others' evaluations which have been previously discussed, as well as the corresponding exits and two alternative exits are incorporated. The disabled individual's passage through the situation and his or her response to self-discrepant or self-congruent categorizations and evaluations by another varies with a number of factors:

(1) His or her current state of self-understanding: The disabled individual's state of self-understanding upon entering a social situation will, of course, influence how he or she reacts to any self-discrepant or self-congruent evaluations by others.

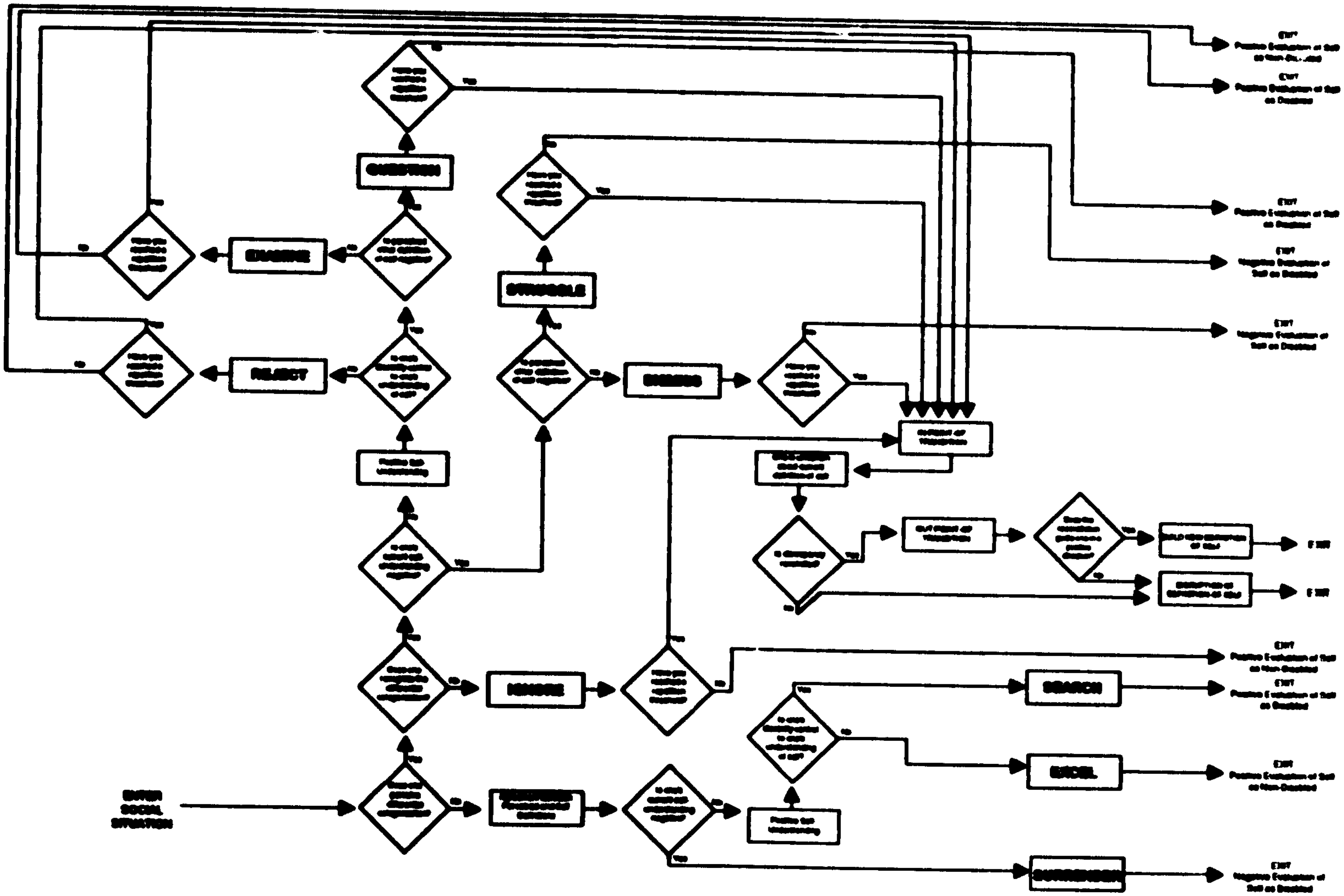
(2) The number of consecutive repetitions of a particular state: For each of the responses to *self-discrepant* categorizations and evaluations by another, there is a point at which the individual can no longer build or maintain their present state of understanding. This point is called a "repetition threshold". The number of repetitions necessary for one to reach a repetition threshold varies with each individual and each response. Nevertheless, there is some threshold point at which the individual becomes highly uncertain about their self-understanding and enters into a time of transition. This repetition threshold applies only to self-discrepant situations. Self-congruent situations have no repetition threshold, as they may be perpetually repeated without the individual being propelled into confusion.

(3) The number of previous transitions in understanding: With an increasing number of transitions in self-understanding over time, the disabled individual may become less concerned with other individuals' evaluations.

(4) The nature of the other individual's evaluation: The nature of the other individual's evaluation and categorization (e.g. negative) will also influence the disabled individual's response.

Following one's entrance into a social situation, one may or may not perceive differential categorization or self-discrepant categorization on the part of the other. If one does not perceive differential categorization, he or she will advance to one of three

Figure D.2 Response System Model of Disabled Individuals in Transition



responses (EXCEL, SEARCH, SURRENDER) depending on his or her current definition-of-self. For each of these routes, his or her response will be one of confirmation, and he or she will exit the situation with this understanding. As no repetition threshold is present, consecutive repetition of any one of these self-congruent routes will further validate the individual's self-understanding. If one does perceive differential categorization, however, he or she will advance to one of six responses (IGNORE, REJECT, EXAMINE, QUESTION, DISMISS, STRUGGLE) depending again on his or her current definition-of-self. As long as one does not reach a repetition threshold, the individual will exit the situation with this definition-of-self intact, but to some degree weakened. At the point where the individual reaches a repetition threshold, he or she becomes highly uncertain of his or her current understanding of self. After reaching this transition into confusion, then, the individual must not only reconcile his or her confusion about the discrepancy between definitions, but also reconcile it in a positive rather than negative direction in order to move on to build a new understanding-of-self. If this reconciliation is negative, the individual will exit the situation with a progressively negative understanding of self. If the reconciliation is unsuccessful, the individual will exit the situation in a confused state. In the case that the individual does not resolve this confusion before entering the next social situation, he or she is likely to perceive the others' evaluations and categorizations as being accurate. In the most negative scenario, a confused individual will perceive that the other individual negatively evaluates him or her as disabled and will "surrender" to this definition. Individuals entering a social situation with a confused understanding-of-self are extremely vulnerable to their perceptions of the evaluations made by others, whether they are accurate or not. A transition in self-understanding can, then, direct one to either a more positive or negative orientation to self and the world.