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Accept me for who I am! : a critical ethnographic study of a participatory research project with people labeled mentally retarded.

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ACCEPT ME FOR WHO I AM! A CRITICAL ETHNOGRAPHIC STUDY OF A PARTICIPATORY RESEARCH PROJECT WITH PEOPLE LABELED MENTALLY RETARDED

A Dissertation Presented

by

MARK R. LYND

Submitted to the Graduate School of the
University of Massachusetts Amherst in partial fulfillment
of the requirements for the degree of

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School of Education

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To my mother

for her undying compassion and support

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This dissertation has been made possible by the efforts of several people, truly too many to mention here. I would like to thank people who were present at the milestones of this project, beginning with Kathy Kelly and Mary Jeannot for their assistance in the founding of the Manna Base Community; Ron and Ruth Bosch for their efforts in the development of Get a Job!, Janet Mittman for her untiring patience with the cast and me in the production of Special, and Peter Park for his assistance and support of my efforts professionally, academically, and personally over the years. A special thanks goes to Francis Bailey for his constant companionship and mentoring. As a result of many hours of work and discussion with him and his wife, Penny, the world of research has become for me something both understandable and exciting. Finally, I would like to extent my sincere thanks and deepest respect to the members of the Friends Support and Action Group for the wit, wisdom and love they have so generously shared with me before, during, and since the writing of this dissertation.

ABSTRACT

ACCEPT ME FOR WHO I AM! A CRITICAL ETHNOGRAPHIC STUDY OF A PARTICIPATORY RESEARCH PROJECT WITH PEOPLE LABELED MENTALLY RETARDED

SEPTEMBER 1994

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This dissertation is a critical ethnographic study of a participatory research project in which a group of eight adults labeled mentally retarded, with the assistance of two nondisabled adults, created and performed a musical theater production called Special. Special was produced as part of a participatory research process in which group members also interviewed friends, advocates of disabled people, and former residents of a local institution for people labeled retarded, in order to find out how ex-residents were treated once they were placed in community living situations. The information from these interviews, as well as accounts from group members' own lives, comprised the content of Special.

This study consists of two main parts - an interpretive section (Chapters 5 and 6), including emic and etic interpretations of group members' experiences, and a critical section (Chapter 7), in which an internalized oppression framework is invoked to examine group members' experiences. Three main findings of the study were: 1) that group members expressed a chronic problem orientation; 2) that group members exhibited a justice orientation; and 3) that group members were largely motivated by the drive to visibility, or the need to be seen, understood and accepted for who they really are. Another major finding of the study was that group members' drive to visibility was not only a major motivation for doing the play, but was also a key to understanding much of their behavior - that when they felt visible, they "acted up," or became positive and productive, and that when they felt invisible, they "acted out," or became destructive, and even violent, evidence of internalized oppression in group members. Group members' drive to visibility, coupled with their resistance to an identity of mental impairment, raises two important questions regarding the issue of social identity with people labeled retarded: (1) Are there reasons to believe that people labeled retarded can feel a sense of pride in who they are, both as individuals and as members of a social group? (2) If people labeled retarded cannot feel a sense of pride, what are their prospects of overcoming internalized oppression, and of working with one another as a group with an identity, a purpose, and a right to have power like all other groups?

TABLE OF CONTENTS

APPENDICES

LIST OF TABLES

LIST OF FIGURES

Figure

Page

CHAPTER 1

INTRODUCTION

The greatest tragedy of being disabled is that it need not be a tragedy. The American Disabilities Act of 1991 defines a disability as "a physical or mental impairment that substantially limits one or more of the major life activities of an individual" (cited in Mohan 1993:81). Yet for too many disabled people, the most limitations are not caused by their impairments, but by the discrimination, ostracism, and even abuse they must face because they are disabled. Disability has become not just an impairment, but a handicap, a "loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers" (cited in Driedger, 1989: 94). Even the origin of the word handicapped is degrading; the word derives from the image of disabled people begging for money, cap in hand, for their survival. Such people came to be known as "handicaps."

For many people, disability is a fact of life; handicappism is a scourge. Approximately 36 million people in the US today are labelled "disabled" (Nagler, 1990), yet for many of these people, the being disabled means that they will always have trouble getting a job, or getting suitable education, or being included in community life. People labeled mentally retarded suffer even more from labeled mentally retarded suffer even more from handicappism. The very word "retarded" saddles them with "socially created valuations that are discriminatory, demeaning, and unnecessary" (Ferguson, 1987:207).

This dissertation is based on the premise that the "mental retardation" is both a disability and a handicap, the latter being a socially created devaluation of people with limited cognitive ability and difficulty with social adaptation. For this reason, I will hereafter call people labeled mentally retarded PLMRs.[1]

This dissertation is also based on the premise that prejudice against PLMRs people has harmed them in two ways. First, it has eclipsed their ability to be seen or heard in any significant way - what I shall call invisibility. Of course, there are some exceptions. Disabled People's International serves as an information network and

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[1] There is no agreement in the disabilities community on what to call people who have been labeled mentally retarded. People who have been so labeled almost categorically reject the label, so the use of the word "retarded" or "retardates" is unacceptable. Personally, I prefer "people with mental impairments," though this word fails to take into account 1) the nature of the impairment - e.g., the difference between a developmental disability, which might or might not include mental impairment, and mental retardation, which by definition includes limited cognitive ability; 2) the social construction of mental retardation - i.e., that the condition was not "discovered," the term was created to refer to a cluster of conditions that are characterized by cognitive impairment, difficulty with social adaptation and productivity; and 3) the enormous stigma attached to retardation based on the misunderstanding that retarded people are stupid, and the contempt with which people view "stupidity." Until the disabilities community finds a more accurate and dignified word, I have elected to use PLMR, People Labeled Mentally Retarded, in order to emphasize the social construction of this category without entirely losing specificity of meaning.

educational clearinghouse for disabled people around the world. The Self-Advocacy Movement, begun in the 1970s in North America, has hundreds of groups of PLMRs in the U.S. who are speaking for themselves in newsletters, conferences and numerous publications. And the ground breaking American Disabilities Act of 1991, hailed as "the 20th century Emancipation Proclamation for people with disabilities" (Tom Harkin, the law's main sponsor, in Time, August 3, 1992:25), finally provides comprehensive legislation to ensure public access and other basic services for disabled people. Yet these are exceptions. Only in recent years have people begun to ask PLMRs for their opinion about mental retardation (e.g., Abel and Kinder, 1942; Edgerton, 1967; Bogdan and Taylor, 1982; Lorber, 1974; Gibbons, 1985; Szivos and Griffiths, 1990). In the main, policies, practices, and legislation about PLMRs is created without their knowledge, consent or input (Varela, 1979). Worse, it is usually created with little knowledge of what it even means to be retarded.

A second effect of prejudice against PLMRs has been the internalization of this prejudice by PLMRs. This process is called internalized oppression, defined by Pheterson (1986) as "the incorporation and acceptance by individuals within an oppressed group of the prejudices against them within the dominant society" (p. 148). Because their words and their perspectives have been devalued or simply ignored for so long, many PLMRs have come to believe that they are worthless. And, having internalized the stereotypes, they have changed their behavior accordingly.

This study is an attempt to respond to these two effects of prejudice - invisibility and internalized oppression. It examines what a group of eight adults who have been labelled mentally retarded revealed about themselves and how they understand the world as they developed *Special*, a musical theater production about the problems they face as disabled people. In particular, it examines two areas of their experience: 1) the talked-about and acted-on issues in their lives - what is important to them, what hurts them, how they think the world should be; and 2) the factors that seem to contribute to internalized oppression in group members' lives.

Background of the problem

In our society, PLMRs are commonly disregarded, mistreated, and abused on a daily basis. The reasons for these kinds of behavior are complicated, but perhaps the biggest is that, in the main, PLMRs are misunderstood. In western societies (not all societies),[2] PLMRs have historically been defined as moronic, deviant, even dangerous - all negative valuations in societies that place a premium on intelligence, conformity, safety and the like. As a result of these devaluations, many people have become

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[2] In Somalia, for example, people with mental retardation are often revered as "saints" with extraordinary powers, such as divination, clairvoyance, etc.

prejudiced against PLMRs, often without even being able to articulate why. Yet they have organized their societies accordingly, sequestering PLMRs in institutions, punishing them, or even banishing them.

In addition to being misunderstood, PLMRs are largely misrepresented in history, in the media, and in literature. Their images tend to consist of people who are weak, scary, ugly, moronic, criminal or bizarre. They tend to be represented at one extreme or the other: either as saints endowed with superhuman powers of clairvoyance, purity or "other-worldliness," or as degenerates engulfed in disease, recrimination, or worse, neglect.

The fact that PLMRs have been underrepresented in the academic and policy literature is of no help. And within the disabilities literature, the issues of PLMRs are least represented:

> An insidious intellectual pecking order seems to operate that subtly assigns worth to objects of knowledge. Some things are more worth knowing about than others. Even some deviancies, some stigmas, are more intellectually acceptable than others. Within this caste system of knowledge, mental retardation as a field of study has remained part of the great unwashed (Ferguson, 1987:208).

Of the types of studies done, "sociologists have devoted little time to mental retardation, and cultural anthropologists, virtually none at all" (Edgerton, 1967:xiii). As a consequence, the voices of PLMRs are rarely heard:

> The predominant mode of research in the field of mental retardation is characterized by the "official" view. That is, researchers have taken for granted the reality

> of the concept of mental retardation. They have assumed the existence of what they have tried to study, rather than treating it as a problem or as a matter to be investigated (Bogdan & Taylor, 1982:205).

The world's misunderstanding, misrepresentation and underrepresentation of PLMRs is made no easier by the fact that they must face a uniquely cruel form of devaluation. Theirs is not simply a matter of being different, therefore less, as in the case of other devalued groups such as ethnic minorities, women, etc. Rather, theirs is a type of devaluation that stems from all people's innate equation of competency with humanness:

> (T)heir problem lies in the fact that their stigma - of all possible stigmata - is closest to what we may call the soul. Of all the attributes of man, mind is the quintessence; to be found wanting in mental capacity - in general intellectual competence - is the most devastating of all possible stigmata (Goldschmidt, 1967:vii).

What makes "retardation" particularly damning is the fact that it forever strips people of ability to function fully as human beings:

> (O)ne might speculate that no other stigma is as basic as mental retardation in the sense that a person so labeled is thought to be so completely lacking in basic competence. Other stigmatized persons typically retain some competencies, limited though they may be, but the retarded person has none left to him. He is, by definition, incompetent to manage <u>any</u> kind of his affairs. And, unlike the psychotic, who at times may be considered (and, in fact, may be) competent to manage his practical affairs, the mental retardate is <u>forever</u> doomed to his condition. As everyone "knows," including the expatient, mental retardation is irremediable. There is no cure, no hope, no future. If you are once a mental retardate, you remain one always (Edgerton, 1967:207).

Yet the inability to function fully as a human being does not mean that PLMRs are less than human. This should seem axiomatic, yet it is precisely this false equation that leads society to conclude that PLMRs are less than human. And most perniciously, many PLMRs begin to internalize this myth themselves. It is at this point that disability truly becomes a handicap, crippling their self-esteem, their ability to do things for themselves, their ability to reach out to one another, their ability to identify with people of different backgrounds.

The effects of being defined, controlled, and made to believe that they are inferior are everywhere visible. In terms of housing, PLMRs have a history of being sequestered into institutions and, when they are fortunate enough to be deinstitutionalized, often end up in independent living situations or group homes where institutional practices continue in decentralized form. In terms of employment, 58% of all men with disabilities (physical and developmental) and 80% of all women with disabilities are unemployed, for which society must pay more than $160 billion a year in benefits (Nagler, 1990: vii). Those who do work hold lower-paid, lower-status jobs, in worse conditions than their able-bodied counterparts (Macmillan, cited in Tomlinson, 1984:12). In 1979, 690,000 adults with mental retardation were without work, while about 400,000 could be gainfully employed if appropriate services were available (Schalock, 1983). In 1987, between 800,000 and 900,000 mentally retarded adults are either not working or making less than $300 per month (Ferguson, 1987:203). In these and so many other ways, society continues to define PLMRs as different, thereby justifying its practices of excluding PLMRs from "normal" activities, condemning them to living controlled, impoverished, boring lives.

Statement of the problem

Much is known about the intentions of policy makers and human services personnel charged with "taking care" of PLMRs, but relatively little is known about how PLMRs see the world and, as a consequence, how they feel it should be structured or changed. What kinds of problems do PLMRs have? What do they value? What hurts them? How do they believe the world should operate? In particular, to what extent do PLMRs experience internalized oppression? And what kinds of experiences are helpful in enabling them to articulate these experiences and change them? As the previous section points out, there is very little research documenting how PLMRs see the world, particularly taken from an anthropological perspective. Similarly, there is little information available which identifies factors that might contribute to the internalized oppression PLMRs face, or what might be done to overcome it. This study is intended to address this gap in the literature and in public understanding of PLMRs.

Rationale

This study provides information concerning how one group of PLMRs understand themselves and the world as revealed in the process of developing a musical theater production called *Special*. Moreover, this study examines of how group members experience internalized oppression, and factors that contribute to their internalized oppression.

Most institutions that work with PLMRs are concerned about PLMRs' behavior and well-being. However, their primary concern is the need to provide and improve services in order to "stay in business." The type of improvements they seek tend to be defined by one of two models: the service delivery model, characterized by vender-provided services, individual service plans, and corporate-style management in which vendors are accountable to the state; and the normalization model, characterized by an emphasis on community living, integration of PLMRs into homes and work places, and avoidance of "devaluing" practices. Neither of these models incorporates a self-conscious approach to learning about PLMRs' perspectives on what it means to be labeled retarded, attitudes they have about themselves or one another, or incorporating these ideas into disabilities policies and practices. Nor do these models include a mechanism whereby the phenomenon of internalized oppression with PLMRs can be identified and addressed.

This study is designed to learn directly about PLMRs' perspectives on being labeled retarded through two processes: first, by engaging them in a self-reflective process of theater production in which they explore how they view themselves and the world, and second, by studying this process through participant observation and interviews in order to learn how they view themselves and the world. Jacques Deleuze once said to Michel Foucault, "In my opinion, you were the first - in your books and in the practical sphere - to teach us something absolutely fundamental: the indignity of speaking for others" (in Foucault, 1977:209). This study is an attempt to continue in the tradition of Foucault and others and cease "the indignity of speaking for others" by finding ways to enable them to speak for themselves.

Significance of the study

The information resulting from this study can be used to influence policy in human service systems, and to change practices that contribute to the internalized oppression of PLMRs. This information can also be used by human services personnel, administrators, and educators who are concerned about understanding better the perspectives in policy formulation and development of agency practices. Finally, it can be used by anyone seeking ways to incorporate PLMRs and their ideas into policy development, legislation, and the shaping of public opinion.

In the following chapters, I will illustrate how group members spoke for themselves, first by introducing this study with an overview of the project, a discussion of methodology, and an introduction to the notions of mental retardation and internalized oppression. I will then present three analytical chapters in which three dominant findings of this study are discussed: the group's chronic problem orientation, their justice orientation, and their drive to visibility. I will conclude with reflections on these findings in light of the relevant literature, and a more in-depth discussion of criticisms of *Special* and other issues to arise out of this project.

CHAPTER 2

OVERVIEW OF THE PROJECT

Introduction

This study examines how the Friends Support and Action Group, a group of people labeled mentally retarded (PLMRs) understand themselves and the world as revealed in the process of developing a musical theater production called *Special*. Yet the development of *Special* actually began three years before conducting this study when the Friends Support and Action Group first came into being. At that time, I did not intend to be working with them ad infinitum, nor did I intend to work with disabled people, much less do popular theater with them. I had never studied special education, cognitive psychology, or theater - all subjects that would have no doubt helped immensely in doing this project. My background had been in teaching English as a foreign language, teacher training, and community organizing.

How I came to this subject, this audience and this project, then, was quite by accident, an occurrence that perhaps can only be explained by recounting some of the events in my life and major ideas which have influenced my thinking, resulting in the development of *Special*. This chapter is an attempt to pull together some of those ideas and how they informed my work with PLMRs, particularly as it related to the development of *Special*. In particular, I will discuss four models that influenced my thinking, and explain how *Special* developed in light of those models. I will conclude this chapter with observations about what cast members learned, how they changed, and what lessons I learned in applying these models to this group in the form of musical theater.

Four influences

It would be misleading to imply that from the beginning, Janet, my co-director, and I consciously knew which specific activities we would use in the development of *Special*. In fact, the design of workshops, rehearsals, and in the end, the actual play, came to us day by day and week by week as we would try one thing and, if it worked, do it again; if it did not, try something different. Of course, our selection of activities was guided by several influences, most specifically the ideas of Augusto Boal (1985). Less explicit but perhaps equally influential were ideas drawn from the Quaker meeting style, the 12-Step movement, the feminist consciousness raising movement, and popular education.

In tracing the development of *Special*, however, four influences can be seen in our work: the base community model, participatory research, participatory theater, and critical pedagogy. These four models might be visualized as the pedals of a flower, all intersecting in what came to be *Special*:

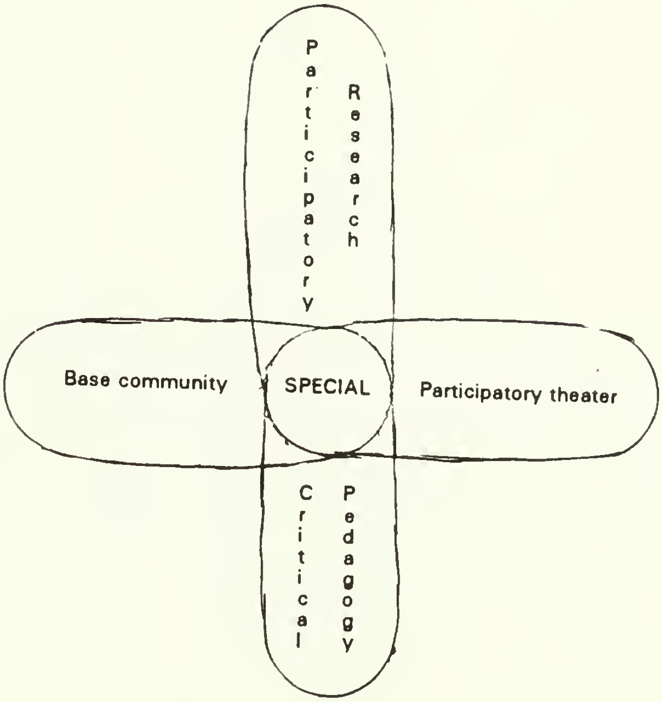

Figure 1[1]
Four influences affecting the development of Special

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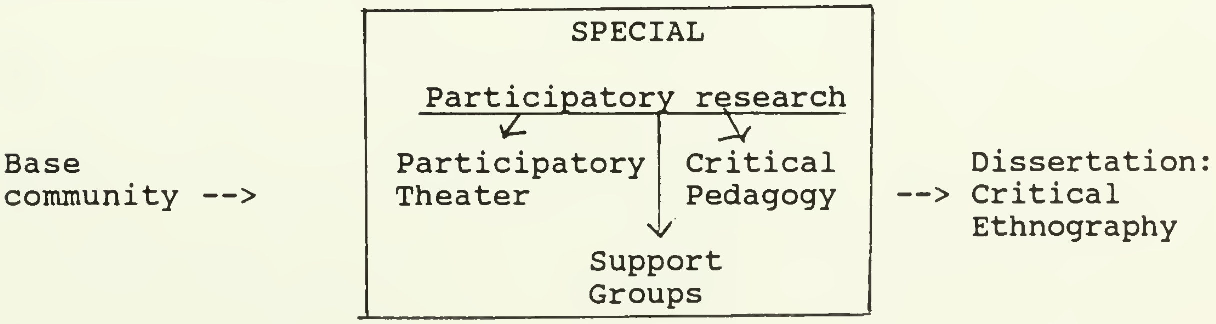
[1] Because these four influences converged in the development of Special, I use a flower diagram as a way of describing the project. The relationships between these influences would be more accurately portrayed if participatory research was placed over participatory theater, support groups and critical pedagogy, which are methods used in participatory research. This alternative depiction might look something like this:



In the following section I will describe each of these influences as they pertained to the work I have done with the Friends Support and Action Group over the last five years, culminating in the production of *Special*.

The base community model

The genesis of this project can be found in my quest five years ago to explore an approach to working with groups called the base community - a model originating in Brazil with the liberation theology movement in the 1950s and 60s. According to liberation theology, Jesus' ministry was not only to save us for life in the hereafter (salvation), but also to help us develop the spiritual and moral strength to work toward a just world in this life (liberation). Liberation theology stressed the importance of the poor in history, and the power of the poor to interpret God's word for themselves in communities of the faithful rather than relying on church hierarchies to interpret the word of God for them, especially from the Bible (Gutierrez, 1973). In the base community model, a group of people come together regularly to "do theology" by applying scripture to their lived experiences, taking some kind of community action, then coming back the next week and discussing what they had done (Berryman, 1987).

Five years ago, I was meeting with an interdenominational prayer group that called itself a base community. The group had been founded to meet the needs of two Guatemalans who had entered the U.S. as part of the Sanctuary Movement, and missed the base community meetings they were used to attending at home. Shortly after I joined, the Guatemalans left. I am not sure why, though I suspect that judging by the way I had seen them facilitate the meetings, the "gringo approach" to spirituality proved to be too sedate, too "talky" for them. They preferred role plays, singing, action. The group continued to meet for two years sans Guatemalans, during which time I was deeply moved by the interdenominational possibilities of such prayer groups (our group included Buddhists, Quakers, Jews, and Catholics, including one Jesuit). I was also struck by the gentle, supportive effect of the Quaker meeting style of sharing in this group.

After two years, the group died a natural death, but I was still intrigued by the base community model. I talked to a friend of mine who had been a member of our group and she, too, wanted to continue with the idea. She was a board member of a local soup kitchen and said that maybe some people there might be interested in trying this with us. In the following weeks, we talked with soup kitchen "guests" as they were called to see if they had any interest in starting a group that would "get together after Sunday meals, hang out, pray, sing, talk, that kind of stuff." We began meeting after the meals and, over the course of the next two years, saw the group fluctuate from 5 to over 15 members, mostly poor people. Some were mentally ill, some were homeless, many were transient. For reasons that I do not understand, most of the group ended up consisting of people labeled mentally retarded (PLMRs). In each meeting, we would typically share what we were doing in our daily lives, discuss some spiritual idea (usually taken from the Gospels), have some kind of activity like role playing or song writing, sing (often improvising lyrics), then close with a prayer. We also took field trips, celebrated birthdays and anniversaries, and performed a small skit for a local church's Christmas program. Excited by this performance and the positive response it drew, members of the Manna Base Community, as we had come to call ourselves, expressed their interest in doing a second play.

Participatory research

At that time, I was studying participatory research, an approach to social change that includes research, education and action (Hall, 1978). Like liberation theology, participatory research is based on the notion that people can create their own knowledge about the world and, in doing so, then acting, then reflecting on their action, reach a deeper understanding of how the world works and the role they can play in changing it. Participatory research had been used in Africa and Latin America (Swantz, 1975; Hall: 1978; Mustafa, 1983), and more recently with low-income groups in the U.S. (Gaventa and Horton, 1981; Maguire, 1987), including one account with a disabled group (Brydon-Miller, 1993).[2]

I was becoming discouraged because the Manna Base Community had not really "taken off" as a base community. We had formed a solid group; we were "doing theology" as evidenced in group members' interpretations of the Gospels, various prayers, etc. But we had not become active in the community, applying our understandings to our work, then coming back to reflect on them. Nor were group members, in my estimation, developing a deeper understanding of the causes of the kinds of problems they were experiencing, especially as disabled people. I was not sure why, but felt that participatory research might better enable group members to do this given its explicit focus on research and education. However, I was concerned about the issue of their cognitive impairments, especially their limitations with reading, writing, and remembering things - essential skills, I thought, for any research project. "Those are valid considerations," my friend who had started the group with me said, "but it might be worth a try."

After two years of meetings, we moved our meeting space into the Center for Community Education and Action, an organization Peter Park and I had founded which promoted participatory research in western Massachusetts. We changed our name to the Friends Action Group and began meeting in

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[2] In Chapter 8, I discuss in greater detail some of the specific components and issues around participatory research, especially as they pertain to <u>Special</u>.

group members' homes instead of the church. More people joined, some of whom had not been associated with the church where the Manna Group had been meeting. The group consisted of about 12 people, half men, half women, ranging from 26 to 62. Most were PLMRs. Two had physical disabilities: one man was blind, one woman wore a leg brace. All were receiving some kind of support from the state: counseling services, assistance with shopping and medical business, rent subsidies, etc. Four members had lived at the local institution for developmentally disabled people (euphemistically dubbed "state school") and were now living on their own in apartments. Two had fallen in love at the state school and, after their release, had gotten married. All were in and out of work, though at any given time, about half of them worked on a part-time basis. Jobs included washing dishes, stocking shelves in a store, cleaning college classrooms, answering telephones, consulting as an educator with former state school employees. No group member, including Janet and me, earned more than $12,000 a year.

Over the next several months, the Friends Action Group continued to meet, renamed itself the Friends <u>Support</u> and Action Group[3], and discussed types of action we would like to take (e.g., writing a group letter to complain about impending state budget cuts that would affect the poor). In

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[3] In order to avoid use of an unfortunate acronym, the Friends Action Group (FAG) added the word <u>support</u> to their name.

time, group members were most enthusiastic about doing another play. As I was still interested in doing some kind of participatory research with this group, I decided to assist them with the development of a popular theater production - a technique of participatory research that effectively combines research, education and action (Cassara, 1987).

We began to meet more frequently to discuss issues we wanted to dramatize, do role plays to draft scenarios, sing songs and change the words where appropriate to fit our budding story. In time, it became apparent that the dominant concern of group members was employment, especially the problems they had getting and keeping jobs. Some of them reported that one reason they had trouble was because employers discriminated against them because they were disabled. In the end, this became the dominant theme in *Get a Job!*, our first musical theater production which we played three times in the community.

After doing *Get a Job!* cast members were eager to set about doing our next play. I took stock in how Get a Job! had succeeded as a participatory research project. We had, it seemed, engaged in research, education and action. Our research had consisted of group discussions and roles plays in which we uncovered life histories, anecdotes, and group members' perceptions about how the world works. The education component consisted of learning how to do theater, learning about our life histories and issues of group members, and sharing these new understandings with the community. The action component overlapped with the education component in our actual performances of *Get a Job!* We had also supported one group member in successfully confronting officials in the Department of Mental Health and winning monies to pay for job training. With the proceeds from the play, the group opened its own savings account, and began discussions on starting a small group-owned business. And in addition to research, education and action, group members had changed noticeably in their self-esteem and confidence in their ability to express themselves publicly.

In making the move from the base community model to the participatory research model, we had become more active in the community as I had hoped. This is not to say that we could not have done the same with the base community model, only that in this case, for whatever reasons, the act of focusing on theater production rather than mutual support and prayer had the effect of moving the group toward interacting more with the community.

Yet to me, the critical awareness that participatory research is supposed to raise did not seem to happen in this production. In particular, I wondered how this experience had helped group members understand the world in a way that enabled them to see the structural reasons for discrimination, and that would motivate them to change it. The types of analysis we had done somehow seemed inadequate to me. True, by creating characters that robbed disabled people of their rights to work, we had illustrated a social problem and how disabled people feel as a consequence. But we had not taken the analysis further to ask why employers behaved this way, why more opportunities for employment did not exist for disabled people, what social forces were in place to make this happen, and what might be done to change this. Where *Get a Job!* had succeeded as a vehicle for self-expression and empowerment, it had at least in part failed as a vehicle for critical education and analysis.

Participatory theater

At this point, I began to research other models of community theater. I found that there are many types of community theater designed to raise awareness or bring about change: popular theater, people's theater, theater for development, "agit-prop" theater, theater for social change, theater of the oppressed, etc. Of all these forms, I understood ours to be most closely aligned with popular theater, defined by Kidd as

> people's theater speaking to the common man his language and idiom . . . dealing with problems of direct relevance to his situation. It is popular because it attempts to involve the whole community, not just a small elite determined by class or education (Kidd & Byram 1978:3).

I learned that in the 1980s, popular theater had become increasingly participatory (Kraii et al, 1979). As with previous models of popular theater, participatory theater aimed for dramatic presentation of commonly held problems and possible solutions, involvement of cast and audience in discussions during or after performance, critical understanding of the problem, and follow-up action. The biggest difference was that it also aimed for maximum involvement of local people in all stages of play production.

This description most closely matched our effort in *Get a Job!* We had presented our problems in a drama that was conceived, written, and performed by all of us. We had discussed our efforts and issues with the audience afterwards. And we had taken some action in the process of developing the play and afterwards. What we had not done, however, was critically analyze a key problem raised in the play: discrimination against disabled people in the area of employment. We had raised these issues, but they somehow got lost in the process of trying to create the play.

Why had we not taken these issues further? I remembered that the material for the play had come solely from cast members' reported experiences and improvisations based on those experiences. I also remembered that I and other facilitators had tried several times to prompt a discussion about reasons for discrimination, but such discussions seemed to go nowhere, often leaving cast members confused, not sure why we (the facilitators) wanted to talk about social analysis and systemic reasons for problems. Personal stories held their interest more.

analysis requires an ability to think abstractly - an ability which was simply beyond some people's ability. For example, some group members do not understand "aboutness." After one performance, when asked what the play was about, one cast member responded "We danced, eating breakfast. I don't know. That's a hard one." Moreover, regardless of a person's ability to think abstractly, most people simply think more clearly when given something concrete to react to. With this group, the question "What are the economic reasons for Bob earning as little as he does?" would draw random and vague responses, whereas "Bob only earns 50 cents an hour stuffing envelopes. Why do you suppose that is?" would be more likely to elicit a reaction. Perhaps the biggest reason for their reluctance, though, is that like all people, unless they have had experience working within a system, it is difficult for them to understand how that system works, much less analyze it. Motivated by these realizations, I decided to encourage the group to develop *Special* in a slightly different way.

As with *Get a Job!*, preparation for *Special* went through scene development and rehearsal stages. In the scene development stage, we experimented with pantomime, role playing, drawing pictures, song writing, dancing, bringing in meaningful objects and talking about them. We experimented with theater exercises such as trust walks and acting out different emotions, and theater games like playing catch with an imaginary ball, body sculpting, and guessing games. We talked about our lives, the most powerful stories arising out of the questions "Can you see the real me? When has someone <u>not</u> seen the real you in your life?" We discussed these stories in terms of theater: how could we dramatize our experiences in a way that would make a point, and what point did we want to make? We also incorporated these stories into music by changing the lyrics of popular songs (e.g., "Can you see the real me?" by The Who). We even wrote two songs from scratch.

The rehearsal stage saw these activities gradually give way to scene construction in which we would role play a piece, then discuss how to flesh out characters, dialogue and plot. That week Janet or I would go home and put together a script based on our discussion, then go over it at our next meeting, act it out, revise it as desired, and add another piece. We made scripts for those who could read and tapes of the dialogues for those who couldn't. As the rehearsal stage went on, group members also took a more central role making decisions about blocking, choreography, prop making, choral arrangements, etc.

What set *Special* apart from *Get a Job!* was the introduction of an interview project into the process. After several weeks of scene development, I introduced the idea of not only including our own experiences as material for the play, but of also finding out more about how the world works, and using that information in the play as well.

I recommended the idea of participatory research,[4] which we defined as a group:

Mark[5]: Does anybody know what research is?

Kim: Yes. Where you look up things in a book or something, or . . . like say if you wanted do an investigation, I'm thinking of saying it in a different term than . . . research.

Mark: Uh huh.

Kim: But like if you wanted to do a investigation, or do a research on like animals or something . . . .

Mark: Uh huh.

Kim: You'd have to go and find a book (so) you'd be able do find what you need out. So that's called a research . . . .

Mark: That's it. It's basically asking a question.

George: Oh, okay.

Upon informing them that interviews also constituted a form of research, they got excited, and proposed three possible topics: how to get transportation services from the city, how people were being treated in the state school which was to be closed down, and how disabled people were being treated in group homes. I was most interested in the first topic since it looked smaller and therefore more manageable. I also felt that if we decided to act on a problem, it would

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[4] When discussing it with the group, I used the term "action research" to stress linking our inquiry to action.

[5] I use my name to identify when I am speaking; pseudonyms were used for all other speakers to respect their anonymity.

be easier with something like transportation than closing down a state school. In the end, however, the group was really more interested in the state school and group home issues, which we investigated.

Over the next several months, group members identified methods for gathering data (primarily interviews, though they also brought in articles from newspapers, news clips from previous struggles with the state school, etc.) and set out to interview several people they knew who had been involved in the human services industry, particularly the closing of Glenview State School. For each of these interviews, we would meet to compose a list of questions, go conduct the interview (which we videotaped), then return and discuss what had been said, sometimes reviewing the video tape of the interview to review key passages. In time, the group interviewed six people who had "expert knowledge" of the state school and the human services system in general: two educators who espoused the "normalization" ideas of Wolf Wolfensberger (1972), one parent of a former state school resident who had started his own advocacy organization, and two former residents of the state school, one of whom was in our group. The final person we interviewed was the public relations officer at the state school itself - an emotional and, at times, painful interview since it involved going to the school and visiting buildings that some group members had once lived and worked in.

After each interview, we would review at least part of the video tape, discuss what the interviewee had said, write our observations down along with suggestions about how to conduct interviews, and determine our questions for the next interview. Two key questions evolved: (1) Is the state school really closing? The answer was yes. Responses included information about when it would close, what would take its place, and where residents would go. (2) Do people leaving the state school have a choice where they go to live, and under what conditions? Again, the answer was yes, and the interviews clarified the conditions.

Out of these two questions arose an additional question discussed in these interviews: Once people are sent to group homes, do they have a say over their living conditions? A seventh interview was conducted to dig deeper on this question, this time with one group member who had lived in a group home, and a former member of the group who was currently living in a group home. Excerpts of these video-taped interviews were shown in the actual play as an example of what the Friends Support and Action Group does as a group.

After seven months of scene development, rehearsals, and interviewing people, the Friends Support and Action Group performed *Special*. It ran one hour and included six scenes. The first half consisted of role reversals in which "SuperGeorge" would fly through the air, cape flapping in the wind (simulated on video with a blue background) and arrive on stage to put "normals" in disabled people's places. The second half consisted of activities we do as a group - meetings, parties, the interview project. We played two nights for audiences of over 100, and were hired a month later by two human services agencies who wanted their staff to come see it. After being dormant for several months, we are again rehearsing for another round of performances this spring. (For a copy of the entire script, see Appendix A.)

Critical pedagogy

By adding the interview project to the development of *Special,* an interesting question arose: Given the traditional role of interviews as a data gathering technique for research, how well had these interviews worked? I began thinking about this question when our second interviewee commented that he his interview had not gone well, and that it was a mistake to try to do this kind of work at all with people with PLMRs. At the time, I didn't know if I agreed, but I did see his point. George, the main interviewer, could not read his notes, though he could when we practiced them earlier. I had posted the same questions on a piece of flip chart paper on the wall, but in the pressure of the moment, he got nervous and could not read them either. Finally, he was able to read some questions, but the effect was that he was skipping around, leaving the interviewee confused. Often, the interviewer would forget what he had asked, or not hear the answer, so even if something relevant or provocative was said, he didn't pick up on it.

But then a curious thing happened. After conducting each interview, we would review the video tape from that interview in order to make sure we understood what had been said, write the key points down on flip chart paper, and determine questions for our next interview. Upon reviewing the tape from the second interview, I stopped it where the interviewee said the following sentences:

> A major problem with programs is that they, services don't necessarily exist for the client of the service, that they exist for other interest groups. And so one of the problems with making programs work is that you have to make sure that the client gets something out of it and so most programs have problems in that regard, making sure that the interests of the person that's supposed to be served come first.

I asked George and other group members what they thought he meant by this. They were silent. I ran the segment again, and asked "Do you have any idea what he means?" Again they were silent. I then asked "What are your feelings right now based on what he said?" George responded, "Why do people talk that way?" I wrote this down on the flip chart paper. No one could explain what the interviewee meant, however, so I paraphrased what he had said, then wrote it down in phrases, explaining what I thought he meant by "interest groups," "clients," etc. Of course, the group knew what these words meant when we discussed them, but the way they had been delivered was so confusing to the group that they couldn't catch the implication: that the human services system is designed to serve itself, to stay in business, to pay specialists high salaries, etc., and that clients' needs were, by comparison, of little or no concern. Again, group members already knew this, and could even tell stories of abuse they had experienced at the hands of human services workers.

I pointed out that what they had experienced is sometimes called oppression (yet another new term to them) and pointed out how just as they had been oppressed, so no doubt had been their workers, and their workers' employers', and the employers' supervisors, on up the chain. This appeared to be new to them. I emphasized that oppression does not always occur in the same way, or to the same degree, so it would be a mistake to assume that the Commissioner of Mental Retardation was as oppressed as a mental health client. Still, the group was able to discuss how workers, employers, etc. whom they had known in the system had all had their troubles with the system, and saw how the problems they had faced in their lives were much larger than abuse by their workers alone. We brainstormed reasons people behaved this way and drew the following diagram to illustrate the point:

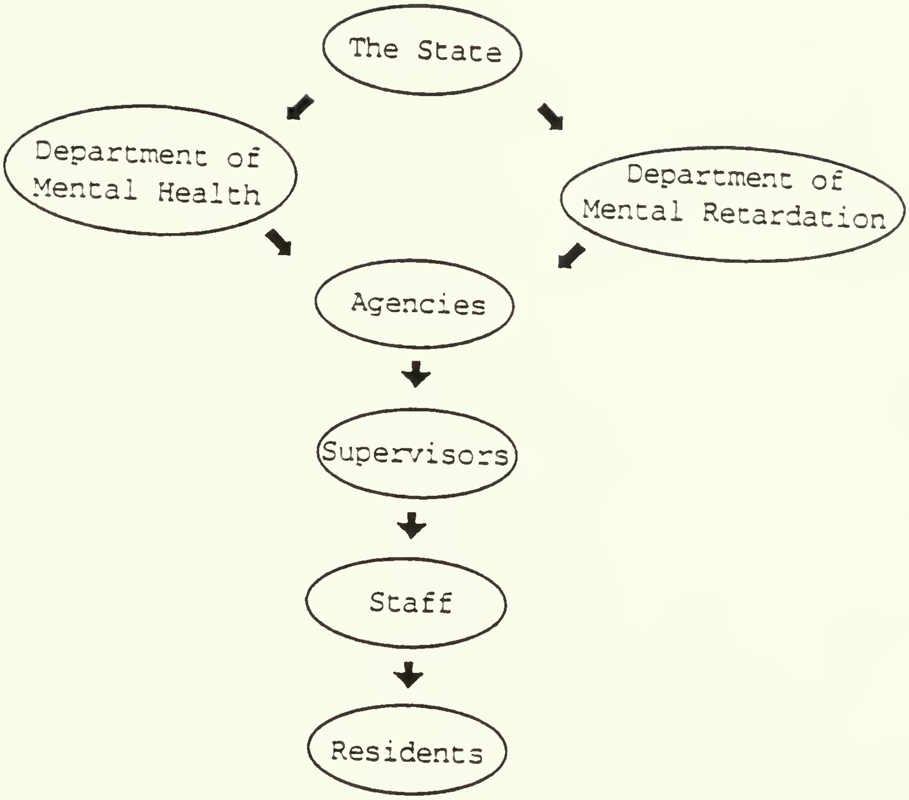

Figure 2
The chain of oppression

As the interviews progressed, group members became bolder about asking questions concerning abuse, staff treatment, and causes of such behavior. By the seventh interview, in which we interviewed group members and friends, George seemed to have gained some composure, picking up on provocative statements and even inserting some of his own opinions. The reasons for these changes are no doubt numerous: practice had improved his skills, interviewing friends did not make him as nervous as interviewing "experts," the subject matter was more familiar to him, etc. What was even more striking to me in this interview was when, in the course of describing how staff treat residents in group homes, Kim jumped up and got the oppression chart which happened to be nearby (Figure 2) and insisted on giving her version of how the system works. She talked not only about "the chain of oppression" as we had discussed months earlier, but also the fact that we as a group needed to "go out and educate group homes and tell people that if staff don't do what residents want them to do, they should get fired. They're there for the residents, they should do what the residents want."

Kim's enthusiasm surprised and delighted me, because I realized that where the interviews might not be serving their traditional role as systematic tools for gathering data, they were serving as what Paulo Freire calls codes: pictures, songs, role plays, etc., that present a situation in problematized form so as to generate discussion around key issues in learners' lives (Freire, 1971, 1973). These key issues, which he calls generative themes, are ideas which, when tapped, the group comes alive with emotion around deeply-felt issues. Generative themes spark the kind of energy that can lead to action (Anne Hope, 1984:57). Through the use of codes, the educator can tap generative themes in order to help learners understand how oppression is built into the social, economic, and political structures of society. As a result of such discussions, learners come to name those structures in order to understand the world in a way that would enable them to change it (Freire, 1971; Brown, 1978).

Our "unpacking" of the second interviewee's comments had led to a discussion about a generative theme (oppression within the human services system) which resulted in a new understanding about the world, at least for Kim. In another instance, George was challenged by another interviewee, Dean, for self-identifying as handicapped, and for calling others handicapped. George insisted on using the word, claiming that "I explain that that way 'cause people will know." That night at rehearsal, George could barely contain himself, eager to share with the group how he had had an argument with Dean, and how he hadn't backed down. Again, the interview had served as a code, prompting a discussion of another generative theme - this time, the use of the word handicapped, when to use the word handicapped, and who defines it. And this new understanding in turn became a code, a group discussion about labels and how "advocates" choose them, often over the protestations of those who are actually being labeled. As a consequence of discussions like these, the main theme of the play became labels - not just how the public labels disabled people, but how people who call themselves advocates, in an effort not to label, put constraints on disabled people that are often even more disabling than the labels themselves. In a discussion with the audience following our third performance, one cast member said,

> We did the play because I wanted to ride on the *Special Transportation Bus* (a bus designed to provide free transportation for the disabled and elderly). But Dwight (an advocate) said I shouldn't ride on the bus because people would see me on it and label me disabled. The problem is, it is a way around, and I don't have any other way around."

In fact, *Special* illustrated just this point: that just as the word "special" can both appreciate and segregate, so can the best efforts of advocates both help and disempower.

Discussion

In addition to learning how to do participatory research with PLMRs, *Special* taught me about how PLMRs think, what activities work under what which conditions and why. Specifically, I learned the following:

Two groups

The group really consisted of two groups. Though all were classified "higher functioning" by their service agencies, there were two clearly discernible levels of functioning within the group. The higher functioning could be characterized as being able to:

a) read and write to some extent;

b) talk about how systems work;

c) stay on the subject in a discussion;

d) "conceptualize," or tell what something is about or what something means symbolically rather than by example;

e) perform tasks that require certain kinds of technical ability (e.g., leaving a message on an answer machine);

f) guess things that were not immediately apparent (e.g., things one might find on a beach); and

g) remember to some extent what was said or done in previous discussions or meetings.

Though I am loathe to use such terms as higher or lower functioning, and while I never used these terms with the group, as an educator and director, this distinction was critical. If a rehearsal or scene writing activity required some of these abilities or knowledge areas, higher functioning members had to be there, or the activity had to be changed. Some of our biggest failures resulted from my ignorance of this distinction, and those rehearsals proved to be demoralizing for cast members and frustrating for us facilitators. The interviews always required the presence of at least one higher functioning person, so every effort had to be made to ensure that they showed up. And every scene in the play had to include higher functioning members or normals in order for lines and blocking to be remembered.

Conditions of successful interviews

Under certain conditions, the interviews worked well - that is, they were interactive and lively, and group members tended to remember the content, bring it up in subsequent discussions or want to use it in the play. Conversely, even when group members were prepared for the interview, if these conditions were not present, group members tended to forget where they were in the interview, ask questions randomly, and forget what was said after it was over. In general, interviews worked well when:

a) the interviewee seldom used words over three syllables long (all group members showed noticeable difficulty remembering, pronouncing, and using words over three syllables);

b) the interviewee seldom used sentences over 20 words long;

c) the interviewee seldom used words interviewers did not understand, or made sure to define them right away when he/she did;

d) the interviewee used a good deal of humor to make points;

e) the interviewee engaged the interviewees, asking them personal questions, trying to make examples relate to their experience, calling them by name, and sometimes challenging them;

f) the interviewee spoke in a lively, animated fashion, using a lot of hand gestures, intonation, etc.;

g) the interviewers consisted of at least two "higher functioning" members of the group;
h) the interviewers had questions written down in advance that they could refer to, and were able to read and understand them in the interview; and
i) the interviewers and interviewees self-monitored, or were able to monitor someone else when he/she carried on too long.

Patterns of successful rehearsals

Like the interviews, successful rehearsals were marked by certain patterns. In general, they worked best when:

a) they were lively and interactive;
b) they included the creation of some new part, or the introduction of some new element, such as a new scene, instrument, cast member or helper;
c) they did not go more that two hours;
d) group members had sufficient time in advance to know about an event;
e) group members had ample opportunity to practice in the place in which they were to perform;
f) friendly faces were in the audience; and
g) lights, cameras or microphones were held up to group members.

In general, rehearsals worked worst when:

a) tasks were too difficult or unclear, or some detail of the task was unclear, such as how long it would last, where it should take place, what its purpose was, etc.;

b) no apparent process was in place to push a decision through or move an activity along.

c) plans had been changed, or had to be changed;

d) they were scheduled in conflict with an important life function (e.g., eating dinner, going to church, etc.);

e) when attendance was poor (often due to bad weather, illness);

f) when people came to rehearsal sick, tired, hungry or angry;

g) when preparation was inadequate, including bring props and set materials, scripts, or directors being able to repeat every line and stage direction.

Conclusion

The four models influencing the development of *Special* - base community, participatory research, participatory theater, and critical pedagogy - serve as a "road map" for a trip through the development of *Special*. Lessons learned from this process - that there were really two groups within one, that certain conversational dynamics worked better than others, and that certain factors meant better rehearsals, provide an insight not only into the nature of the activities undertaken, but into the nature of group members themselves, suggesting why some activities worked, and why some did not. As Chapters 5 - 7 illustrate, there were additional reasons why activities worked the way they did, particularly group members' chronic problem orientation, their justice orientation, and their drive to visibility.

CHAPTER 3

METHODOLOGY

Introduction

Over the course of eight months, the Friends Support and Action Group, a group of nondisabled people and people labeled mentally retarded (PLMRs), conducted a participatory research project. In this project, they met on a regular basis to talk about their lives, do theater exercises, and create a musical theater production entitled *Special*. As part of that project, group members interviewed advocates of disabled people, administrators from the recently-closed Glenview State School, and their peers in order to learn about the conditions under which people released from Glenview were going to live. As a result of these efforts, the Friends Support and Action Group performed *Special* on several occasions, conducted educational workshops on disabilities issues in schools, and in some cases, began making changes in their own lives.

Special is an example of participatory research, an approach to social change that involves research, education, and action, usually with disenfranchised people, in order to bring about material changes in their lives, and structural changes in society (Hall, 1978; Park, 1989). I chose to use participatory research with this group because of its potential for helping group members create knowledge, take part in empowering action, change the social structures that keep disabled people oppressed. In contrast to other types of research which are designed to test some theory or prove the effectiveness of some product or process, participatory research was used here for the sake of educating oppressed people and their allies so that social change might come about.

This dissertation is an ethnographic study of that participatory research project. It is, then, "research on research" in which I have used ethnographic methods of data gathering and analysis in order to investigate how group members revealed their understandings of themselves and the world through the development of *Special*. As such, my primary interest was anthropological - observing their behavior, trying to understand their words, their meanings. My secondary interest was epistemological - observing what these understandings tell us about the way group members understand themselves and the world. In time, I developed an additional interest in trying to understand why group members understood themselves the way they did, in particular, why they were given to chronic outbreaks of hostility, what role internalized oppression might play in these outbreaks, and in particular, what it meant for them to reject a social identity of mental impairment. In time, I found that they were "hardwired for joy," yet they did have a chronic problem orientation, that they shared a strong sense of justice, and that their need to be seen, or what I call their "drive to visibility," explained at least in part why they often acted in a destructive manner. These findings represent comprise Chapters 5, 6 and 7 of this dissertation. In the remainder of this chapter, I will explain the research questions and the assumptions and definitions on which they are based, how they evolved, and how I consequently designed this study.

Research questions

The primary research question of this study is: How did members of the Friends Support and Action Group understand themselves and the world as revealed in the process of developing *Special*, a participatory theater production? The implementing questions of this study are:

1) What do group members value? What concerns them?
2) How did group members enact these values and concerns in this study?
3) What do group members' enactment of values and concerns mean? I.e., why do group members enact their values and concerns the way they do?
4) How can insights from this study enable PLMRs and people who work with them to better understand their perspectives?

Because the data from this study were initially analyzed inductively, a second set of research questions arose out of that initial analysis. They were:

1) What accounts for the volatility of the group?

2) What role does fear play in the volatility of the group?

3) What role does visibility play in overcoming fear and developing a sense of pride?

4) How does understanding internalized oppression help us understand the reason for fear, and the role of visibility in the lives of PLMRs?

5) Why do PLMRs refuse a social identity of impairment, and what are the implications of this refusal?

Assumptions

This research was based on the following assumptions:

1) PLMRs are oppressed in a variety of ways in the US. One principle source of this oppression is ignorance about them, which often leads to prejudice. Another principle source of oppression of PLMRs is the tendency for "normals" to ignore PLMRs, and to speak for them in terms of policy, practices, legislation, and media exposure.

2) Most PLMRs are capable of thinking for themselves, making important life decisions, and expressing their views on a range of topics from their own life histories to how the world should be.

3) Participatory research, especially in the form of participatory theater, offers a viable way of helping PLMRs learn about the world, express their views, and

initiate change. Participatory research also offers a viable way of educating "normals" about the issues of PLMRs, helping normals overcome their prejudices and find ways to listen to PLMRs and help them in more empowering ways.

4) Within the world of human meaning, reality is a social construct (Berger and Luckman, 1967), and as such, can be understood as arbitrary, context-specific, and changeable based on social circumstances.
5) Ethnographic research is an effective means of capturing how PLMRs understand themselves and the world.
6) Inductive analysis is a viable means for analyzing ethnographic data in order to develop categories and hypotheses about how these PLMRs understand the world.

Definitions

1) Mental retardation is a "behavioral syndrome," not a disease or a physical illness, "characterized by prolonged and severe deficits in thinking and reasoning (cognition), as well as deficits in meeting the needs of daily living (adaptive behavior)" (McGarrity, 1993:38-42).
2) Oppression is a force that occurs when social power and prejudice are combined, usually against devalued people or groups.

3) Internalized oppression is "the incorporation and acceptance by individuals within an oppressed group of the prejudices against them within the dominant society" (Pheterson, 1986:148).

4) Visibility consists of two parts: expressive visibility, or being oneself fully, openly, undefensively, and expressively (Pheterson, 1986:148); and acceptance visibility, defined by group members as being seen, understood and accepted for who one really is.

5) Social identity as defined by Tajfel (1981), claims that belonging to a group and having a positive social identity with that group is necessary for mental health, and that it is possible "to attempt to construct a positive identity based on being different" (cited in Szivos and Griffiths, 1990:333).

Evolution of a research question

As described in Chapter 2, I began this study with an interest exploring how participatory research might help the Friends Support and Action Group become more action-oriented and more critically reflective than they were the first two years of their existence as the Manna Base Community. When we began to develop *Special*, I also began gathering data in order to investigate the role theater could play as a participatory research technique with PLMRs, as well as the role of the facilitator (me) in this process. I soon realized, however, that certain factors made this project too idiosyncratic to be generalizable or useful. For one thing, the origin of the group as a base community made it unique. To what cause could I attribute the group's ability to be supportive of one another, for example, the base community or the theater experience? Additionally, we used a good deal of music in our rehearsals, and one member in particular, Sam, had a gift for remembering words to songs and improvising lyrics wherever he saw fit. To what extent could other groups do what we were doing giving these idiosyncracies? Finally, my role had become so multifarious that tracking it for the purposes of analysis seemed nearly impossible. At turns, I found myself serving (not always well) as teacher, counselor, mediator, friend, ride-giver, co-researcher, musician, set designer, carpenter, supervisor, audio-video technician, actor, director, talent scout, and producer.

I now realize that careful ethnographic description of the theater process and my role as facilitator would have been sufficient to account for what happened and in what ways, and that others could learn from this and adapt it to their situations without necessarily focusing on one discrete phenomenon or utilizing an experimental design to show causality between methods and outcomes. Having put the theater and facilitator questions aside, however, I began searching for another focus. At that time, I was becoming intrigued with the ways in which group members talked about the world, often with passion and clarity, particularly regarding their own life histories. At the same time, when interacting with other "normals," especially in the interview project, they would often shut down, or change their personalities in a way that I barely recognized them. I also realized that they were making sense of the interviews in different ways. Some would remember details, others would not. Some would find particular points problematic, others would not. I began to wonder just how group members actually put their ideas together. I also began to wonder what role their ideas might play in helping to bring about change in the disabled community. I was particularly concerned at that point that in spite of the fact that these people seemed perfectly capable of expressing their ideas and interests, few people in the human services system took them seriously enough to listen to them, or include them in decision and policy-making activities. This study, then, became a vehicle to "have their voices heard" in a way that might enable policy makers to understand that PLMRs do in fact have something to say, and should therefore be listened to, particularly about issues affecting their lives.

My goal, then, was to chart "disabled people's ways of knowing," a goal I quickly abandoned when I realized that in order to make such a claim, (a) I would need a much larger sample than the eight regulars in my group, and (b) I would be attempting to answer an enormously difficult question, one which would require a background in areas with which I was unfamiliar, such as cognitive psychology and development, learning disabilities, the philosophy of knowledge, and the like. In an effort to narrow my question, I decided to focus on what group members simply said and did in the course of developing *Special*, and how I might categorize the types of knowledge that emerged from it. For an analytical framework, I modified Gurvitch's (1971) formulation of types and forms of knowledge and wrote my dissertation proposal with the primary research question: In the participatory research project under study, what was the relationship between the kinds of knowledge created and used by the Friends Support and Action Group, and activities, roles, language and discursive categories used in the project?

Much to my dismay, once I began analyzing data, I realized that even with this restricted focus, I would still need to have more knowledge about cognitive processes, and I would probably need to have set up the design differently from the beginning if I wanted to chart how group members were thinking. For example, Charles might have used a deductive approach to verifying that he knew something, but what did this mean? Had he done it correctly? Did he do it often? Did other group members do it too? I felt stymied because I could not answer these questions without some level of cognitive testing of group members, and in any case, this was not my primary interest. What I wanted to find out was how group members made sense of the world, what this understanding can teach others about the reality of their world, and how to enable PLMRs to speak for themselves so that policies, practices, laws, and public opinion might emanate from them rather than from people speaking for them.

My question changed one more time to one that I could answer, and one that I wanted to answer: How do group members understand themselves and the world? My research question was motivated by the assumption that given the chance, these people could no doubt produce knowledge just like anyone else. This question was also much simpler in that it essayed to find out not how they know, but simply what they know, and what their knowledge means in terms of their struggle for a better life as PLMRs.

A social constructionist approach to research

In contrast to positivist approaches to research in which facts or causes of social phenomena are investigated in order to explain, predict or control reality, this study employs a more phenomenological approach, which is concerned with understanding human behavior from the actor's own frame of reference (Bogdan and Taylor, 1975:2). According to Bogdan and Taylor,

> (T)he phenomenologist views human behavior - what people say and do - as a product of how people interpret their world. The task of the phenomenologist, and, for us, the qualitative methodologists, is to capture this process of interpretation (p. 13).

This study attempts to capture group members' process of interpretation in order to learn how they view themselves and the world. This phenomenological approach is appropriate for this study for two reasons. First, within the world of meaning, reality is socially constructed (Berger and Luckman, 1976) and that, as such, can be understood on the basis of how people interpret the way it is constructed. Thus, if I wish to find out how group members understand the world, the most reliable source of information is group members, the "constructors," themselves. Second, one of the main subjects of interpretation in this study - mental retardation - is itself a social construct (i.e., category) and, as such, can be understood more critically if seen through the eyes of those who did <u>not</u> construct it, but instead received its negative consequences. A phenomenological perspective, then, lays bare not only what people construct, but more importantly, how people have been constructed, in this case with damaging effects, and thereby experience the world.

The phenomenological approach, which has also been called a social constructionist approach (Taylor) and an interactionist approach (Abberly, 1987), is based on the ideas of symbolic interactionism, a term coined by Herbert Blumer (1969), though originally elaborated by George Herbert Mead (1934). According to symbolic interactionism,

> a situation has meaning only through people's interpretations and definitions of it. Their actions, in turn, stem from this meaning. Thus, this process of interpretation acts as the intermediary between any

> predisposition to act and the act itself (Bogdan and Taylor, 1975:14).

If interpretation determines action, then we can determine why people behave the way they do on the basis of how they explain reality. Thus, if a group member says that he hit his staff worker because his staff worker called him a retard, a symbolic interactionist perspective would maintain that this was in fact why he hit his staff worker. Of course, the group member's account must be balanced against what others observed in his behavior, and other motivating factors might also be identified by the observer. Nevertheless, symbolic interactionism maintains that a reliable account of "reality" can be obtained by collecting the interpretations of all relevant actors in a given event. As such, the symbolic interactionist school makes two unique claims: first, that self-reports can be considered a reliable form of data; and second, that the interpretation of people's behavior is a reliable method of determining the social meaning of events.

Critical theorists often take issue with these claims. Freudians maintain that people's actions do not necessarily stem from the meaning people give them, but from unseen forces such as the id or superego. Neo-Marxists maintain that regardless of what people think, the reason they behave the way they do is because of unseen forces such as exploitation of surplus labor or hegemonic ideologies. Structuralists and poststructuralists argue that human behavior can best be understood as a response to the logic and structure of language on the one hand, and the social structures within which we are nested (e.g., kinship systems) on the other (Ehrmann, 1966; Poster, 1990). Finally, some theorists claim that whatever the unseen factors are, interpretation is simply impossible. Augusto Boal, for example, says that we cannot "know" what others intend, that they might not be able to know themselves. All we can honestly do is "project" our meanings on them, as he does in his Forum Theater exercises (1985, 1992).

Interactionist studies have also been criticized for their failure to be critical. One such criticism faults interactionist studies of disability for their "failure to link interpersonal relations with the material base upon which interactions take place" (Abberly, 1987:14). Because they tend to be descriptive without being critical, says Abberly, impairment is viewed as a "given," a

> "natural" property rather than a social product (which) ultimately "explains" discrimination and disadvantage for such analyses appeal to some social mechanism parallel to the posited "basic ethnocentrism" employed in some studies of race (p. 14).

Abberly's criticism is well taken. Of the interactionist studies that have been done with PLMRs, and they are few (e.g., Bogdan and Taylor, 1982; Gibbons, 1985; Szivos and Griffiths, 1990), none has invoked a critical framework to highlight the oppressive dimensions of subjects' reported reality. This is not to say that studies have been uncritical. Some have focused on the problem of labeling, particularly the word retarded, as a destructive social consideration - reflexive inquiry - weaves throughout this dissertation in my reflections on why I chose the methods I did, the effect group members' actions and the overall process had on me, and how my impressions guided subsequent decisions.

I also argued in my comprehensives papers that the biggest danger in doing critical ethnography is failing to first listen to people and their understanding of reality before invoking a critical framework that faithfully reflects their lived reality. This problem has been discussed at length by the poststructuralists. For example, Michael Foucault argued that Marxism's tendency to totalize all people's issues under the rubric of exploitation of labor failed to look at people's struggles in their historic specificity, resulting in irrelevant, useless, even oppressive analytical claims. Poster (1989) claims that this totalizing tendency was one important reason for the demise of some critical theories and the rise of poststructuralism. By attempting to understand all world problems through the prism of class conflict, neo-Marxists, particularly some members of the Frankfurt School, had failed to account for 1) Western forms of domination associated with the decolonization movement; 2) patriarchy and the issues raised by the feminist movement; and 3) the escalated use of technology in social regulation, especially through electronic systems of communication, cybernetic construct (Mercer, 1973; Bogdan, 1980). Szivos and Griffiths' 1990 study examined the role the loss and social role identity paradigms can play in understanding PLMRs' views of themselves. Yet these studies leave untouched the question of social forces that militate against the just treatment of PLMRs as oppressed people. For this reason, I argued in my comprehensives papers (Lynd, 1990) that when the ethnographer's agenda includes both cultural understanding and social justice, a critical approach to ethnography is necessary. Otherwise, we risk stopping at the level of interpretation, failing to provide a view of reality that also reveals the forces that keep oppression operative, and the possibilities for social justice to be achieved. In order to attain this perspective, one must conduct a critical ethnography. According to Simon and Dippo, in order for an ethnography to be critical, it must consider three things:

> 1) a particular "problematic" that defines data and analytic procedures in a way consistent with one's pedagogical/political project; 2) the engagement of such work within a public sphere that allows it to become a starting point for social critique and transformation; and 3) the inclusion of a reflexive inquiry which would identify the limits of its own knowledge claims (Simon & Dippo, 1986:195).

In this dissertation, the "problematic" was the type of oppression experienced by PLMRs, and the concomitant problem that emerged in the study of internalized oppression. The "public sphere" dimension was the live performance of *Special*, out of which continued discussion with audiences and revisions of the play became possible. The third devices, and the massive institutional growth of science (p. 3).

In order to provide a critique that is relevant, useful and unoppressive, then, I have argued that we should first try to understand the insider's perspective, or the emic perspective, before invoking a critical framework. Otherwise, we risk falling into the same totalizing trap of other critical theorists, thereby dominating the people we are attempting to assist. Based on this argument, I have made an effort in this study to include both emic and etic perspective in Chapter 5, and 6. Then, on the basis of what I found, I invoked an internalized oppression framework to analyze one aspect of these data, visibility, in Chapter 7.

Design of the study

According to Bogdan and Biklen (1982), "qualitative methodologies refer to research procedures which produce descriptive data: people's own written or spoken words and observable behavior" (p 4). Qualitative measures are used in this study because the aim is to learn how members of the Friends Support and Action Group understand the world in their own terms. In contrast to quantitative measures, which commonly attempt to survey a broad spectrum of phenomena,

> Qualitative measures describe the experience of people in depth. The data are open-ended in order to find out what people's lives, experiences, and interactions mean to them in their own terms and in their natural settings. Qualitative measures permit the evaluation

> researcher to record and understand people on their own terms (Patton, 1986:22).

This study employs the methods of ethnographic research, a type of qualitative research which emphasized the importance of understanding "the experiences of people in depth" both from an insider's point of view, called the emic perspective, and from an outsider's point of view, or an etic perspective. Given my interest in understanding how group members view their problems and what needs to be done to solve them, the type of ethnographic research used here is what Spradley calls "strategic research":

> Another way to synchronize human needs with the accumulation of scientific knowledge is through what I call "strategic research." Instead of beginning ethnographic projects from an interest in some particular culture, area of the world, or theoretical concern, strategic research begins with an interest in human problems. These problems suggest needed changes and information needed to make such changes (1979:15).

This study, then, is a critical ethnographic account of a participatory research project, an account that aims to understand group members' interpretations of their world, to assess the data derived from these interpretations in light of a critical framework that suggests why oppression of this group exists, and to explore what can be done to change it.

Research methods

Data gathering, analysis and reporting methods used in this study typified ethnographic methods, described below.

Data gathering

Over the eight-month course of this project, I gathered data in meetings, rehearsals, performances, interviews, and informal settings such as parties, walking around town, and telephone conversations and messages. Principle methods of data gathering were participant observation, interviewing and group discussions, gathered through audio and video taping, taking field notes, and collecting real objects. Interviews and group discussions used in the study included: eight interviews conducted by group members of advocates and human services workers as part of the participatory research project; individual and group interviews I conducted with cast members; group discussions with cast members and audience members; and interviews conducted with cast members by our videographer. Interviews I conducted were semi-structured and open-ended. Many events were audio- or videotaped; all interviews conducted by group members were videotaped and transcribed, as were other events. When transcribing these passages, I attempted to preserve their language and speaking patterns as much as possible. Editing decisions were made when ideas seemed unclear, when there were excessive redundancies (e.g, uh uh uh), or where I felt the person speaking might appear "stupid" if their words were left in the original form. I did, however, include certain types of errors in order to preserve the feel of the person's speech pattern (e.g., inlegally), and refrained from the disparaging practice of using the term _sic_.[1]

Data analysis

Data were analyzed first inductively, then by using a framework of internalized oppression as delineated by Pheterson (1968). Approximately 250 pages of transcripts, and four dozen audio and video tapes were examined following the coding procedure outlined by Bogdan and Biklen (1982:155-170). Categories were identified following a procedure similar to Spradley's procedure of identifying cognitive principles, or

> something that people believe, accept as true and valid; it is a common assumption about the nature of their experience (e.g., men are superior to women). . . . Themes are assertions that have a high degree of generality (Spradley 1979:186).

Data expansion stage. In an attempt to make this process as inductive as possible, I started with no categories or codes, but simply asked the question: "How do group members understand themselves and the world?" I came up with approximately 30 codes which I grouped together in categories which I called discourse, knowledge, themes, and other. As noted in _Evolution of a research question_ above, in the early stages I was interested in learning _how_ group members knew things, and how they created knowledge. I

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[1] My thanks to Francis Bailey for raising my awareness on the issues surrounding the use of the word _sic_.

began by examining the data for types of knowledge: inductive, referred, anecdotal, etc. I soon realized I did not have sufficient data to make any claims about how group members expressed new thought (i.e., created knowledge). To do so would have required not only observations as I had done, but some verification of these observations using some instrument to assess cognitive factors that occurred before, during and after the project. It was also at this point that I realized this had never been my interest. Rather, I wanted to show that these people could think and speak for themselves. I also wanted to present evidence that what they thought about was intelligent, worthwhile, and important to understand. Thus, I decided to eliminate the question of <u>how</u> group members appeared to know things, and to focus instead on <u>what</u> they knew.

On my second pass through the data, I asked the following questions:

1) How do they define things?
2) What do they value?
3) What do they fear?
4) Where do ideas come from?
5) How do they validate knowledge?
6) What makes them happy?
7) What makes them sad?
8) What do they get confused about?
9) What do they do well?
10) What don't they do well?

11) What do they claim to know?
12) What do they claim not to know?
13) What do they claim not to know, know how to do, be able to do?

On this pass, I kept the same categories, but added more codes, now totalling 64. I was beginning to realize that of primary importance to me was finding out what their knowledge suggested about who they were, and how they perceived themselves and the world. That is, what does group members' knowledge suggest about their knowledge of the world <u>and</u> their own self-perceptions? I knew that my research was taking an ethnographic turn from "the knowledge question" to "the meaning question." On the third pass, I developed 11 categories with which to categorize the data:

1) Rules and suggestions
2) Language and words
3) Their views of retardation - avoiding or denying their handicap
4) Power differentials - e.g., teacher-student rapport
5) Identity issues
6) Evolution of the word special
7) Evolution of the "checking in scene" (in which they talked about what problems they were facing that day)
8) Visibility issues
9) Stories of resistance
10) Stories of resistance/being held captive
11) Stories of sadness and joy

Out of this third pass, instead of reducing my scope, these 11 questions yielded a total of 192 codes. At this point, Francis Bailey, a friend and colleague who had recently finished his ambitious dissertation, noted that I was still in the data expansion stage. I realized that this could probably go on forever, and that I needed a way to start reducing my data.

Data reduction stage. I grouped my codes and categories into five prominent themes: (1) identity issues: being misunderstood and/or mistreated, not being accepted for who one is, being labelled, feeling invisible, wanting to be someone else; (2) values: of friendship, of family, being in community, of being smart or capable, of helping others, of being recognized; (3) problems: of being bored, mistreating each other, loneliness, loss of loved ones, poverty-related issues, abuse by would-be friends; (4) norms: how people should treat each other, that people should be able to live free of harassment, that people should be able to choose where to live, how and with whom, that people should be able to live "normal" lives like everyone else; and (5) fear: of being seen as useless; of being told no, of being wrong, of angering others, of appearing stupid, of being reinstitutionalized, of failing.

This last theme intrigued me because I was having trouble reconciling why group members would at one minute be so happy, then the next minute be fighting. Because of evidence I found in other categories - for example, their use of disparaging words to put themselves down, or the anger they showed when they forgot something or appeared stupid - I wondered if some of their fear might be related to internalized oppression. When I searched the literature on internalized oppression, I found an article by Gail Pheterson in which she noted that visibility contradicts internalized oppression. This resonated with me as I had noted visibility as one of my coding categories, and certainly the idea of visibility was prominent throughout, down to the passion with which cast members sang the song "Can you see the real me?" In a fourth and final pass, I used some of Pheterson's categories, including visibility, pride, solidarity, self-hatred, and internalized domination, along with some of my own categories, to determine how internalized oppression might be operating within the group.

Having made this final pass, I grouped these themes and related issues into three categories which I call chronic problem orientation, justice orientation, and the drive to visibility. I selected (created) these categories for several reasons: first, because they captured what appeared to be the most prevalent patterns in the group in a modicum of categories; second, because they revealed both the greatest successes we had had as a group and the greatest difficulties, thereby rendering an even-handed account of the process; and finally, because they allowed for sufficient treatment of what emerged as a significant phenomenon in this group - internalized oppression. These three categories became the content of Chapters 5, 6 and 7 of this dissertation.

Validity

An effort was made to include four types of validity in this study: triangulation, face validity, reflexive subjectivity, and catalytic validity.

Triangulation

Data were sampled from different sources group members, friends, associates, people who attended the plays and discussions. Different methods of data collection were also used: participant observation, interviewing, group discussion. Samples of the data were reviewed by group members and colleagues, including Janet, my co-director.

Face validity

Observations and findings were continually verified with group members, associates and colleagues. Once key categories and themes emerged, more data was gathered within these categories to confirm or disconfirm working hypotheses. An extended interview was conducted with two group members to verify my coding scheme. Excerpts of this interview appear in Chapter 7.

Reflexive subjectivity

"Documentation of how my assumptions had been affected by the logic of the data" (Lather, 1986) was achieved by the inclusion of personal reflections at the end of each analysis chapter (Chapters 5, 6 and 7) in which I discuss how findings have affected my assumptions, and how my own perspective influenced my choice of categories and methods of analysis. I have also made an attempt to reveal as much as possible about myself and my relationships with group members through the vignettes and analyses in order to establish my position, perspectives, and life experiences for the reader.

Catalytic validity

"Documentation that the research process has led to insight and, ideally, activism on the part of group members" (Lather, 1986:78) was attempted by examining the kinds of action group members took as a result of this project. This assessment is based on the understanding that within the participatory research framework, one test of validity of knowledge is the extent to which it moves people to action. The extent to which this project moved group members to action is examined in detail in Chapter 8.

Conclusion

This chapter has been an attempt to guide the reader through the admittedly emergent design I followed in this research process. In the next chapter I will present an overview of the concepts of mental retardation, oppression, and internalized oppression. I will then present two chapters that deal with group members' understandings of themselves and the world, followed by a chapter analyzing these understandings using and internalized oppression framework. I will conclude with a summary of the findings, and a discussion of these findings vis-à-vis the literature, criticisms of *Special*, and additional issues.

CHAPTER 4

OVERVIEW OF MENTAL RETARDATION, OPPRESSION, INTERNALIZED OPPRESSION, AND OPPRESSION OF PEOPLE WITH DISABILITIES

Introduction: What is mental retardation?

This chapter aims to orient the reader to the concept of mental retardation as it is understood in the U.S. today, the development and current meanings of oppression and internalized oppression, and the particular kinds of oppression faced by people with disabilities. This background is not intended to be a comprehensive review of the literature, but an introduction to the relevant literature on the mental retardation, especially as it pertains to the definition and social construction of mental retardation, and as it pertains to the oppression of people with disabilities in general. Many of the concepts introduced in this chapter will be used again in Chapters 7 and 8, particularly internalized oppression and the issue of social identity.

Mental retardation defined

The term mental retardation only came into existence in the last hundred years (Gerdtz, 1993:1). Until then, people with mental impairments were referred to as mental deficients, mental defectives, mental subnormals, exceptional children, aments, and perhaps most generally in feebleminded (Edgerton, 1967:2). No distinction was usually made between people whose mental development had been slowed or stopped (i.e., mentally retarded) and people with other types of mental abilities or disabilities, or people of other lifestyles. All were considered deviant. Connecticut's first house of correction, for example, was founded in 1722 "for rogues, vagabonds, the idle, beggars, fortune tellers, diviners, musicians, runaways, drunkards, prostitutes, pilferers, brawlers, and the mentally afflicted" (Deutsch, 1949). The role of "retardate" has changed over time from sick person (therefore requiring medical care), to subhuman organism (often compared to animals), to menace (therefore requiring imprisonment), to object of pity (requiring help), to burden of charity (therefore entitled to food, shelter, etc.). People with mental retardation have also been viewed as holy innocents (therefore worthy of veneration), developing persons (therefore entitled to evolving education and other opportunities), eternal children (therefore always treated as children), and as objects of merriment and ridicule (hence the "retardate" as court fool or jester) (Wolfensberger, 1972:23).

Today, mental retardation is a descriptive term applied to those individuals who develop intellectually at below average rates and experience unusual difficulties in learning, social adjustment, and economic productivity (Wiegerink & Pelosi, 1979:7). Mental retardation is understood as a condition, not a disease or a physical illness. It is "a behavioral syndrome" (McGarrity, 1993:38). As the American Association on Mental Retardation notes,

> Mental retardation is not something you have, like blue eyes or a bad heart. Nor is it something you are, like being short or thin. It is not a medical disorder, although it may be coded in medical classification of diseases. . . . Nor is it a mental disorder, although it may be coded in a classification of psychiatric disorders. . . . Mental retardation refers to a particular state of functioning that begins in childhood and in which limitations in intelligence coexist with related limitations in adaptive skills (AAMR, 1993:9).

For the last 30+ years, the "semi-official definition" of mental retardation has been the one coined by The American Association on Mental Deficiency (AAMD) in 1959 which stated that "Mental retardation refers to subaverage intellectual functioning which originates during the development period and is associated with impairment in adaptive behavior" (cited in Edgerton, 1967:3). Last year (1993), the American Association on Mental Retardation (AAMR) redefined the term:

> Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18 (AAMR, 1993:1).

In addition to expanding on the types of adaptive skill areas which are problematic for people with mental retardation, this new definition includes the notion of present functioning, highlighting the understanding that mental retardation is not a trait but a state. In other words, "it shifts the emphasis from measurement of traits to understanding the individual's actual functioning in daily living" (AAMR, 1993:10). This new definition is also different in that it recognizes diversity, specific needs for support, people's strengths, and ability to grow, as delineated in the following assumptions which are "essential to the application of the definition":

1) Valid assessment considers cultural and linguistic diversity as well as differences in communication and behavioral factors;
2) The existence of limitations in adaptive skills occurs within the context of community environments typical of the individual's age peers and is indexed to the person's individualized needs for supports;
3) Specific adaptive limitations often coexist with strengths in other adaptive skills or other personal capabilities; and
4) With appropriate supports over a sustained period, the life functioning of the person with mental retardation will generally improve (AAMR, 1993:5).

The AAMR's definition and their discussion of how it was developed is also significant for two other reasons. First, instead of requiring subclassification into four levels of a person's mental retardation (mild, moderate, severe, and profound - see <u>Types of mental retardation</u>

below), it subclassifies the intensities and pattern of support systems into four levels: intermittent, limited, extensive, and pervasive (p. x). Second, in their deliberations over this definition, AAMR acknowledged that "many individuals with this disability urge elimination of the term because it is stigmatizing and it is frequently mistakenly used as a global summary about complex human beings," but that "after considerable deliberation, we concluded that we were unable at this time to eliminate the term, despite its acknowledged shortcomings." In order to write a current manual, they argued, they "had to use the commonly understood term for the disability" (p. xi), suggesting that, given the right conditions, even AAMR might some day consider dropping the term mental retardation.

Characteristics of mental retardation

In spite of the nuances identified by the recent AAMR definition, mental retardation is still commonly understood to be characterized by the following:

1) Mental retardation is identified and diagnosed during a person's developmental period (i.e., during childhood or adolescence).[1] It is difficult to diagnose a child before the age of 3.

2) Mental retardation involves significant and prolonged difficulties and deficits in a person's ability to

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[1] The Bayley Scale and the Vineland Maturity Scale are the two most common indexes.

think and reason. A person with mental retardation will not be able to think, use and understand language, or make use of abstract concepts with the same degree of skill and ability as others. This type of ability is usually measured through a psychological test which produces the score known as the Intelligence Quotient (I.Q.). People who are diagnosed to have mental retardation usually have IQ scores of 69 or less, with 100 being the average score for people the same age in that society.

3) Mental retardation involves severe and prolonged difficulties and deficits in a person's adaptive behavior. Adaptive behavior refers to those skills which enable us to function as members of our society, and live up to the demands of independent living (e.g., ability to dress, eat, etc.).

4) A mental retardation diagnosis implies a condition that will continue for an indefinite period (McGarrity, 1993:38).

Three other characteristics should be added to McGarrity's list. First, mental retardation is a heterogeneous condition. While people with mental retardation often share certain characteristics, some of which are listed above, in fact people with mental retardation can be as different from one another as they are from so-called normals in terms of intelligence, functioning and adaptability. This fact makes mental retardation difficult to characterize, and has implications for people with mental retardation identifying with their condition as a unifying characteristic.

Second, for most people, mental retardation is lifelong.[2] If people lose their cognitive and adaptive behavior skills later in life, or as the result of an accident, illness, or even extreme stress, they are not considered mentally retarded (McGarrity, 1993:38).

Finally, in many cultures, mental retardation is a stigmatizing condition. Consequently, a person who is labeled mentally retarded must endure a life time of ostracism, ridicule, and discrimination, and will usually have difficulty socializing with "normals," feeling a sense of self-worth, and even growing (discussed more fully in Oppression issues and disability below).

Mental retardation is one of several types of developmental disabilities, "a recent term, born in federal legislation in 1970 to signal a new concept and philosophy of services for persons handicapped by mental retardation, cerebral palsy, autism, or epilepsy," later to include dyslexia (Wiegerink & Pelosi, 1979:7). In an important shift, the Developmentally Disabled Assistance and Bill of Rights Act of 1978 (PL 95-602) changed the definition from categorical to functional meanings. This shift had the effect of expanding the pool of possible beneficiaries of DD

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[2] Some types of retardation can be treated. For an account of someone who was "cured," see Ozer, 1990.

legislation; more importantly, it "declinicalized" (and therefore in some ways destigmatized) the notion of developmental disability by shifting the focus from the category of "deficiency" to the type of services needed for specific types of needs. Although the 1978 Act defined developmental disability as "a severe, chronic disability attributed to a mental and/or physical impairment, which is manifested before the person reaches age 22" (cited in Wiegerink & Pelosi, 1979:5), the underlying concept of developmental disabilities is that

> all individuals who are disabled early in life by substantial lifelong handicaps have common needs for special services. (A developmental disability) is likely to continue indefinitely and results in substantial functional limitations in three or more of the following areas of major life activity: self-care, learning, self-direction, economic sufficiency, receptive and expressive language, mobility, or capacity for independent living. Finally, it reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are of lifelong or extended duration and are individually planned and coordinated (Wiegerink & Pelosi, p. 7).

The federal mechanism for funding is through state Developmental Disabilities Councils, which are by mandate staffed half by people with developmental disabilities. "D. D. Councils" are charged with advocating for people with developmental disabilities within each state, and educating the public about the nature and issues surrounding each of these disabilities. The largest group within the developmentally disabled population is the mentally retarded.

Types of mental retardation

Though the new AAMR definition has shifted its focus from types of retardation to types of support systems necessary, mental retardation in the US is commonly understood to occur in four levels of severity. The scheme was originally developed by the AAMR, and identifies four levels of severity of retardation, each based on I.Q. scores and adaptive behavior skills. They are: mild (I.Q. 55-69), moderate (I.Q. 40-54), severe (I.Q. 25-39), and profound (I.Q less than 25)(McGarrity, 1993:42). Heber (1961a) also notes a fifth category: borderline (70-84)(cited in Edgerton, 1967:5).[3]

Over the years, people with mental retardation have been classified in four different ways (Smith, 1971): by levels of severity as described above; by etiological variables such as birth injuries or genetic conditions (Heber, 1959, 1961a, 1961b); by syndromes, such as Down's syndrome or certain behavioral or educational syndromes (Gellis, 1968); and by behavioral classifications which focus on how a person responds to the environment as compared to behavioral syndromes previously mentioned in which behavior is indexed by intelligence test performance (Smith, 1971).

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[3] The 1993 definition of mental retardation proposed by the AAMR defines "significantly subaverage intellectual functioning" as an IQ standard score of approximately 70-75 or below (AAMR, 1993:5).

Etiology of mental retardation

There are over 200 causes of mental retardation, and perhaps many more which are not known. Factors which cause or contribute to the development of mental retardation generally occur in three periods. They can occur before birth in the form of injuries and accidents, genetic and metabolic factors, exposure to toxic substances, and exposure to infectious agents. They can occur as a result of factors encountered during the birth process: exposure to infection, injury during birth, premature birth, and low birth weight. Finally, they can occur after birth in the form of accidents and injuries, exposure to environmental hazards and toxins, malnutrition and other deprivation associated with poverty, including cognitive deprivation, illness and infection (McGarrity, 1993:46-48; Edgerton, 1969).

While the genetic connection with mental retardation is unclear, it appears that the causes of mental retardation are directly correlated to the levels of severity of retardation. It is generally understood, for example, that people with mental retardation in the moderate to profound range are likely to suffer from an identifiable medical or genetic condition which caused or contributed to the condition. Most people with mild retardation, on the other hand, do not have an identifiable medical condition which causes mental retardation (McGarrity, 1993:46). Some recent research, however, suggests that there may be a genetic basis to almost 40% of mental retardation (Janicki, 1988), and we now know that the chance of producing offspring with mental retardation is 40% when both parents have mental retardation, 15% when one parent has mental retardation, and only 1% when neither parent has mental retardation (Hall, 1975, in Abramson et al, 1988).

Whatever role genetic factors play in the etiology of mental retardation, two things are clear. First, social factors play a large, if not dominant, role in causing retardation. For the mildly retarded, it is a social phenomenon through and through" (Edgerton, 1967). We now know that lack of cognitive inputs from an early age, lack of "normal" role models in the socialization process, mistreatment and abuse by friends, family and other society members, and experiences in institutions all have a "dehabilitating" (Sharman, 1966) effect on people labeled retarded. As Alex, the case worker for five of the eight cast members in this study noted, "Many of these people spent a significant amount of their lives at Glenview. So we really don't know how to diagnose their condition, or what might have caused it. Living there would have messed anyone up."

Description of mild mental retardation

Because all of the participants in this study are mildly retarded, with the possible exception of Bob, this section will focus exclusively on a description of mild retardation (IQ 55-69). Approximately 75-85% of all people with mental retardation fall into the mild category (Edgerton, 1979). According to McGarrity,

> People with mild retardation can usually speak and understand oral language, but they often have difficulty with more subtle use of language in terms of humor and sarcasm, relatively complex words and phrases, and the use of abstract concepts. Generally, people in this category can do very basic reading, writing, and arithmetic. Most people in this category require special education services in school. These training and educational programs need to be clear, concrete, and direct in order to be effective. Children and adults in this category are usually able to manage their own basic needs fairly well (for example, eating, dressing, personal hygiene, and basic communication)(1993:43).

Robert Edgerton (1979) found that many people with mild retardation seem to fade into the general population after leaving school. Some do not need any kind of special services as adults, whereas others need assistance with job training and support, housing, etc. Unfortunately, people with mild mental retardation typically have marginal employment and low income, and often need assistance coping with the demands of daily living. This assistance tends to be provided by friends, neighbors, relatives, coworkers, and others in the community, though most often it is provided by agencies which are charged with assisting the mentally retarded. Edgerton calls this kind of help informal assistance and observed that it is crucial for adults with mild mental retardation to survive in the community (1967, 1979).

Demographics of mental retardation

Mental retardation is the single largest category of lifelong handicaps (Seltzer and Krauss, 1987). About 3% of the general population in the U.S. is likely to be mentally retarded (Wiegerink & Pelosi, 1979), or about 6 million Americans (McGarrity, 1993).[4] One out of 10 Americans has a mentally retarded person in their family (Wiegerink & Pelosi, 1979:8). Only mental illness, arthritis, heart disease, and cancer afflict a greater number of Americans (Edgerton, 1967:2). These proportions reflect worldwide patterns.

Class patterns

Rates of retardation are positively correlated with socioeconomic class. As McGarrity notes,

> (M)ost research appears to agree that mild retardation is associated with poverty. . . . Research found that programs which reduce poverty and the many problems associated with poverty also have the benefit of reducing the most common type of mental retardation (p. 52).

In a study in Riverside, California for example, most of the children who were diagnosed as retarded were from lower

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[4] This figure has varied throughout history as the definition of retardation has changed. In 1959, for example, Bogdan and Taylor (1982) point out that "the AAMD revised the definition of psychometric mental retardation to correspond to a score of one or more standard deviations away from the mean on general intelligence tests. According to this definition, 16 percent of the population would be eligible to be designated mentally retarded. In 1973, a subsequent committee of AAMD once more redefined mental retardation to include only those who performed two or more standard deviations away from the mean on intelligence tests; according to this definition only about 2 percent of the general population were retarded" (p. 12).

socioeconomic statuses (Mercer, 1973). Seventy-seven percent of them were from homes in which the head of household had a blue-collar job (p. 265). According to Robert Edgerton (1974): "It has been estimated that a child born in an impoverished rural area or in an urban ghetto is fifteen times more likely to be diagnosed as mentally retarded than a child from a middle-class suburban background" (p. 4). These statistics reflect the overall rate of disabilities amongst the poor.[5]

The danger of correlating mental retardation with poverty is that it can be a result of misdiagnosis: to what extent do tests account for differences that might not be related to I.Q., adaptability or functioning per se, but to cultural differences? This remains an issue for all groups, including low-income, ethnic minorities, and others. Nevertheless, most people who are labeled retarded are low-income, and most are unemployed or underemployed. Ferguson (1987) says that about 800,000 to 900,000 mentally retarded adults (approximately 15% of all retarded people) are either not working or making less than $300 per month (p. 203). Of course, there is a connection between poverty levels and prevalence of mental retardation. As Rainwater (1959) noted, the conduct of people with mental retardation does

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[5] Gliedman and Roth (1980) maintain that "physical disabilities, sensory handicaps, and chronic health impairments may be twice as common among poor children as among other children" though they hasten to add that they "<u>believe</u> this is the case, but the health survey data are ambiguous" (p. 5).

not seem notably different from that of other low socio-economic status persons described in American cities. Edgerton (1967) noted a similar phenomenon in his research:

> It is certainly true that their utilization of leisure is limited by a shortage of money, transportation, and in some cases, by time itself, but (people with mild mental retardation) do have interests and they do enjoy their leisure. Their preeminent joy is television; but that their leisure time should be dominated by television is by no means unusual. And they are not interested only in TV. They also enjoy conversation, on a surprising variety of topics, and a few enjoy music or sight-seeing or sports. They do not read, but it would also seem that their normal counterparts of low socio-economic status also read very little. They also have few hobbies, almost never "eat out," and seldom entertain. Their most unusual practice is riding buses to the end of the line and back for sight-seeing purposes (p. 141).

Gender patterns

Worldwide, males are more likely to be mentally retarded than females (McGarrity, 1993:53),[6] though gender patterns vary within types of retardation. Class issues also affect men and women differently. Of those who work, higher functioning men are more likely to be employed than higher functioning women, lower functioning women, and lower functioning men. In the mild retardation category, 87% of males and 33% of females are employed; for persons with

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[6] This higher ratio of males to females is also found in a number of other handicapping conditions in addition to mental retardation (McGarrity, 1993:53).

moderate retardation, 12% of males and 12% of females are employed (McGarrity 1993:164).[7]

While mildly retarded men appear to be at an advantage over women in the world of employment, women appear to be at an advantage in the world of love and relationships. In his study of 48 mildly retarded adults (20 men, 28 women) who left an institution for the mentally retarded in the 1960s, Edgerton (1967) found that eighteen women had married, whereas only twelve men had. Moreover, fifteen of these eighteen women had married normal men, whereas two men had married normal women. As Edgerton noted, "(I)f male former patients have difficulty locating normal wives, the obverse is not true. Female expatients do marry normal men, and often" (p. 120). However, with three exceptions, he goes on to note, these men have not permitted their wives to work. Gibbons (1985) also noted that women tend to prefer normal men when they date, and they tend to date more often.

Race patterns

In many cases, misdiagnosis of retardation occurs. Particularly in some school programs, there has been a tendency to diagnose mental retardation simply on the basis of I.Q. scores without taking into account the person's culture and adaptive behavior skills. This has resulted in

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[7] These employment figures are also reflective of patterns in the disabled population in general, in which unemployment figures are at 58% for all men with disabilities (physical and developmental) and 80% for all women with disabilities (Nagler, 1990: vii).

a disproportionate number of African-American, Native American, and Hispanic children being diagnosed as mentally retarded and placed in special education classes (McGarrity, 1993:50). In Mercer's (1973) study cited above, for example, she noted that when children were re-tested with "pluralistic" diagnostic tests which account for group differences based on class and ethnicity, children from ethnic minority groups were consistently overrepresented in classes for mentally retarded; "disproportionately large numbers of children reclassified as quasi-retarded and normal rather than mentally retarded were Mexican-American and black (p. 265). Interestingly, in these tests age and sex did not appear to be differentiating factors.

Mental retardation, then, knows no single social group. Most people who have been labeled retarded experience multiple oppressions, simultaneously living as a member of more than one devalued group (poor, ethnic minority, oppressed women, etc.). In this way, people who have been labeled retarded are not unique amongst people with disabilities, or people elsewhere in the world; probably more than half of all disabled people in Britain, for example, suffer the additional burden of racial and/or sexual oppression (Abberly, 1987:7).

The social construction of mental retardation

More and more people are arguing that the real problem with the use of the word retardation lies not in its diagnosis or misdiagnosis, but in its use at all. This problem seems to be twofold, both semantic and social. On a semantic level, the word retardation is misleading insofar as it implies that there is such a thing as retardation where in fact, some argue, it is a reification, a category that has been socially constructed to account for a constellation of conditions that we still do not really understand. Building on the idea that reality is socially constructed (Berger and Luckman, 1967), for example, Bogdan and Taylor (1982) argue that

> To name something is, in a sense, to create it. Because the objective existence of the condition it is supposed to describe has never been questioned, the phrase "mental retardation" has become an obstruction to understanding. Rather than pointing to a clear and discrete phenomenon, the concept creates the illusion that disparate and amorphous conditions and behaviors are similar. Like all cliches, it tells more about the people who use the term than it does about the "condition" it is thought to point to. . . . Mental retardation is a misnomer, a myth (p. 7).

As an illustration of just how subjective the determination of retardation is, Bogdan and Taylor note that the proportion of persons identified as retarded in the general population has increased dramatically over the past century. Prior to the latter part of the 1800s, many who might be called retarded now either blended into the general population or were defined as part of the homeless poor (Rothman, 1971). Because the word retardation did not exist, they were not retarded! More and more, people are arguing that mental retardation, as the definition of any person, is not a reflection of who that person is. Rather,

> . . . the definition of a person is to be found in the relationship between the definer and the defined, not determined either by personal characteristics or the abstract meanings attached to the group of which the person is a part. This position illustrates a less deterministic approach to the study of deviance and suggests that people with what are conventionally thought of as extremely negatively valued characteristics can have moral career that lead to inclusion rather than exclusion . . . and that a sociology of acceptance needs to be added to the more common focus on rejection (Bogdan and Taylor, 1982:136).

The second problem with the use of the word retardation is that it is almost universally seen by those to whom the label has been attached as demeaning and stigmatizing. For many, it has also been damning, for it has meant institutionalization, denial of due process, forced sterilization, denial of life-saving medical treatment, incarceration without trial, denial of the right to date or marry, and subjection to various abuses. Hence, retarded is an odious and dangerous word, rejected by almost all to whom the label has been attached. This was Edgerton's finding in his 1967 study documented in The cloak of competence - so much so that Edgerton advocated the creation of a new word to characterize mild mental retardation. This was also true of Szivos and Griffith's (1990) study, and it was true of the study presented in this dissertation.

Current trends

Over the centuries, disabled people in general, and what have come to be known as mentally retarded people in particular, have been viewed as subhuman, deviant, and finally human.[8] Responses to having a child with mental retardation has followed these definitions:

> Until recently, parents who gave birth to a child with a handicapping condition were painted a bleak picture of hopelessness and given a list of institutions in which to place their child. "Tell the relatives the baby is dead" - out of sight, out of mind. This was an expected route, as if removing people with handicapping conditions from society would remove the handicap (McGarrity, 1993:197).

Today, the emphasis is on normalization, deinstitutionalization, community integration, and quality of life (Blatt, 1987, in Cole and Meyer, 1989). In the following pages, I will discuss the most important of these ideas - normalization - and one current response to normalization theory - social identity theory.

Normalization

In the 1960s, the world was becoming increasingly aware of the effect of institutionalization on all people: prisoners, hospital patients, the mentally ill, and the mentally retarded. In his famous work Asylums (1961), Goffman discussed the effects of the total institution which he defined as

> a place of residence and work where a large number of like-situationed individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life (p. 1).

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[8] For a history of the changing concept of deviancy and the treatment of the retarded, see Wolfensberger, 1969 and 1972. For a comprehensive history of the concept and treatment of mental retardation, see Scheerenberger, 1983.

Goffman's conclusion in Asylums is that the most important factor in forming a resident of a total institution (in his study, a mental patient) is not the person's illness, but the institution. In his seminal work Stigma (1967), Goffman went on to elaborate a sociology of deviance in which he coined several important terms that were to be used by sociologists and the human services industry for years to come - terms such as passing, denial, visibility, and social identity. We will return to these terms later in this study. Of importance to the discussion here is Goffman's notion of stigma, which he defined as

> an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed. An attribute that stigmatizes one type of possessor can confirm the usualness of another, and therefore is neither creditable nor discreditable as a thing in itself. . . . A stigma, then, is really a special kind of relationship between attribute and stereotype. . . . (A stigma is) an undesired differentness from what we had anticipated (1963:5).

Goffman claims that stigmata (the plural of stigma) serve the function of reducing uncertainty in the general population. Once we know "those people" are different, we can get on with life.

Goffman's stigma theory was a departure from previous theories for two reasons: first, because it defined devaluation from the perspective of the devalued person - that it is stigmatizing; and second, because it highlighted the social construction of stigma - that a person is stigmatized not because of some innate characteristics, but "a language of attributes" which lead to devaluation and discrimination:

> By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances. We construct a stigma-theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences, such as those of social class (Goffman, 1963:5).

Throughout the 1950s and 1960s, a number of theories emerged which addressed the notion of stigma and devaluation in their definition and treatment of people with mental retardation. The most significant was the theory of normalization. Originally described by N.E. Bank-Mikkelsen of Denmark, this principle of normalization was "to let the mentally retarded obtain an existence as close to the normal as possible" (cited in Nirje, 1969b:181). Nirje, who Wolfensberger credits with being the original major proponent of normalization, defines it as "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (Wolfensberger, 1972; Nirje, 1969b:181). Today, normalization is generally understood to mean "that services for people with mental retardation be structured as closely as possible to the everyday lives of ordinary people in the regular community of the same chronological age" (Gerdtz, 1993:31).

In the U.S., the term normalization has changed to social role valorization (SRV). This change was initiated by Wolf Wolfensberger, the major proponent of normalization in the U.S. Wolfensberger argued that the name change was necessary because the term normalization was "so simple and straightforward" that people tended to assume what it meant without reading the literature and, as a result, misunderstood it. The change to social role valorization was based on the observation that

> the most explicit and highest goal of what (had) been called normalization must be the creation, support and defense of valued social roles for people who are at risk of social devaluation, because if a person's social role is a societally valued one, then other desirable things will be accorded to that person almost automatically, at least within the resources and norms of his/her society. Indeed, attributes of the person which might otherwise have been viewed negatively by society would come to be viewed positively (Wolfensberger, 1985:5).

Like Goffman's stigma theory, normalization/SRV[9] maintains that a person becomes perceived or defined as devalued 1) by being different from others 2) in one or more ways 3) which are considered to be significant by a majority or a ruling segment of a society 4) who value this difference negatively. Normalization/SRV argues that as a result of being devalued, societies create devalued roles - e.g., menace, subhuman organisms, object of ridicule, object of pity, etc. The only way to reverse these roles is through normalization/SRV, which is "the use, as much as possible, of culturally valued means to enable, establish, enhance

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[9] Not all proponents of normalization have adopted the SRV name, yet both theories espouse the same principles. I shall therefore refer to these theories together as normalization/SRV.

and/or maintain valued social roles for people."[10] Culturally valued means of role enhancement fall into two categories: enhancement of social image (e.g., integrating devalued with nondevalued people, juxtaposing devalue people to valued images, etc.), and enhancement of personal competencies (e.g., creating a challenging environment, programmatic individualization, etc.). Normalization/SRV proponents argue that society in general, but particularly people working in the human services, should, wherever possible, aim to enhance the social images and personal competencies of people "at risk of devaluation," especially those who have been labeled retarded. For example, Wolfensberger argued that following the normalization/SRV principle, "a person should be taught not merely to walk, but to walk with a normal gait; that he use normal movements and normal expressive behavior patterns; the he dress like other persons his age; and that his diet be such as to assure normal weight" (Wolfensberger, 1972:33).

Normalization/SRV has been touted as a step forward from previous thinking in which devalued people were categorized under the medical model with "clinical" conditions that required "treatment." According to normalization/SRV, devaluation occurs not as a result of some objective test that irrefutably establishes someone's deficiency, but as a result of social constructions that

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[10] Source: SRV workshop notes, Jo Masarelli, facilitator, 1992.

prevent a devalued person from having access to the resources and opportunities which are the rightful inheritance of all citizens. Normalization/SRV has led to or inspired various human rights movements within the disabled community, including deinstitutionalization[11], the Citizen Advocacy Movement[12], the Self-Advocacy Movement,[13] and the Independent Living Movement[14]. At the time of this writing, Normalization/SRV is the most influential theory guiding human services policy concerning people with mental retardation in the U.S. (Gibbons, 1985). Normalization/SRV has also been influential internationally in the development of documents such as The United Nations Declaration of the Rights of Mentally Retarded Persons (Roeher, in Wolfensburger, 1972).

Critics of normalization/SRV have argued that while making "normal" opportunities available to people with mental retardation is a worthwhile and necessary goal, normalization/SRV does not take into account other important goals such as the need for those who have been labeled retarded to deal with their experience of being retarded as retarded people, not just attempting to pass for normal. As Szivos and Griffiths (1990) argue,

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[11] For a discussion of this movement, see Tracy & Guskin, 1981, and Emerson, 1985.

[12] See Wolfensberger and Zauha, 1973.

[13] See Williams & Shoultz, 1982.

[14] See De Jong, 1979.

> There can sometimes appear to be an assumption that as long as passing for normal is maintained the major aims of normalization or social role valorization (Wolfensberger, 1983) are being fulfilled. . . . There is relatively little reference to the subjective quality of the individual's experience or, indeed, to the individual as a feeling, sensate, being (p. 334).

Szivos and Griffiths go on to argue that the problem is deeper than simply not acknowledging the life experiences of people who have been labeled retarded. By touting integration and community life as the goal toward which all must strive, normalization/SRV is positing "normal" life as ideal:

> As Brown and Smith (1989) pointed out, the good intentions enshrined within the normalization principle of creating valued social roles . . . neglects the question of how "value" is conferred and by whom. In normalization writings (e.g., Wolfensberger & Thomas, 1983), value often seems to be conferred insofar as the individual adheres only to choices that fall within the range of highly valued options; that is, the dominant "normal" group decides who should and should not be valued (Szivos and Griffiths, 1990:340).[15]

Social identity theory

Over the last 20 years, there has been a growing consensus among some researchers that the basic goal of normalization/SRV - making valued social roles available to people at risk of devaluation - is a necessary but not sufficient condition for dealing with the problems faced by

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[15] Brown and Smith (1989) equate normalization's error with with liberal feminism, claiming that just as liberal feminists encourage women to "buy into" the male way of knowing and behaving, normalization advocates are encouraging devalued people to "buy into" "normal" ways instead of working toward the legitimation of their own ways of knowing and behaving.

people who have been labeled retarded. While making "normal" opportunities available to people who have been labeled retarded is a necessary part of their well-being and growth, what is lacking is a sufficient treatment of the problem of social identity. How are retarded people to view their retardation? Should they name it? Should they accept it? Should they feel o.k. about it? And how should "normals" who work with retarded people deal with the subject of retardation? These questions address what has been called, for people living in institutions, a "group concept problem":

> One factor that is likely to have a major impact on their level of social activity, satisfaction, etc., is their opinions of their peers. In this regard, research with institutionalized retarded persons has provided evidence of what has been termed a "group concept" problem, specifically, negative reactions or low opinions of other retarded persons. For example, institutionalized retarded people in Gibbons and Gibbons' (1980) study reported that they would prefer nonretarded roommates and work mates. Gibbons and Kassin's (1982) institutionalized retarded subjects provided more pessimistic assessments and expectations of themselves and other retarded persons relative to nonretarded people on dimensions of social behavior (e.g., getting married and raising a family (cf. Budoff & Siperstein, 1980)(Gibbons, 1985:98).

Realizing that the "group concept problem" also exists outside of institutions, researchers have recently been studying the effects of labeling on the retarded (Mercer, 1973; Bogdan, Taylor & Dudley, 1983; Gibbons, 1981), the experience of being retarded from an etic perspective (Mercer, 1973; Briginsky and Braginsky, 1971; Bogdan, 1980), and the experience of being retarded from an emic perspective - i.e., from the perspective of retarded people themselves (Blatt and Kaplan, 1966; Edgerton, 1967; Bogdan and Taylor, 1982; Lorber, 1974). This last group of studies has focused on how mentally retarded people define themselves, how they understand and accept their condition, whatever they might call it, and how to help people who have been labeled retarded to accept and work with their conditions and roles rather than simply trying to get them "to walk without a gait" as normalization/SRV recommends.

Two of these studies are that of Gibbons (1987) and Szivos and Griffiths (1990). Gibbons (1987) studied the attitudes of 120 retarded people - half in institutions and half in community settings - to ascertain their attitudes concerning the desirability of other retarded adults as possible dating partners. He found that (1) institutionalized people tended to consider themselves more likely to have a date than their deinstitutionalized counterparts living in the community, although the staff ratings suggested that they were actually less adjusted socially to their residence; (2) institutionalized people rated themselves "smarter" than their community counterparts even though their actual I.Q.s were significantly lower; (3) participants, especially the women in community residences, found nonretarded men more socially skilled and physically attractive than retarded men, and therefore more desirable candidates for dating and marriage; (4) there was a tendency to be self-disparaging; despite expressing some confidence in their own smartness and friendliness, many participants had fairly pessimistic opinions of their chances for success at social behavior; and (5) participants had a tendency to compare themselves favorably to others of lower I.Q. or social skill (1985:105). Gibbons described this last finding as an example of downward comparison, a phenomenon described by Taylor et al (1981) as something stigmatized or victimized persons do because it helps them feel better about their own plight. From these findings, Gibbons (1985) concluded that

> To the extent that their group concept, and the downward comparison that may be part of it, interferes with normal social interaction and inhibit romantic relationships among retarded persons, then it is likely to make adjustment to their environments - no matter how independent or nonrestrictive - much more difficult (p. 105).

For Gibbons, one of the biggest problems facing people with mental retardation, especially ones who have spent considerable time living in institutions, is adjusting to community environments. Without dealing with the problem of social identity, it appears that these adjustments will continue to be problematic.

Szivos and Griffiths (1990) claim that social identity theory might help explain the nature of the problem and what can be done about it. Social identity theory as elaborated by Tajfel (1981) proposes that

> disadvantaged group members have two main options when they cannot leave the group that is the source of the disadvantage. The first is to assimilate or to pass into the mainstream group, which has several unpleasant psychological consequences, such as disaffiliation from one's group, guilt, and derogation . . . . The second opinion is to attempt to construct a positive identity

> based on being different (Szivos and Griffiths 1990:333).

Instead of advocating for "assimilating or passing into the mainstream group," Szivos and Griffiths are interested in exploring how to "construct a positive identity based on being different." They refer to this option as consciousness raising, or engaging in activities that were designed to

> make individuals aware of the implications of their labels insofar as they were used to perpetuate social inequalities, thereby motivating them to work for change. . . . First, by making individuals (or their representatives) more aware of the specific nature of their handicap, (consciousness raising) enables them to ask for disability-appropriate services and reject nonappropriate or global ones that may carry additional stigma (Szivos and Griffiths, 1990:339).

In their study, Szivos and Griffiths used a self-esteem group model with seven retarded adults over a 13-week period to explore the ways in which the ideas of consciousness raising and loss (following the ideas of Kubler-Ross) are applicable to mental retardation. In particular, they wanted to find out whether it is possible, on the one hand, to forge a positive group identity and on the other, to "accept" the handicap (p. 336). Their findings, discussed in greater detail in Chapter 8, indicated that in-group emotional support was strong, that other members, and the group itself "were worth fighting for," but that in-group identification was not strong, as evidenced by the fact that, as in Gibbon's study, group members frequently made downward comparisons. Szivos and Griffiths conclude by asking whether "acceptance" is ever completely possible for anyone with mental retardation, at least anyone who understands the stigma attached to the description (p. 338).

The question of social identity, then, remains problematic for people with mental retardation. Is it possible for mentally retarded people to accept their condition? Edgerton (1967) argues that it is not, that "the stigma is too great, too global, and to self-destructive. Acceptance of this affliction is incompatible with self-esteem, thus should acceptance occur, the prospect of independent community life is thereby rendered difficult, and perhaps impossible" (p. 212). What is needed, he argues,

> is a stigma-free explanation that helps the retarded person to explain his relative incompetence without suggesting that his affliction is one of basic and ineradicable stupidity. . . . Another explanation, another word must be found, and the world must avoid the stigma. Call the condition an "adjustment deficiency" or "educational deprivation," or provide a medical neologism. Whatever the euphemism, it must suggest that the affliction is a partial one - not an all-encompassing "mental" deficit - and that it is amenable to treatment and training. If a non-stigmatizing label can be found which can be employed consistently, then it may be possible to enlist the mildly retarded as willing participants in their own improvement (pp. 212-213).

As noted above, Bogdan and Taylor (1982) concur that the word "retarded" is a myth and should be eliminated. Yet Szivos and Griffiths are not so optimistic that mere elimination of the word, or changing it, would solve the problem.

> (S)ubstituting new euphemisms for old labels may not be the answer. Such terms quickly acquire negative connotations themselves and, perhaps worse, perpetuate the global notion of handicap, thereby doing nothing to

> actively destigmatize it. Pretending that such categories do not exist by eliminating labels altogether, as is also occasionally advocated, does not seem to be the answer either because the source of the rejection is often the objectively existing disability itself (p. 340).

I would argue that the source is not the "objectively existing disability itself" but the prejudice that accompanies our view of an objectively existing disability. Nevertheless, the point remains that without a stronger sense of personal and social identity, community integration is problematic, and the prospects of accepting oneself, identifying with others with similar experiences, and working together for change are greatly reduced.

Oppression and internalized oppression

Oppression and internalized oppression are oft-covered subjects, yet surprisingly, no single text explains the origin, development, or current meanings of these notions. This section, then, will be an attempt to "stitch together" some of the available literature in order to illustrate the origins of the ideas of oppression and internalized oppression, some of their current applications, and their relevance to people with disabilities, particularly those who have been labeled mentally retarded.

Origins of the concept of oppression

The notion of internalized oppression is rooted in the idea of oppression itself - a concept which, until the 1960s, was largely understood as a psychological condition or a social pathology. Accordingly, studies of oppression before the 1960s focused on personality and deviations from social norms. Throughout the 1930s and 40s, for example, Rorschach and Thematic Apperception tests were used to determine why blacks, women, poor people, etc. experienced oppression the way they did (Kardiner and Ovesey, 1951). In 1951, Kardiner and Ovesey used psychodynamics as an analytical framework in their study, The mark of oppression: A psychological study of the American Negro. Until the 1960s, professionals studying the needs of black children and adults looked almost exclusively through a social pathology lens (Gliedman and Roth, 1980:46). Even though these studies often concluded that the reversal of oppression was a societal, not individual, problem, they shed little light on the societal causes and forms of oppression, much less what to do about them. Studies like these also assumed that oppression was a phenomenon contained within a homeostatic society - a view based on the writings of Talcott Parsons and others which maintains that society is inherently stable, and when phenomena such as oppression are "corrected," society is brought back to its natural state of equilibrium. In 1957, a new wave of oppression literature was begun with the publication of The colonizer and the colonized in which Albert Memmi argued that oppression could be understood by studying social formations - in this case, colonialism:

> For me, oppression is the greatest calamity of humanity. It diverts and pollutes the best energies of

> man - of oppressed and oppressor alike. For if colonization destroys the colonized, it also rots the colonizer. . . . (O)ppression has assumed the face of England and France (pp. vii, 152).

Memmi's publication established a tradition of oppression writings that marked a significant departure from the psychological writings of the previous decades.[16] These writings developed a social analysis of oppression based on a dialectical view of the world and historical materialism. Memmi's analysis of the colonizer's motivation, for example, was chiefly material - "profit, privilege, and usurpation" (1965:9). Franz Fanon (1963, 1967) used a Marxist analytical framework to argue that oppression illustrates the dialectical nature of history; we exist in a Manichean world in which oppressor and oppressed are two different species in perpetual conflict, as in Whites vs. Blacks, colonizers vs. colonized, etc.

In the 1970s, two significant books depicted oppression chiefly as a class issue, another application of dialectical materialism. Yet their view of the role of material wealth differed markedly. In the seminal book, Pedagogy of the oppressed (1971), Paulo Freire argued that

> (T)he oppressors develop the conviction that it is possible for them to transform everything into objects of their purchasing power; hence their strictly materialistic concept of existence. Money is the measure of all things, and profit the primary goal. For the oppressors, what is worthwhile is to have more - always more - even at the cost of the oppressed

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[16] Memmi was not the first to take up a social or dialectical position. Sartre, who wrote the Introduction to *The colonizer and the colonized*, had been writing about oppression from an existentialist point of view throughout the 1950s.

> having less or having nothing. For them, to be is to have and to be the class of the "haves" (p. 44).

Arguing from a Third World (Brazilian) perspective, Freire viewed oppression in stark, material terms. Arguing from a First World perspective, Sennett and Cobb (1972) argued in The injuries of class that material incentives were not ends in themselves; rather, they had come to be proof of one's inner worth, a psychological motivation for class conflict:

> In addition to the old material incentives, the striving to become a developed, and therefore respectable, person is an incentive that keeps men consuming and working hard. The goal now for most individuals is not to possess, to own, to wield power; instead, material things are aids to creating an inner self which is complex, variegated, not easily fathomed by others - because only with such psychological armor can a person hope to establish some freedom with the terms of a class society (p. 258).

By invoking a perspective of dialectical materialism, Fanon, Memmi, and Freire shifted the focus of oppression theory from the individual in a homeostatic society to social groups and forces in a conflictual, contradictory and inherently unstable society. At the same time, they introduced a dimension of humanism to the definition that raises the question of how oppression affects both the oppressor and the oppressed, a subject to be taken up in the next section. Here, it is important to note that since the 1960s and 1970s, oppression theorists have developed analytical frameworks that expand the motives for oppression beyond material ones. These frameworks examine the dynamic of oppression as it pertains to women, people of color, Third World people, disabled people, young and old people, etc. Hence the proliferation in the last 30 years of "isms." In addition to the traditional oppressions - sexism, racism, and classism - we now have homophobia, heterosexism, ageism, adultism, ablism, and so forth. We also have studies of abuse that can, in some instances, be viewed as examples of oppression, such as physical, sexual and/or psychological abuse, battery, growing up in a dysfunctional family, living with an addict, etc. Finally, we now have the concept of "multiple oppressions, in which somebody experiences a variety of types of oppression at the same time - for example, a black lesbian suffering racism, homophobia and heterosexism.

These developments take us beyond earlier conceptions of oppression in which "A objectively exploits B or hinders his pursuit of self-affirmation as a responsible person" (Freire, 1971:40). All acts of exploitation are not necessarily oppression,[17] and not all acts of oppression occur for material reasons. Nor is oppression the sole domain of the colonizer, the imperialist, or the upper class. Rather, oppression is the domain of anyone who "has the societal power to define and enact reality," anyone or

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[17] Some authors have noted that oppression and exploitation are not equivalent concepts. Eisenstein, for example, argues that "exploitation speaks to the economic reality of capitalist class relations for men and women, whereas oppression refers to women and minorities defined within patriarchal, racist and capitalist relations. Exploitation is what happens to men and women workers in the labor force; women's oppression occurs from the relations that define her existence in the patriarchal sexual hierarchy - as mother, domestic laborer and consumer. . . . Oppression is inclusive of exploitation but reflects a more complex reality" (1979:22-23).

any group that is able to determine what is "normal," "real," and "correct" (Jackson and Hardiman, 1980, 1986). That is, oppression is potentially the domain of everyone. According to one training consortium, Diversity Works[18], oppression = prejudice + social power. To be sure, oppression is still viewed as "A dominating B," but in this case, it is because (1) he/she has the social (not just material) power to do so, and (2) he/she believes that others are inferior because of their social identity - an identity which might or might not be linked to material conditions. Oppression, then, is based not solely or even primarily on material interests, but on prejudice, defined as

> inaccurate and/or negative beliefs about another social group and its members without basis in fact. Prejudice is often based on stereotypes and can occur on a conscious or unconscious level (Diversity Works training materials).

By claiming that the motivation for oppression is prejudice, current oppression theorists are changing the meaning of oppression in two significant ways. First, they are "dematerializing" it, claiming that oppression can also apply to relationships that are not materially based. For example, within the middle class, heterosexuals can (and do) oppress homosexuals not on the basis of their material power, but on the basis of their social power. Second,

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[18] Diversity Works is a nonprofit organization in western Massachusetts that does training in schools, communities and work places on diversity issues (e.g., racism, sexism, homophobia, etc.) and multicultural organizational development.

oppression theorists are "psychologizing" the definition of oppression, enabling us not only to see it "out there" between social groups, but also "in here," inside all of us. It is claiming that, having been raised in prejudiced societies, we are all prejudiced and therefore have an opportunity and a responsibility to stop it both at the sociological level (i.e., between groups or individuals) and at the psychological level (i.e., within ourselves).

This discussion is not intended to imply that the definition of oppression is a settled issue. Mohan (1993) argues that "there is no universally accepted profile of an oppressor. When a person or a class of person's act(s) as perpetrator(s) of self-serving irrationalities against others, we speak of an oppressive situation" (p. 57). Thus, according to some definitions, oppression can be seen not only as a function of material or social power, but also as a display of sheer physical power, blurring the line between oppression and violence. Nevertheless, the above conversation is intended to illustrate how our understanding of oppression has changed over time, and in particular, how it has affected the oppressed.

Internalized oppression

In their analyses of oppression, Fanon, Memmi, Freire, Sennett and Cobb and others have gone to great lengths to describe the effects of oppression on the oppressed.[19] These descriptions can be summed up in one phrase: internalized oppression. That is,

> (E)xternal oppression becomes internalized and is manifested in feelings of inferiority, hostility to self and others, self-doubt and self-blame, and in powerlessness (inability to take full and effective charge of life and environment). These, along with other distress feelings, including accidental trauma, become the distress patterns that lock and maintain the individual in the oppression (Ramos-Diaz, 1985:14) .

According to Morris Barry (1987), internalized oppression is not restricted to peasants or colonized people, or the lower classes. Rather,

> Internalized oppression is a part of the socialization process that we all experience in all phases of life. However, it is a part of the socialization process that has resulted in the disempowerment of the human spirit. It has caused us to deny our experience, knowledge, abilities, and our desires, in an effort to please those individuals, groups, and organizations with whom we must live, and on whom we depend. It causes the student to assume that the teacher has the right answer; the worker to assume that only a superior in the organization knows what should be done next; and the child to assume that there is a right time and a wrong time to cry (pp. 12-13).

In their descriptions of this phenomenon, people who have written about internalized oppression have identified seven characteristics. They are: self-hatred, mistrust, denial, inability to create change, imitation of the oppressor, horizontal violence, and playing host to the oppressor.

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[19] These authors were not the first to talk about the internalization of dehumanizing feelings. For example, Furst (1953) noted that dehumanization caused by external social circumstances becomes internalized.

Self-hatred. Internalized oppression is marked first and foremost by a rejection of the self. This has been called self-hatred (Pheterson, 1986) and self-depreciation (Freire, 1971):

> Self-depreciation is (a) characteristic of the oppressed, which derives from their internalization of the opinion that the oppressors have of them. So often do they hear that they are good for nothing, know nothing and are incapable of learning anything - that they are sick, lazy and unproductive - that in the end they become convinced of their own unfitness (p. 49).

Self-hatred can also consist of self-denial in the sense of losing one's own identity, cultural confusion (resulting in "bilingualism," the plight of the middle-classed colonized), or forgetting that one has a history altogether (Memmi, 1965).

Mistrust. Freire (1973) notes that

> With no experience of dialogue and participation, the oppressed are often unsure of themselves. They have been consistently denied their right to have their say, having historically had the duty to only listen and obey. It is thus normal that they almost always maintain an attitude of mistrust toward those who attempt to dialogue with them; actually this distrustful attitude is also directed toward themselves. They are not sure of their own ability. They are influenced by the myth of their own ignorance (p. 120).

Denial. People tend not to admit their oppression, or the role they play in the maintenance of oppression (Barry, 1987:63). Perhaps this is because, as Freire points out, "It is better for victims of injustice not to see themselves as such" (1971:20).

Inability to create change. People who have internalized their oppression have great difficulty changing their surroundings because they behave in ways consistent with the system they want to change, rather than the one they want to create. Conscious attempts to change are blocked by the unconscious maintenance and recreation of oppressive systems that have been internalized by the individual (Barry, 1987:323).

Imitation of the oppressor. Freire (1971) notes that

> at a certain point in their existential experience, the oppressed feel an irresistible attraction towards the oppressor and his way of life. Sharing this way of life becomes an overpowering aspiration. In their alienation, the oppressed want at any cost to resemble the oppressor, to imitate him, to follow him (p. 48).

Memmi (1965) offers a startling description of Jews in Tunisia who

> passionately endeavored to identify themselves with the French. To them the West was the paragon of all civilization, all culture. The Jew turned his back happily on the East. He chose the French language, dressed in the Italian style and joyfully adopted every idiosyncrasy of the Europeans (p. xiv).

At the same time, Memmi noted that the oppressed typically hated their colonizers while loving them passionately, and confessed he too felt this admiration "in spite of himself" (1965).

Horizontal violence. In The wretched of the earth, Fanon described how "The colonized man will first manifest this aggressiveness which has been deposited in his bones against his own people" (1963:52). Freire called this tendency toward aggressiveness on the part of the oppressed horizontal violence:

> Submerged in reality, the oppressed cannot perceive clearly the "order" which serves the interests of the oppressors whose image they have internalized. Chafing under the restrictions of this order, they often manifest a type of horizontal violence, striking out at their own comrades for the pettiest reasons (Freire, 1971:48).

Playing host to the oppressor. Finally, people who have internalized their oppression often collude with the oppressor. Having internalized the oppressor's values and attempted to be like the oppressor (what Memmi calls "assimilation"), people who have internalized their oppression often choose to work with the oppressor as well, what Freire calls "playing host to the oppressor" (1971).

Responses to internalized oppression

In response to these seven characteristics of internalized oppression, the above writers have posed several solutions. People who have been oppressed, whether they have internalized their oppression or not, must break away from the oppressor, experience some physical release, and redefine themselves and their group.

Breaking away from the oppressor. The oppressed person can either choose to assimilate or carry out "a recovery of self and of autonomous dignity" (Memmi, 1965:128). To do this, Memmi argues, the oppressed person "must start with his oppression, the deficiencies of his group. In order that his liberation may be compete, he must free himself from those inevitable conditions of his struggle" (p. 128).

Experience physical release. This is perhaps the most controversial of Fanon's proclamations - that only by using violence can the oppressed purge themselves of the oppression that they have internalized. Re-evaluation counseling also maintains that some sort of physical purging is required to eradicate the self-hatred and other negative feelings associated with internalized oppression, yet it does not advocate violence to accomplish this but some sort of "discharging" action in the counseling context: crying, shaking, yawning, etc. (Ramos-Diaz, 1985).

Redefinition of oneself and one's group. Most theorists agree that some sort of redefinition of oneself or one's group is necessary if the oppressed person is to reconstruct an independent, healthy identity. First, the oppressed must reject the definitions ascribed to them by the dominant group (Memmi, 1965). According to Freire, this rejection can only be accomplished if the oppressed "see examples of the vulnerability of the oppressor so that a contrary conviction can begin to grow within them" (Freire, 1971:51). Then, as Barbara Love (1989) notes about the struggle of African Americans in the U.S., people must rename themselves.

> The right of a people to name themselves is the first task of liberation. What we name ourselves will determine the course our struggle for liberation will take. Clearly, we can choose a name that keeps us mired in the internalized oppression which has characterized our sojourn on this continent (p. 9).

As we shall see, this notion of the right for a people to name themselves in order to become liberated is problematic for people labeled mentally retarded, owing primarily to the odiousness of their identity as "stupid." The last section of this chapter will briefly explore the nature of disability oppression and its implications for PLMRs.

Oppression issues and disability

Where does oppression against people with disabilities come from? Why have most societies throughout history, continue to devalue, stereotype, sequester, abuse, and oppress people with disabilities? This section will offer some responses to this question, and propose several conditions for a theory of oppression of people with disabilities.

The nature of disability oppression

As discussed in Normalization above, one reason for the oppression of disabled people is the simple cultural universal of devaluation, a phenomenon which leads to the construction of a deviancy and its handmaiden, stigma:

> The concept of deviancy has been elaborated in the recent past by social scientists, and it is a very useful one. A person can be said to be deviant if he is perceived as being significantly different from others in some aspect that is considered of relative importance, and if this difference is negatively valued. An overt and negatively valued characteristic that is associated with the deviancy is called a "stigma" Wolfensberger, 1972:13).

Most societies stigmatize disabled people not on the basis of inherent characteristics, but on the basis of images or stereotypes created by those societies. In the US, four stereotypes are common (for a more complete treatment of views toward disabled people, especially PLMRs, throughout history, see Wolfensberger, 1969):

Disabled as sick. Most disabilities are chronic conditions, not diseases. Some, such as polio, were caused by a disease at one point in a person's life, and have long since gone away. Some are a result of events that occurred before, during or after birth, some are caused by genetic factors, some by accident, some by aging. Nevertheless, the dominant perception if the disabled is that they are sick, as evidenced by the use of such phrases as "combatting mental retardation" as if it is a disease in need of eradication, rather than a condition to be accepted and even valued (President's Committee on Mental Retardation, 1967).

Disabled as immoral. It may seem unreasonable to correlate disability with moral worth, yet one of the standard stigmas disabled people bear is that of being immoral people. Wilkins (1965) suggests that

> our attitudes toward deviance derive from the platonic notion that goodness, truth, and beauty are related to

> each other, and that deviations from norms (truth) are "errors" that, by analogy, must be related to evil and ugliness. Thus, attitudes toward deviance may be rather generalized. For instance, a person may react with similar emotions toward retardation as he does toward blindness, delinquency, and senility (cited in Wolfensberger, 1969).

Thus, by some bizarre twist of logic, disabled people have been saddled with the reputation of having committed some "error," and the misfortune of being associated with other disabled people with whom they share no common qualities. Having made such logical leaps, impugning someone's moral worth on the basis of disability hardly seems unreasonable.

Disabled as weak and dependent. Societies have long detested their weaker members.

> In a hunter and gatherer society, infants born with severe handicaps probably did not survive long after birth. Many of these societies also practiced infanticide of unwanted children, and killed those who could no longer hunt or find food for the group. At the same time, there is archaeological evidence that some hunter and gatherer groups supported these group member with handicaps, and these handicapped people lived full life spans (Gerdtz, 1993:3).

Disabled people by definition need special supports in order to carry on with their daily lives. With these supports, most disabled people can live normal lives. Yet because of these supports, the disabled are associated with weakness, dependence, welfarism and the like.

Disabled as ugly. Society, principally through the media, engages in sins of commission and omission. Sins of commission include the representation of disabled people that emphasize disability over ability, weakness over strength, awkwardness over agility, pathetic over dignified (e.g., the Jerry Lewis telethon). Sins of omission lie principally in the absence of disabled people in roles of status or glamour, constituting beauty and personal worth exclusively as slender, young, energetic, intelligent, and able.[20]

One of the biggest difficulties faced by disabled people in combatting these stereotypes is the fact that the lack obvious characteristics with which to identify, or around which to organize:

> unlike blacks and Hispanic Americans, the disabled do not form a distinct cultural community (although their oppression bears a striking resemblances to that practiced against ethnic minorities). Nor are handicaps produced or transmitted in a way that parallels the perpetuation of racial characteristics from one generation to the next. (Most handicapped children have able-bodied children). Yet, as the social psychologist Kurt Lewin long ago noted, the members of an oppressed group often have little in common except the fact that society singles them out for systematic oppression (Gliedman and Roth, 1980:4).

The problem faced by PLMRs is even more acute, for in addition to lacking obvious characteristics with which to identify, the characteristics they do share, which often are obvious, are viewed by society as odious - so odious that they should be avoided at all costs. Hence the alleged need for passing and denial. If a person is deaf, identifying with the culture of deaf people might or might not hold some attraction. There is nothing attractive about being retarded, or being a member of "the culture of the

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[20] For a discussion of the negative portrayal of disabled people in the media, see Biklen & Bogdan, "Media portrayals of disabled people: A study in stereotypes, Bulletin, Vol. 8, No. 6-7.

retarded," if there is one. Identification with others who are labeled retarded is seen by most only as damning.

Toward a theory of disability oppression

Given the heterogeneity of the disabled community, the misperceptions of disabled people as sick, immoral, weak, dependent, and ugly, and the odiousness of some types of disability, especially mental retardation, several authors have noted that a theory of disability oppression is in order. Such a theory, according to Abberly (1987), should consider the following:

1) It should acknowledge how disabled people are in fact treated as inferior.

2) It should acknowledge that disability oppression is rooted both in social perceptions and physical realities.

> While in the cases of sexual and racial oppression, biological difference serves only as a qualificator condition of a wholly ideological oppression, for disabled people the biological difference, albeit as I shall argue itself a consequence of social practices, is itself a part of the oppression. It is crucial that a theory of disability as oppression comes to grips with this "real" inferiority, since it forms a bedrock upon which justificatory oppressive theories are based and, psychologically an immense impediment to the development of political consciousness amongst disabled people (Abberly, p. 8).

3) It should acknowledge how oppression is carried out against disabled people. This includes how society has and continues to socially construct disability as sickness, immorality, weakness, dependency, and ugliness. It also includes such practices as

exclusionary housing and employment practices, impediments to community integration, and deathmaking (Wolfensberger).

4) It should acknowledge who is benefitting by the oppression and how. While some work has already been done (e.g., see Conley, 1973; Stone, 1984), more studies need to be conducted that address the structural factors that enable individuals and institutions to profit from the maintenance of "the disabled state" to use Stone's term.

5) It should assert the value of disabled modes of living, at the same time as it condemns the social production of impairment. To this proviso I would add that it should acknowledge that people with certain types of disabilities in fact have their own cultures, and that members of those groups should try to identify the positive characteristics of that group. That is, it should in some way encourage a positive social identity amongst people in that group.[21]

Discussion

The perspective of retardation presented in this chapter is decidedly a social constructionist one; the alternative view of disability, particularly mental

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[21] The deaf community has perhaps gone the farthest with this idea, some of whom assert that recent medical advances that make the reversal of some types of deafness possible is tantamount to genocide. See Abberly, 1987.

retardation, as an objective biological and social fact, has admittedly not been given equal consideration. There are two reasons for this. First, the "objective" view is the dominant view in the literature and in the human services industry, and in this author's view, has been sufficiently described elsewhere. Second, as noted in Chapter 3, this study takes a social constructionist position in its assumptions about the definition of mental retardation, and takes an interactionist approach to its assumptions about the nature of research and reliable knowledge.

This is not to say that within an interactionist research methodology, there is no room for the "objective" view of mental retardation. This position, in fact, is perhaps best represented by the work of Edgerton, who is not willing to go as far as Bogdan and Taylor in claiming that mental retardation is "a myth." This study perhaps falls somewhere in between: mental retardation is neither "a myth" nor "an objective fact." As we shall see, mental retardation is at the same time an unfortunate category that should be abandoned, and a condition which is shared by millions of people, forming a "population" with its own characteristics and, as I argue in Chapter 8, its own reasons to be proud because of those characteristics.

Conclusion

This chapter has presented some of the basic concepts, definitions, and issues surrounding the ideas of mental retardation, oppression, internalized oppression, and the oppression of people with disabilities. In particular, it makes the claim that the concept of mental retardation is, in the main, a social construct, one with devastating consequences for those so labeled, and that PLMRs are often the last to be consulted about their own condition and perceptions about that condition. This description suggests that more work needs to be done both to redefine the conditions experienced by PLMRs, and to learn more about how they themselves experience their conditions. This study is an attempt to address some of these concerns.

CHAPTER 5

CHRONIC PROBLEM ORIENTATION

Introduction

How do group members understand themselves and the world? The next three chapters answer this question in three different ways. The next chapter, entitled Justice orientation, explains how they view the world as an unjust place, and what should be done to change it. Chapter 7, The drive to visibility, presents group members' understanding of the notion of visibility, and postulates how it is related to internalized oppression amongst group members. This chapter shows how group members' understanding of the world was largely characterized by a chronic problem orientation, or a proclivity toward discussing, attempting to deal with, and even creating problems. By problems, I am not referring to their historical experiences of mistreatment, harassment or abuse as treated in the next chapter. Rather, I am referring to the day-to-day worries, anxieties, fears, situations and unresolved issues that came up regularly during project activities.

In the first part of this chapter, I will present a series of vignettes that illustrate some of the problems or issues group members have raised over the course of this project. These vignettes are not verbatim accounts of actual scenes, but rather compilations of experiences I have had with group members that are intended to illustrate my relationship with them, some typical behavior patterns I have observed, and the types of problems they experience. Next, I will attempt to present an emic perspective on what group members mean by problems. Specifically, I will ask three questions:

1) For group members, what are problems?
2) For group members, what causes problems?
3) For group members, how are problems solved?

After examining group members' understandings on these subjects, I will present an etic perspective by examining what I call chronic problem orientation. Specifically, I will ask two questions:

1) What do I mean by chronic problem orientation?
2) What are the possible reasons for their chronic problem orientation?

In this section, I will examine group members' words and behavior in order to better understand why they orient around problems in a chronic way. I will conclude with thoughts and observations about what these patterns might mean in terms of how this group sees the world.

Vignettes

The following are descriptions of events that were observed ethnographically, though assembled in composite form. The purpose of these vignettes is to illustrate group members' problem orientation in real life situations, while at the same time providing the reader with a fuller picture of group members' personalities, their ways of interacting with one another, and the role I played in the group.

Fred

Fred walks into the office looking a bit lost. He glances around, sees me sitting at the computer in the corner, where I can almost always be found. He saunters up to me, a slight gait to his walk, and grabs me in a half-hug, half-Nelson. I'm supposed to guess who it is. I shut my eyes.

"Let's see. Could it be Peter?"

"Nope." He doesn't get the joke. Peter was a professor of mine, friend and colleague. Together we had founded the Center for Community Education and Action, with whom this project was associated. He would never greet me this way.

"Hmmm. Who do I know that's really strong?"

"I am," he says.

"Must be Fred!" I say and turn around. He's beaming. I stand up and he sidles up to me. "My wife's not feeling good," he says. "Why don't you go talk to her?"

Fred and Marcia met at Glenview State School[1] where, with several hundred other people labeled retarded, they lived for 17 years. They "dated" there, though illicitly,

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[1] Glenview State School is a pseudonym for the actual institution where half of the group members had lived.

sneaking out of their rooms late at night to meet behind Building H where they lived. Fred also claims he escaped one time, making it as far as Vermont and working on a logging crew before someone offered him a ride home. After they were released, they got married and had lived together for eight years at the time of doing *Special*. Their wedding pictures hang on my bedroom wall, a fact Marcia and Fred check whenever they come over.

"Where is she?" I ask Fred, knowing that she's probably out in the atrium. Marcia and Fred are never separated, except when he works, proudly, as a dish washer at Antonio's Family Restaurant 30 hours a week. "Out there," Fred says, pointing toward the door. "Well she can come in if she wants," I offer.

Fred is looking thinner than usual these days. At 58, he has a distinguished appearance - gray, thin hair, cobalt blue eyes that jump out at you on video, and a long, often whiskery face. I had only seen him not wearing a suit and tie once before. We were visiting a mutual friend in Toronto a couple years prior. I had gone to wake them up one morning. He and Marcia, both wearing pajamas, sprang out of bed, excited to face the new day in Tow-ron-tow as Marcia was fond of saying.

But Fred's looking bony these days, and he's complaining more and more of achy joints and sore muscles, especially when he strains his back trying to grab a pot from a shelf that's just a little too high at Antonio's.

All these aches and pains don't seem to deter him from lifting me up - literally - whenever he gets a chance. I worry less about his muscles than his weight.

"Are you eating much these days, Fred?" I ask.

"Yep," he replies predictably. I hand my bag of potato chips to him, and he shoves a handful down.

Marcia

Marcia finally comes in, no doubt tired of sitting out in the atrium waiting for me to come console her. Marcia says she has lost 20 pounds, and she's proud. She still is a sufficient contrast to Fred, her sweat suit hiding her chunkiness. Marcia has close-cropped black hair - at 48, a little gray - sometimes permed curly. Today it is straight, making her look more like the descendent of a Mohawk chief, bangs chopped straight across her forehead, wide, prominent, squared-off jowls, black almond eyes on fire.

"If he does that again, I'm going to the cops!" she huffs in a low voice, stomping around the office, mashing her lips together and sticking her chin out in tough determination. "Just wait and see if he does it again. He'll see!"

"Does what, Marcia?" I say softly, hoping I can calm her down. Fred looks at me as if he's still lost and looks at Marcia again.

"Does this," she says, showing me a fist. "He was gonna hit me!"

"Who?"

"Georgie. Georgie Bell," she prattles as if tattling on George, a member of the cast.

"George?" I say, deliberately showing my astonishment. My experience of George is that he is pleasant, innocuous, more likely to crack a joke than deal with conflict, much less cause it.

"He did," Fred chimes in obsequiously, looking at me, then Marcia again. I know one time Fred's ideas cannot be treated as original is when he is mimicking Marcia, especially when she's in the room.

"He probably didn't mean it," I continue.

"He did," Marcia quickly responds, almost singing. The door opens. George appears, sees Marcia, then disappears. "Get the fuck out of here!" she screams.

"Marcia!" I exclaim. I'm shocked now. Even if George had a passing moment of anger, he would never get violent. How could she think such a thing? But it's too late. Fred is trying to restrain her, grabbing her and trying to hold her hands. Now Susan is in the room, trying to help Fred, but it's no use. Marcia is screaming, hitting herself in the face, now wet with tears, biting her arms, and casting frequent, desperate looks my way.

For reasons I don't entirely understand, I feel able to deal with it today. It doesn't feel like she's going to throw anything at me, and it doesn't seem like she's just trying to get attention. I take one of her hands, not too hard, but firmly. It is clammy and shaking.

"Come on Marcia," I again say in a lilting voice. "Let's go for a walk."

Marcia and I walk out of the office holding hands, leaving Fred and Susan behind. We walk outside, down the street a ways, talking about how hard it is sometimes to deal with problems, especially when someone is giving you a bad time. She's not hitting herself now, though she lets out an occasional scream and grabs my hand more tightly.

"It's o.k.," I keep saying over and over. "It's hard to deal with this stuff sometimes. But it'll be ok. I'm sure George will be your friend. We can talk about it if you want. We can talk about it if you want."

"O.k.," she says. A minute or so later we turn around and walk back. When we enter the office, the rest of the group, minus George, is sitting in a circle, talking about the play with Janet, the co-director. She is asking them what they think of the idea of marching through the audience during one of the scenes, pausing at intervals to say things like "I'm sorry, you can't have a checking account" or "You're not qualified for this job." All turn and look at us. Some say hi. Fred and Susan keep looking at Marcia as we sit down. The others keep talking with Janet. Marcia is wagging her head now, as she is accustomed to doing. Everything is going to be all right, at least for now, I realize.

Susan

She and Marcia are two peas in a pod since Susan's husband died. It seems that only Susan considered his death a tragedy, maybe owing to the fact that at least she had someone she could take care of, giving him his pills for his arthritis several times a day. She didn't seem to mind him constantly belittling her, or keeping her at home (she couldn't do the last play with us because she was always "grounded"). At least he didn't beat her, as far as I know.

But since Susan came home and found her husband lying on the couch, stiff and blue, she is a changed person. She seems happier, more carefree. Her dyed black hair is now a natural gray. At 62 she seems to be more at ease with herself than she was when I first met her five years ago. Yet it also seems that she has too much time on her hands. She frequently complains of getting bored, and when Marcia is gone, lonely too. The two of them like to come by and vacuum the office, empty the garbage. They want to do the same at my house, but somehow that just doesn't feel right to me. As a Peace Corps volunteer in Africa, I had had a cook and guard, as Peace Corps advised us to do, but I haven't gotten over how colonial I felt. Anyway, I've refrained from bringing them over to clean.

One of the sights of Pleasantville is Marcia and Susan hanging out, sometimes with other group members, sometimes alone, in front of the Pleasantville Theater. Whenever S.S.I. checks come in, Susan has money and wants to take everyone out. She at least goes out and buys a new outfit - matching sweats or a dandy combination of black pants and black patterned shirt, often the same ones Marcia just bought. They are a pair, Susan and Marcia in their matching duds.

When Marcia leaves with Fred for her week-long vacation to Camp Seaside every August, Susan starts crying, usually about two weeks in advance. One week in advance, she and I make plans for the week of Marcia's absence. Then Marcia leaves on a Sunday, and Monday Susan and I have breakfast.

"I'll pay, dear," she says.

"Ok," I say.

"How's your mother?" she asks. She's never met her before, but she talks about her as if she knows her. In a way, she does, having heard the story several times about how Fred pushed her around Mt. Michael College campus (she's in a wheelchair) like he used to with his mother.

"She's good," I say. "I just talked to her last week."

"Tell her we said hello," she says. I know what she's going to ask next. "We're good friends, you and me, ain't we?"

"We sure are," I reply.

"How long we been friends?" she asks. Marcia is usually the one to ask this, so I guess Susan is acting as her spokesperson.

"I don't know. Maybe about five years," I say. "Ask Sam. He's the group's resident historian."

Sam

I'm always a little cautious about telling the world about the fact that Sam is a savant. It too quickly becomes a freak show. He already sticks out as one of our town's characters, his white cane clacking down the sidewalk a common sight. And his appearances at community events are a common sound, especially when he belts out "Peggy Sue" by Buddy Holly, except he's substituting the lyrics "Peggy Sue" with "Sally Jesse Raphael," whom he lusts after, and would gladly tell her on her T.V. talk show.

One night a bunch of us were having dinner at Ponderosa, a family steak house and a favorite haunt of several group members. I was feeling a little punchy, so on a lark I told our waitress that Sam could tell her what day of the week her birthday fell on. She looked at me incredulously. "Ask him," I said. Sam overheard us. "Yep, yep," he said, rocking back and forth, swinging his fingernail clipper between his right thumb and forefinger. "Any day. Yep." I could tell he liked the sound of her voice.

"Ok," she says. "August 18, 1972." "Yeah, let's see that'll be, that was a . . . Wednesday. Yep. The 18th was on a Wednesday."

"Oh my God!" she gasped and ran back into the kitchen. Oh no, I thought. That was no doubt flattering for Sam, but she was a little too amazed. Before I knew it, two more waitresses and a dishwasher were lined up at our table, ready to blurt out their birthdays and be amazed. Oh well. Live and learn.

This of course is one of Sam's many quirks. Some are less dazzling. Like his infatuation with Old Spice and Brut colognes (which he dubbed "Old Sprut") which he splashes on every half hour he owns it. Or his obsession with quitting smoking, even though "it's only pipes," he always reminds us. Or his even greater obsession with finding a lover, so intense that he ran up a $5,000 phone bill calling 900 numbers late into the night, breathing heavily to pretty voices that always said "Call back."

Perhaps more than anyone in the group, though, with the possible exception of me, Sam seems to have trouble knowing his limits. The morning we were going to go to Glenview to interview people there, Sam showed up at the office, not sure if he could stay because he had double-booked with a music lesson, but not wanting to say no to either. For about a half hour, our efforts to plan our interview questions were punctuated with phone calls, first when Sam thought his agency worker could reschedule his music lesson, then because she couldn't get ahold of his piano teacher, then when she finally did. When it was on, he would say, "Well, tell me what else I can do," and when it was off, he would say, "Good, now what was the question?" By the time we got to Glenview, we were all exhausted.

George

Back during the Manna Base Community days, we used to act out scenes from the Bible. One time we acted out the parable of the Good Samaritan. Several group members played the passers-by. George played the Levite in a truly "Georgian" way, running into the room, jumping over the person, and scurrying off, laughing. While we were developing *Special*, Janet picked up on this energy and came up with the ingenious idea of having him play SuperGeorge. He would fly through the air (this we could do on video tape with a blue background, trees whizzing by), then appear on stage bedecked with cape, red shirt and big "S" on his chest, ready to right wrongs against disabled people, or at least instigate a few role reversals so we "normals" can see how we like being discriminated against. George immediately loved the idea, jumping in, trying a few lines and, unable to contain himself, said, beaming, "I love this role." On opening night, Tim and Ron, our videographers, asked what his favorite part of the play was. "I played it," he said, still giddy.

In fact, he always plays some sort of gag role. "George, it's nice to see you around," I remember saying once.

"Well, Mark, it's nice to see you a square," he replied, laughing. He often made others laugh, too.

But not always. Marcia's anger at "Georgie's" making a fist might have been exaggerated, but not unfounded. At times George could show a level of exhaustion that bordered on belligerence. I remember the morning after we finished our first round of performances. George had offered to come by and help strike the set. Ten o'clock and no George. Fortunately, Marcia and Susan were around and, as usual, had nothing to do, though that day all they were able to muster in the help category was a coffee run. I think they had new outfits on, and didn't want to break a sweat in them. Ten thirty came and went. By 11:30, we were almost done and I, for one, was pissed. George happened by just as we were loading stuff into the truck and laughed, "Oh are you almost done? Maybe you don't need me."

"You owe me an apology," I responded coolly. He got it. "Why, why, wh wh why d did didn't you g get other people, Mark?"

"George," I said, "if you make a commitment, you should keep it. You said you'd be here at ten."

"M Mark, I I know w what I s said. I was tired. My alarm went off late, and I don't know, maybe it's broken. But y you should of told us earlier. Y you shoulda got s someone else. I, I a already do enough, you know what I mean?"

"Yeah, I know what you mean, George, but we really didn't have enough people helping today, and all I'm saying is that if you said you would . . . ." At which point he began screaming, his face turning beet-red. I was taken aback. I had never seen him like this before. He had always been so amiable around me, so helpful, so willing to listen, to try to understand. Now he was halfway down the block, still screaming. I remember how he got to the end of the block about 30 yards away from the church door where I was standing, turned and continued screaming at me, shaking his fists to the sky, then marching off. He called a couple days later and continued to scold me on my message machine, something about how I should stop using him, shouldn't push people so hard, and how other people should help out.

Bruce

Bruce, George's housemate, had reached his breaking point much earlier. Funny, he had never missed one rehearsal for our previous play, *Get a Job!*, he was so into it. But over the course of the development of *Special*, his attendance had flagged to the point where he wasn't coming at all, and it was getting demoralizing for the cast. We discussed what to do and, at that point, everyone felt that he should be allowed to stay, and that he should be given another chance. I was designated to tell him, so I went to his house to pay him a visit. I remember approaching his front door and hearing him talking, using different voices, as if a conversation amongst several people was taking place. I knocked on the door.

"Who is it?" he yelled.

"Mark," I yelled back.

He opened the door, smiling broadly as he did when he saw me in those days, extending his hand and saying "A-a-a-y." We shook hands and went inside. No one else was there. I sat down in his living room, a mess really, clothes everywhere, dirty dishes stacked up on the counter, a stale smell in the air. Newspapers were stacked up on his coffee table, along with literature from every religious denomination imaginable - a fascination of his. He looked fatigued, often averting his gaze, combing his fingers through his hair, smacking his lips, occasionally picking his skin. Bruce had eczema, a condition I shared, so I could empathize with him. His outbreaks were worse than mine, though, covering his arms and hands. Bruce was also born with down syndrome and so was at times difficult to understand.

"That the door Chuck Bolan come, robbed me," he said, pointing to the front door. Bruce's house had been burgled a couple years prior by Chuck Bolan, Kim's brother. Kim, a group member, was Bruce's unrequited love. I nodded, having heard the story before. "Ah be, my mom, she pass away."

"She did?" I said. I wondered why he often started sentences with "ah be," or whatever he was saying. "I didn't know she passed away," I said. "I thought your dad did, but . . . ." There was a pause. Bruce was staring at me blankly.

"She will," he said.

"Yeah," I said, "some day. That's right."

"Ah you be my friend?" he said.

I smiled, not knowing what to say. "You know I'm your friend," I said, trying to buy time until I figured out how to explain that I probably wouldn't live in Pleasantville forever, maybe not even in Massachusetts.

"Ah, me busy, ah need house, me go to Montrose. Me gotta move."

"You <u>have</u> to move?" I asked, a little surprised. I knew he was getting assistance from D.M.R. so I couldn't figure out why he should have to move to Montrose. The only reason he might even want to move there is because Kim has recently spent a week in the hospital there, getting a shunt revised. Kim is hydrocephalic, requiring a shunt to be surgically implanted in her neck so the excess water in her cranial cavity could drain into her esophagal tube, thus relieving the pressure in her head. Shunts normally get blocked or kinked in time and must be revised. Bruce had visited Kim whenever he could, and now he wanted to go to the hospital, even though she had already been released.

"Why do you need to go to the hospital?" I asked.

"Ah be, a clock in my head."

"What?"

"A clock. In my head."

"You have a clock in your head?" I asked.

"Yep, he said. "Ah be, my friend, Dr. Ryan, he want me there. Montrose College."

"To do what?" I asked, still not sure what he was talking about. Dr. Ryan is a doctor of education, teaching at Springfield College. What did this have to do with Bruce needing to move to Montrose, or getting a clock removed from his head?

"Ah get clock. Surgery. My head me worry about."

"Did Dr. Ryan tell you that?" I asked, not sure what "that" meant.

"Yep."

In one of our interviews with human services advocates, Bruce had described his undying love for Kim. The interviewee, who knows both Bruce and Kim well, was impressed. "Bruce, I am impressed with your devotion. It is absolute," she had said.

I'm not sure if it was Bruce's unrequited love that caused the downturn. In time, he became less and less communicative, finally opting out of the play altogether, saying he had to stay home and do his laundry or go shopping. He's still living with George, though George tries not to disclose too much about Bruce, perhaps not knowing himself what's really going on. Group members say they see him once in a while on the street. Those who know him better say he isn't doing well. He doesn't go out much, his spirits have been down. For a while he was calling and leaving longish, weird messages on my answer machine at work, singing certain phrases, impersonating someone in a high-pitched voice, now panting heavily, now whispering. My comprehension of what he was saying had gone down from about 50% to about 30%.

Kim

So had Kim's. She didn't know what to make of Bruce, only that whenever she saw him, he was still madly in love with her, so she didn't talk to him much. Bruce's "absolute devotion" must have been a striking contrast to what Kim perceived as her usual treatment in the world. A heavy woman in her mid-20s, Kim, like all other members of the group, had struggled throughout her life with labels. She was "cross-diagnosed" - a ward of both the Department of Mental Health and the Department of Mental Retardation. She was labelled mentally ill, retarded, and "crippled," able to walk, yet with difficulty, needing a full leg brace since she had had "corrective" surgery on her right knee some years prior. The surgery had failed.

Kim's take on life was simple really. No one understood her, and she was pissed. "I go to sleep singing that song," she would say frequently, referring to "Can You See the Real Me?", her anthem in life during this project. Hers was a story of constant misunderstandings: being fired from jobs for being associated with other "retarded" people, not being able to get jobs because "no one would give her a chance," squatting in doctor's offices when she didn't get explanations she understood (or wanted to hear) and subsequently being arrested. Kim's was a "hot potato history" in the human services system; it seemed that no one wanted to be her case worker, or it seemed that she didn't want them. In any case, it was usually just a matter of time before some issue arose upon which Kim would become cantankerous, making people angry, at which point they would stop cooperating with her, at which point she would accuse them of not giving her what she wanted, and not understanding her. I shuddered when I heard her stories, mostly because I knew someday I would be in her line of fire.

One night in rehearsal, we were practicing a scene where she and Charles are sitting on a park bench and Janet and I walk up to ask them about a movie that's playing in town. After getting a closer look at them, I turn to Janet and say "No, on the other hand, let's not ask them. They're . . . different." At which point Kim turns to me and says, calmly, "What do you mean different?"

We had probably rehearsed this scene 20 times, and had fought over how to say the word <u>different</u> - a generative theme which I talk about in the next chapter. The resolution had been, at my original suggestion, that she say it calmly because this would emphasize how reasonable the disabled were in the face of the neurotic normals. But tonight Kim was testy, so when I repeated "different," she retorted,

"You're criticizing me!"

"No I'm not," I said.

"Yes you are."

"Kim, I'm directing. I do this with everybody. We're doing a play."

"You just don't understand what it's like to be disabled," she continued.

"You're right," I said. "None of us knows what it's like to be someone else." At which point, she got up and started stomping around, threatening to quit. "You need to make a decision, Kim," I said. "If you want to quit, that's your choice, but if you want to stay in the play, we have to learn to work together." A couple cast members pleaded with her to stay, but I said "If she wants to leave, it's her decision."

"Then I quit!" she screamed, and slammed the door.

"Who wants to take Kim's part?" I asked. Marcia volunteered, reluctantly, so we continued practicing the scene while Kim continued screaming at us from outside the door.

"Mark, come here!"

"Don't talk to me that way, Kim," I responded. "I don't talk to anyone who treats me that way." She softened.

"Mark, please come here." Janet took over, so I walked outside and said,

"What's the problem?"

"You're always criticizing me," she said.

"Kim, when I make a suggestion . . .

"You don't know what it's like to be disabled."

"You're right," I said, "I don't, and you don't know what it's like to be in my shoes."

""Yeah," she said, "but I'd rather be in your shoes than mine."

"Ooooh," I moaned, and hugged her, though only briefly, knowing that she had had a crush on me in the past, perhaps had been in love with me, and I did not want to encourage that feeling. "I know you're having a tough time, and you have reason to feel the way you do. But you know others also have their troubles." I told her the story of a guy I knew who had no friends, and of my mother who has multiple sclerosis and is bound to a wheelchair for life. She probably couldn't understand these people either, but we were doing a play, so she needed to make a choice what she wanted to do. I walked back into the rehearsal. Some minutes later, the door opened quietly. She walked back in, stayed near the wall for a while, then gradually, without any ballyhoo from the cast, she was in another scene, rehearsing.

Charles

Of the eight core cast members, the only one I really can't recall presenting many problems was Charles. To be sure, Charles had his troubles, primarily related to his dialysis treatment three times a week. Since Charles had gone on dialysis, his life had changed dramatically, not only because of this intense therapy schedule, but because of his diet, which was greatly restricted, and because of his need for regularity in his life, especially rest. Toward the end of the project, Charles was missing more and more rehearsals because he was tired, or sick because dialysis had not gone that well that day. Since the project, Charles was unable to join us. He was in and out of the hospital because the dialysis did not take, his blood was clotting, and most recently, according to his home health nurse, because he was developing an allergy to his own skin, resulting in blisters on his hands, his feet, his arms, his mouth. At the time of this writing, Charles is still struggling with dialysis-related ailments. He lost a lot of weight and most of his color through it all, yet remained hopeful he will be able to bounce back, or at least stay out of the hospital.

"How do you deal with this day after day?" I said to him once. He pointed toward the ceiling, saying "You gotta look up."

Emic perspective

Given the above descriptions, it is clear that these people are no strangers to problems - some minor, some quite severe, some unannounced, some broadcasted on a daily basis. In this section, I will look more closely at their perceptions of these problems, asking first how they understand the word problem, then looking at what kinds of problems they have, and how they understand their causes and possible solutions.

Group member use of the word problem

In attempting to answer the question: For group members, what are "problems"? I reviewed 250 pages of transcripts of meetings, interviews, rehearsals and related activities in order to understand group members' understanding of the word "problem." I found only 21 cases in which it was used, and group members never defined it.[2] Usually, when discussing problems, they referred to experiences directly.

However, upon examining the 21 cases in which they did use the word, I observed that group members tended to use the word more in public than in private settings. Fourteen of the uses (66%) occurred in a "public" event - when group members were interviewing outsiders, or outsiders were present, such as when I interviewed the group while being taped by a video crew, and the post-play discussion. In these "public" settings, group meetings used the word in reference to how others are doing (e.g., "he's having some problems"), or the kinds of problems "the system" creates (e.g., "a problem I have is when they call you client"). In "private" settings - i.e., one-on-one or within the group -

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[2] This should come as no surprise since, as Spradley (1979) points out, "(M)ost cultural themes remain at the tacit level of knowledge. People do not express them easily, even though they know the cultural principle and use it to organize their behavior and interpret their experience" (p. 188).

group members used the word seven times (33%), usually in reference to a personal difficulty (bad leg, difficulty making up words to songs, feeling depressed about something) as opposed to more generalized problem statements about how people are treated. The prevalence of the use of the word problem in interview contexts (me interviewing them or them interviewing others) suggests that the interview process is conducive to the use of the word problem in some way. It should be noted, however that one of the main interview questions of the participatory research project was "How will people leaving Glenview be treated?" which in itself suggests problems. It should also be noted that one of the interviewees, Bob, whom I have included as a member of the "outer circle" in this study, clearly has a muckraking orientation on disabilities issues, using the word five times in our interview with him, thus skewing the number of times the world problem was used toward interview settings.[3]

Problem defined

Though group members rarely used the word problem, some working definition of problem is necessary in order to organize and analyze their experiences. Because they never

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[3] While Bob was not a member of the group of eight in this study (the inner circle), he was a friend of several group members, and was a member of other PLMR advocacy groups to which they belonged. More importantly, he had been labeled retarded and had spent several years at Glenview. I have therefore included his comments where relevant. Other "outer circle" members include Lyle and Frank, people who have also been labeled mentally retarded and took part in the production of Special at other points.

defined the word, however, I will use a standard definition as a starting point. The American Heritage Dictionary (1982) defines problem as "a question or situation that presents uncertainty, perplexity or difficulty." Yet group members never referred to questions as problems. Perhaps this is because they tend to talk about the world in concrete, not abstract ways. This is not to say that they are incapable of thinking abstractly, only that the way they tend to express their understanding of the world is in direct, experiential terms. For them, problems are situations, not questions. Moreover, as we shall see, group members tended to become extremely anxious when dealing with problems, sometimes because they felt personally threatening, sometimes because they seemed unsolvable. For this study, then, I will operationally define problem as a situation that presents uncertainty, perplexity or difficulty, and that generates a considerable level of anxiety.

Types of problems

Based on the above definition, I have identified seven kinds of problems with which group members struggled throughout this project, many of which are illustrated in the preceding vignettes.

Dealing with interpersonal conflicts. Group members spent a significant amount of time and energy dealing with interpersonal conflicts that arose from a variety of sources. Sometimes, they misunderstood someone else, someone misused a name, or situations were inaccurately described or understood, resulting in conflict between at least two persons. Sometimes group members felt harassed by others, either other group members or people on the street. Such harassment could take the form of name calling, of showing fists, of being pushed or even hit. Sometimes harassment resulted in out-and-out fights, both within and outside the group. I never saw group members being physically abusive with each other, though group members occasionally accused other group members of hitting them. I did observe some side choosing, name calling, and at times even chair throwing, due to the anger one person felt toward another. Reasons for anger varied. Sometimes someone had "stuck his head up" at someone, often there was no reason I could discern. Group members also struggled with being denied permission - by an employer who refused to let someone change a schedule, by a group home staff who refused to let someone rehearse, or by an agency worker who wouldn't let a group member cash a check. In general, group members struggled with being put down, controlled, or denied opportunities, especially by people who should be on their side - a subject taken up in greater depth in Chapter 6.

Dealing with feelings of loneliness, loss, and unrequited love. Group members frequently recounted experiences of missing friends, family members, or housemates who had passed away, moved out of the area, or abandoned them. Sam and Bruce were constantly consumed with the need to have a romance - Bruce with Kim and Sam with anyone from Sally Jesse Raphael to Valerie Harper to Janet to my ex-wife. Bruce suffered from unrequited love with Kim; Marcia and Kim with me, though my refusal to oblige them did not stop them both from insisting on riding in the front seat with me, a constant source of tension between them and other group members. Susan constantly felt lonely, often asking to be dropped off last so as to have company a little bit longer. Most called me at home on a regular basis, often out of loneliness.

Dealing with the fact that others are in pain, or potentially in pain. Bruce frequently called or wrote letters (actually dictated them to others) about his concern for Kim when she was in the hospital, or when his mother might die. Marcia's regular phone calls to my home often included the latest news on who was in the hospital, sometimes friends of hers, sometimes someone she just heard about. She would fill me in on who had had a heart attack, even stories about dead kittens in the street. Fred exhibited an uncanny ability to cry spontaneously when Marcia cried, though I'm not sure he knew why. In prayer, group members frequently asked for help for people they knew who were sick, dying, or in the hospital.

Getting basic needs met. One of the dominant characteristics of this group was their tendency to talk about personal care issues. Sam would often come to rehearsal not having eaten dinner. George frequently complained of being tired, having worked too many hours that day. Marcia and Fred constantly asked for rides to and from rehearsal in spite of the existence of regular bus service. Kim needed rides to the hospital or store on a regular basis, especially following the bus incident (see The bus incident, Chapter 6). Most group members complained at one time or another about not having a job - hence, the creation of our first play, *Get a Job!* Some complained about not being satisfied with work, but also feeling unable to change their situation. Kim constantly expressed a need for job training. Susan, George and Bruce had difficulties finding tutors for reading lessons, Sam a tutor for music lessons. Several said they consistently had trouble getting assistance paying bills.

Physical/health problems. As the vignettes above describe, most cast members had some physical problems, some of them chronic: Kim and her shunt and leg brace, Charles and dialysis, Marcia with bouts of vomiting and nausea (Marcia's confidential file at her agency reveals a history of chronic medical problems and complaints), Fred with achy muscles and joints, Bruce with chronic skin rashes and a "clock in his head."

Mobility problems. Group members often expressed difficulty with mobility issues. Sam, being blind, had trouble getting around when there was a lot of traffic. When we would schedule a rehearsal for Sunday night, Fred and Marcia would predictably say "How are *we* going to get there?" The busses ran at that time, though at irregular hours. Marcia would often say "They just took off without us."

Keeping up with the "normals." Group members occasionally talked about feeling embarrassed when they were unable to read, write, or do math. They often felt anxious when expected to remember things such as lines or blocking, or when they had trouble keeping schedules straight. They would often become upset when asked to change their schedules, and when things were moving too fast. Doing the play often made them feel overloaded, some of them referring to it as a job, or if they already had one, as a second job. (This changed a bit when group members started getting paid for performance in the second year of production.)

Dealing with systems and/or their personnel. Kim often felt discriminated against because her doctor did not sufficiently explain her problem to her. Legal battles often ensued when she would get arrested for refusing to leave doctors' or agency personnel's offices. Marcia said she was falsely accused of hitting a coworker at Grace Manor nursing home, resulting in her getting fired. Several group members complained about problems they were having getting money or services from DMR and DMH. Paul had recurring arguments with house staff about schedules, housing conditions, and getting assistance (discussed more fully in Chapter 6).

Of course, these categories are not conclusive, and descriptions within each are not intended to be exhaustive. Rather, these descriptions are an attempt to illustrate the breadth of types of problems group members continually face, and the complexity of types of problems when all occur together, which of course in this project they did.

Causes of problems

In response to the question: For group members, what causes problems? three basic responses emerged from the data.

Other people.

I found that in most cases, group members reported that other people caused problems for them. For Marcia, Susan, Fred, and Bruce, the source of their anxiety was most often someone on the street, usually a friend or acquaintance, who called them a name, or made a threatening gesture, or pushed or hit one of them. Sometimes the source of anxiety was someone in the group, usually because of something that person had said (e.g., "Get out of my way") or done (e.g., pushed someone). Bruce regularly reported being bossed around by his housemate, harassed by his rep payee (agency staff hired to assist him with paying bills), and robbed by Kim's brother. The cause of much of Charles' anguish was his mother, who continued to wish Glenview was open and Charles was back in. Paul talked about the difficulties he had with staff members at the group home where he lives:

> Uh, what happens to me is when I ask about staff schedules, I keep getting told, "It's none of your business, Paul, about the staff schedule. You do not keep track of staff schedules." And I say to Sheri, "Why? Why can't the clients uh, keep track of the schedule?" Sheri says, "Because Paul. It's none of your business."

<u>Institutions</u>. In rare cases, group members spoke of problems as being caused by institutions, and when they did, institutional workers as a group were usually identified as the problem, such as the behavior of staff at Glenview, in group homes, and in sheltered workshops.

Mark: Why did (the staff at Glenview) treat you so poorly?

Charles: They were feeble-minded.

Kim: I mean it's like when they put people in a program, the staff control the people . . . instead of the other person telling them what to do for them.

Paul: Right now people that work in my house don't bother to tell us who works there, I mean, they don't bother to tell us who gonna come in new. They just hire 'em and they turn around and say to me, "You gotta respect the staff that work here."

Memory problems. Group members frequently expressed frustration over their inability to remember things and, as a result, their inability to do things that required a good memory - for example, acting. Sometimes this problem would take the form of simply not remembering something mid-sentence, then quickly moving on. Sometimes they would acknowledge this openly. For example, group members would use the wrong word, or call someone the wrong name, and laugh. Less conspicuous were Kim's asides, a typical discursive pattern where she would stop mid-sentence and mutter something to the person next to her (often me) or to herself. Often, these asides included phrases like "stop me if I'm remembering this wrong," or "I can't remember the word."

In some cases, group members would attribute their problems with memory to something else. For example, one night George blew up at me for calling out one of his lines when he was having trouble remembering it - a problem all actors deal with.

"Mark, I can't do this!" he screamed.

"Yes you can," I said, assuming I knew what this meant.

"No, no, I I can't keep working two jobs - my job during the day, and this. It's it's too much for my head. See what happens is I get too tired, and then I can't do, remember anything."

Solutions to problems

In response to the question: For group members, how are problems solved? I found that just as group members tended to identify individuals as the primary causes of their problems, so did they tend to identify those individuals as the people who should change. The following are some of the strategies they used or proposed.

Confrontation. George believes that people who cause problems should be confronted, as in the following passage:

Mark: So if you were with Susan when something like this happened (someone calling her a name), what would you do?

Marcia: Tell Mark.

George: I I I pro, probably would say something to 'em. Of course this guy he's talking about is twice my size and a lot bigger than me and I better watch out. (laughs)

Mark: Susan, what do you think is a good way to respond to that? Just walk on the way you did?

Susan: No.

Mark: Mm, hmm. Anybody else have any ideas?

George: Well you can just tell 'em "My name is Susan and I wanna leave it that way" or something like that.

Marcia: Walk on the other side of the street Susan.

George: No, no, you don't, ...you don't owe respect for anybody. I I I mean if the guy's gonna (say) something you don't like, you've got a right to respond to it.

Marcia: You can't, you can't go around calling her like a handicapped people, thing. 'N he said "Oh you belong in Glenview with the handicapped people." "No she does not. She's n's doing anything to him, and, and he can't go around calling her names like that.

George: Well, respond to it, just don't say say nothing to him.

Marcia: She tried it. It's hard, George, right now. Just ignore that guy.

Other group members advocated confrontation as a solution to problems as well; Sam's advice to Kim (see <u>Sam's 6 tenets of respect and care</u>, Chapter 6) provides another example. Yet such examples are rare; group members usually confronted "trouble makers" in an angry fashion, as in the vignette about George above, or they didn't confront them at all.

<u>Empathy</u>. As the excerpt above also suggests ("she tried it . . . . It's hard, George, right now"), some group

members showed a great deal of empathy in their way of dealing with problems. Marcia was often one of the most empathetic members, frequently saying things like "He can't help it" or "It's not his fault." Sometimes they would empathize with people in superior positions or organizations, as when Sam said:

> What I wish could happen is that I could make some extra money you know in my pocket. But I know that's not the fault of Mass Businesses because of the fact that jobs are scarce . . .

Identity change. In response to problems, some group members showed a curious tendency to want to change their identity in some fundamental way. Kim, at one time fed up with the problems she was having with bladder infections, said to me, "Mark, can I have your body?" Bruce so feared his mother's death and his impending loneliness, and so wanted to distance himself from his own family's past, and so loved Kim, that he wanted to change his last name to hers. In fact, throughout most of the project, his effort to change his name was a dominant subject for him in discussions and, when he was with the group, everyone else as well.

Consolation. Another problem-solving strategy was seeking consolation, usually by Marcia, in the form of telling me or her agency worker if she was having a tough time. At times, seeking consolation turned into tattling, when Marcia would threaten to tell the cops. One night during one of her "episodes," she marched over to the police station, threatening to turn me into the cops. I followed her into the station, sat down next to her and held her hand while she dutifully rattled off to a sympathetic young cop what dreadful things had befallen her that day. Twenty minutes later we walked back to rehearsal, Marcia a calmer woman.

Levelling. Another problem strategy was what I would call "leveling" - that is, comparing themselves to normals to show that what they were doing was not so different. Again, the memory issue provides an example. In one scene of the play, Susan was to say "Anyone want more food?" upon which Marcia's response was: "More food! I'm stuffed. But . . . " and then a song came on. One night in rehearsal, Marcia remembered her line, but it all came out as one word: "MorefoodI'mstuffedbut." We worked on separating them and, once she felt some sense of mastery, we tried to get her to rub her stomach at the same time, mostly to take her mind off remembering the line, which was having the effect of making her stand rigid like a Roman soldier. "Mark!" she screamed at one point and burst into tears. "No one's perfect! You forget stuff too, you know." We spent the next 15 minutes trying to console her, moving to another part of the scene, then coming back. She finally got it, though until opening night, no one knew if Marcia was going to remember her line. She did. Now we're working on getting her to look less startled when it comes, while rubbing her stomach.

Avoidance. When no other way could be found to deal with a problem, which was frequent, group members resorted to avoidance. "I just ignore them people," Susan would often say. Kim once looked ahead at her week in which she had to go to court, see her doctor, and continue struggling to find a job, saying "Can I skip this week?" Sometimes group members wanted to avoid the wrath of other group members. Once when Bruce was angry at one group member, he stopped coming to rehearsals. No one in the group wanted to call him to invite him back because they said then he might get mad at them.

Collective action. Significantly, the least-used strategy I observed was for the group to try to organize a collective response to a problem. To be sure, group members often chose to share problems with the group, sometimes even to the extent that we discussed the problem for a significant portion of our meeting time. One time, Kim even asked to have my tape recorder turned off so she could confide in the group a problem she and Bruce were having with a Bruce's rep payee and Kim's friend Sheri, both of whom believed that the bank account the group had opened was in Kim's or Bruce's own name, changing their economic status and thus their eligibility for assistance. Bruce seemed concerned about his benefits and making his rep payee angry; Kim seemed concerned about making her friend angry. But such conversations usually stayed at the level of the group, either with advice to the person seeking help (usually forgotten in subsequent group discussions), or simple encouragement like "hang in there." Rarely did the group decide as a group to do something as a group (except in the case of Kim getting DMH money, which was really more a case of Kim soliciting support from individuals. Even more rarely did group members identify solutions to problems on the level of policies, systems or ideology.

Given the preceding discussion, it is clear that group members feel beset by a large number of problems from relative to absolute in nature, and that some group members seemed to feel free to share their feelings and observations at every available opportunity. Looking over the duration of the project, it also appears that the rate at which these problems arose or remained problematic did not change - hence, a chronic problem orientation.

In this section, I have attempted to take an emic perspective by presenting group members' perspectives on the nature of problems they have in their day-to-day lives, and the causes and solutions of those problems. In the next section, I will switch to an etic perspective in order to build on what they said and did with my own explanations of the nature, causes and solutions of problems.

Etic perspective

In this section, I will attempt to define what I mean by chronic problem orientation. Again, the notion of chronic problem orientation is mine, not theirs. This is not a phrase they (or I) ever used in the course of this project. It is what I have observed as a result of analyzing these data, and would define as _a proclivity toward discussing, attempting to deal with, and even creating problems_. Moreover, these problems themselves are ongoing. By chronic, then, I am referring both to group members' orientation to problems and the problems themselves. My claim that group members have a chronic problem orientation is based on three observations. I will deal with each of these in turn.

Problem orientation

My first observation is that group members frequently and spontaneously bring up problems. By frequently, I mean that a dominant feature of my relationship with group members as individuals and as a group, and a dominant feature of the way they interact with each other, is for them to bring up and be concerned about problems in their lives and in the lives of other people. That is, they bring up problems all the time. By spontaneous, I mean that even when a discussion of problems is not solicited by me, or required by the activity we are doing, group members bring them up. For example, in Scene 4 of *Special*, we sit in a semi-circle, sing "Great change," a lively gospel song, and then "check in," or talk about how each of us is doing that day. On opening night, even though three group members did talk about good things in their lives, everyone except Fred talked about problems they were having. Granted, in rehearsals, group members had received compliments for their ability to talk about their problems, so they no doubt felt compelled to do the same in the performance as well.

But this was not unique. In any typical group discussion, the subject was likely to be how group members were doing, how others (group members' friends, neighbors, and family) were doing, and problems. Rare was the time someone brought up a question of general curiosity or interest such as "What's happening in town this weekend?" or "What do you think of the Gulf War?" More than any other group I've ever worked with, this group shows the greatest proclivity to talk both about how well people are doing, and how difficult people's lives are. In fact, after the very first meeting, Valerie Faith, who worked with us in the beginning of the project, proposed "hard times" as a possible theme for the play.

In addition to bringing problems up, group members demonstrated their chronic problem orientation in various ways they behaved. One pattern was what I would call urgent behavior - a pattern of interaction in which they would present themselves in way that would demand an immediate response. For example, several group members exhibited a tendency to interrupt, to get off the subject, or to dominate the conversation on a certain points. Sometimes, group members would present a question or situation as an urgent problem which must be solved at that moment: "How are we going to get there?" "The bus doesn't come at that time." "My doctor's gonna get mad." "My tape (of dialogues) doesn't work." Another form of urgent behavior took the form of care or concern about oneself or others: "I've gotta have coffee." "How's Charles doing?" "Someone should go get Sam." Finally, urgent behavior sometimes meant being assured that someone's request was going to get honored: "Are you going to play that video (of me describing the chart?)" "Can I get that money now?" "Remember you said you'd call." While none of these needs or requests is of itself unusual or extreme, the urgency with which they were presented in the context of group meetings and rehearsals meant that if they were not responded to immediately and satisfactorily, the result would usually be that new problems would arise in the form of continued interruptions, snide remarks, or outright disruptions such as self-abuse, tantrums, or stomping out of the room (see <u>Problem causing by group members</u> below).

Chronic problem orientation

My second observation is that many of these problems seem to be chronic, meaning that problems keep recurring, and that group members seemed to have trouble putting an end to these problems. That is, group members' problems often seemed to be "absolute problems." The clearest example is jobs, the subject of our first play *Get a Job!* Sam, Bruce, Marcia and Kim expressed concern about getting a job throughout most of the project. Eventually, Bruce and Sam got jobs, but then the subject became Sam's dissatisfaction with his telephone sales job, as expressed on opening night of the play: "The one difficulty I have is people clicking on me. I do not like people hanging up on me." (Sam quit his job shortly thereafter.) Other examples of "absolute problems" include "people not understanding me" (Kim), physical problems (Kim, Marcia, Charles), difficulty quitting smoking (Sam), difficulty dealing with loneliness (Sam, Bruce), inconveniences and life-threatening medical complications from dialysis (Charles), "people giving me a bad time" (Marcia and Susan). This is not to say that group members are chronic complainers. To the contrary, I seldom experienced their discussion of problems as complaining, but as bona fide attempts to understand and deal with problems that truly seemed unresolvable to them and in many cases, such as Charles's dialysis, were.

Problem causing by group members

Group members often created problems. As described in Problem orientation above, urgent behavior was usually a response to already-existing problems. Yet depending on the way it was received, group members often actually created problems in the group. Sometimes they created problems for no known reason. On a couple occasions, Marcia and Susan, whom I described as two "peas in a pod" in the vignettes above, inexplicably tore into each other so aggressively that only by separating them and taking them for a walk were they able to overcome their anger which, just as inexplicably, disappeared within minutes.

Sometimes group members created problems in their choice of strategies for dealing with problems. Some threatened to drop out, or chose self-removal, as a strategy for dealing with problems, such as the time we were discussing where to do the play and, because she felt no one was listening to her, Kim announced she was going to drop out of the play, then left the room. When she came back in, I told her that I didn't like her behavior, that no one had the right to sabotage the group process, upon which she started crying, upon which Bruce jumped to her defense, upon which Marcia jumped on Bruce for jumping on me. Of course, Marcia's self-abuse causes great trauma for others. Sometimes their problem-causing behavior was less sensational, however, such as Bruce's habitual absence from rehearsals, which had a demoralizing effect on the group.

I occasionally observed group members starting heated arguments, sometimes inadvertently, sometimes as a result of apparent hostility, with other group members. Examples of inadvertent causes include misunderstandings, being irritated or offended by the behavior of others, or just taking things personally. Sometimes it felt more hostile.

Janet: There’s been some difficulties. People haven’t been attending, there’s reasons why (the play’s) not ready yet.

Kim: Well excuse me, Janet, but I can’t attend when I’m in the hospital!

Janet: It’s not about blame, Kim. We’re just talking about real things that happened that we have to deal with.

Kim: I heard what you said.

Janet: You took it the wrong way.

In short, a kind of "problem tone" often hung over the group while doing this project, the nature of which varied from lifelong problems to problems actually created within the project itself. Though some were chronic, not all were; for periods of time, Sam did have a girlfriend, Kim did have a job, and Fred’s achy joints did stop aching.

Perhaps the only thing that can be said about all these problems is that they were real. I never felt an effort on any group member’s part to sabotage this project for the sake of ruining it. The closest example would be when Kim tried to sabotage the decision-making process the night we were trying to decide on a location.

Kim: How many of you think Mark is trying to use the group?

Marcia: Kim! No he's not!

Kim: I think he is. He doesn't have a fucking date for the play, and now we don't have a fucking place to put it on. I'm leaving!

But given the fact that Kim had just gotten out of the hospital that night and stated that she was in pain, and given the fact that she loves this play and continues to push for more performances, it is unlikely that her interest was in sabotaging the project or the group. Her behavior, though obnoxious, was understandable, her pain real. What is unclear, however, is why this general "problem tone" hung over the group so frequently, a subject I will turn to in the next section.

Reasons for chronic problem orientation

Several factors contributed to the group's chronic problem orientation: group dynamics, dynamics of activities, "researcher influence," my misunderstanding/not helping them, conflicting logics, memory problems, and the congregation effect.

Group dynamics.

Over the group's five-year history, certain dynamics have persisted: Marcia's tendency toward outrage and at times self-abuse, Fred and Susan's tendency to defend Marcia when others appear to be attacking her, even if all they are doing is holding her accountable for her behavior, Paul's tendency to needle people, especially Susan, Kim's tendency to dominate the group and to challenge my leadership when she could not, among others. These dynamics sometimes take on a life of their own, eclipsing the main reason the group came together to begin with, and in turn, causing additional problems that sometimes become the main activity of the evening. In time, we developed techniques for dealing with such dynamics, such as raising our hands until everyone is silent when a disruption is occurring then, once everyone is silent, asking "What's happening?"

Dynamics of activities. One problem with some activities in this project was that they simply did not sufficiently allow for group members to share what was on their minds. When we felt compelled to move to the next activity, or someone interrupted, some members would respond by screaming or otherwise voicing their frustration. Another problem was ambiguity. Sometimes the rules or structure or purpose of an activity were unclear. Sometimes the activity was too difficult, or unfolded too quickly for group members to understand or be able to master. Some group members did not enjoy the trust walk, for example; Marcia said she was scared, and Sam thought it was a waste of time. Many of the Boal exercises we tried also seemed to fail, perhaps because they required a level of cognitive ability that many group members simply did not have. When we played imaginary toss, we had people pretend they were throwing an apple, then an orange, then a banana. No one could remember the sequence, so we limited it to "apple," which they liked. Sometimes group members felt rushed. One the night we tried to decide where and when to perform the play, George called for a vote from the group:

George: We do it right away like Mark said and rehearse real fast, or we can wait 'til Janet finds us another place and we can maybe take our time rehearsing the play... So I have a proposal. Should we do the play right away? Raise your hand, yes or no.

Marcia: You're pushing

George: No, there's two things here.

Marcia: You're pushing and we don't like to push, George. We don't wanna push and make a mistake, you know (raising her voice), stupid!

Curiously, in this example, I went on to ask Marcia if she felt we could do it in three weeks, and she said "we should." So the concern didn't seem to be the actual amount of time, but the feeling that it was too rushed. When put another way - in specific terms of time, it seemed to feel less threatening. In general, the greater the level of ambiguity in terms of time, place, or purpose, the greater the level of tension amongst many group members.

<u>Need for attention</u>. One of the dominant factors in the group's chronic problem orientation was my (and Janet's) influence. For example, my mood greatly affected the moods of others. If I appeared edgy or rushed, others immediately picked up on it and often felt ill at ease. The amount of attention and affection I showed them also greatly affected their temperament (especially when women had crushes on me). I was surprised and a little disappointed once when Tim, our videographer, commented that the reason he felt group members did these plays was not because of their desire to make a statement, but because of the attention they got, primarily from me. Though I believe there were many reasons they belonged to this group - support, entertainment, meaningful reflection, the chance to be on stage, etc. - I think he was partly right. For many group members, my attention was important, and when I ignored them or worse, when I admonished them for behavior I felt was out of line, they responded with everything from withdrawal to outright attacks. What usually helped was to stop and take a minute or two to deal with someone's need for attention on their terms, or for me or Janet to take the person outside so their attention needs could be met while the rest of the group continued rehearsing.

Me misunderstanding/not helping group members. In some ways, my inability to understand group members no doubt created anxiety for them, and for me as well. For example, I probably only understood, on average, about 50% of everything Bruce ever said, even less of what he meant. Also, my inability to help them no doubt led to feelings of rejection on their part. However, some of these situations were unavoidable, for example, when they needed help in areas that were the appropriate domain of their agency workers - e.g., shopping, bill paying, doctor visits, etc.

Conflicting logics. Undoubtedly one of the biggest reasons for the group's chronic problem orientation was my inability to solve problems with them. One big reason for this was the fact that I tended to deal with emotional problems on rational level. As with the case above of George failing to show up at ten o'clock to strike the set as he had promised, I tended to address group members' "logic of pain" or "logic of justice" with my "logic of commitments" - a rational position over which "normals" can claim dominion.[4] In retrospect, I realize that in such cases perhaps I should have tried to refrain from the "logic of commitments" and instead tried to ascertain what group members were feeling, why they were feeling that way, and what assumptions they were making that they felt justified

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[4] My thanks to Peter Park for pointing this pattern out to me.

their behavior. Given this line of reasoning, perhaps I would have seen that George got mad at me after the performance because he had been assuming all along that we all should work equally, that plans should be made in advance, and that it was my responsibility to make them. Had these assumptions been made explicit in advance, perhaps we could have decided whether all people shared them, and therefore how a decision should be made about who should strike the set.

Memory problems. Group members' chronic problem orientation is at least partly attributable to the memory problem described in the Causes of problems above. Their fear of forgetting, of appearing different, of getting yelled at, of being punished or hurt, or of losing out on an opportunity, seems to be related to the problems they raise, wrestle with and cause. Their urgent behavior, for example, often appears to be based on their fear of being limited (e.g., not getting time off work), of failing ("How did I do?"), of appearing yet again to be less ("Why can't I remember these lines?"). Perhaps their urgent behavior is a way of asserting themselves because they feel out of control, and need to somehow take control. To compensate for the memory problem, we used a variety of strategies. For rehearsals, we would brainstorm situations and dialogues, then give scripts to those who could read and make audio tapes for everyone to listen to. We held special rehearsals, pared scenes down to their bare essentials, and practiced endlessly. For music, we chose songs that had short verses, never more than two, with simple choruses, or had cast members improvise lyrics. In performances, we would call out lines when necessary, have "normals" sit next to group members to feed them lines, or have group members with better memories sitting with ones with worse. In one case, we used an audio overdub of a dialogue while two cast members held mirrors in front of their faces, moving them in time with the talking, to symbolize how "normals" project their "stuff" onto disabled people rather than seeing them for who they really are.

In general, the acting worked fine as long as the scenes weren't too long, as long as no one person had too many lines to memorize (never more than two or three in a row), as long as no words went over three syllables (most cast members had trouble with longer words), and as long as the dialogue was based on the kind of content that, if forgotten, could be improvised in a pinch. On stage, group members were able to "speak from the heart," as we did in one scene in the play in which we went around and shared how we were doing that day. However, they were never able to achieve on stage the kind of heart-felt stories that they came up with in rehearsals - about abuse at Glenview, about something that had happened to them the other day, or just about how they understand prejudice against disabled people. Some of these rare moments we did capture on video tape, so we interspersed the scenes of the play with video projection to include these pieces.

In truth, I don't feel we ever satisfactorily dealt with the memory problem. Adding to scenes was always a source of contention because of the onus of memory, losing scripts and tapes was always a source of great consternation. And I always split a gut right before a performance, not knowing if Marcia would freeze up, making the rest of the cast freeze up (as had happened occasionally in rehearsals), or afraid that Paul would just start talking about his life and I would have to cut him off. These things never happened, though perhaps it also goes without saying that the play was never the same twice.

The congregation effect. This idea refers to the possibility that group members had and even created problems because given their painful histories, having too many congregated in one place inevitably led to outbursts of anger. This idea is discussed more fully in Criticisms of Special, Chapter 8).

Discussion

The literature notes that PLMRs often have a "heightened level of fearfulness and anxiety" (Levine, 1985). Several reasons are given. One is the general problem PLMRs have with anxiety. Edgerton (1967) noted that a prominent characteristic identified by expatients in his study was a problem of "nerves," sometimes leading to outbursts that got people fired. Deutsch (1989) states that people with mental retardation experience more, rather than less, stress that their nonhandicapped peers. She goes on to say that stress may emerge from three sources: (1) situations that are typically stressful to the general population, (2) ordinary situations which are typically handled with ease by the general population; and (3) stresses that are unique to them (e.g., not being able to drive, being compared to normals). Levine (1985) also notes that these anxieties may result from having been sheltered from everyday stress and opportunities (cited in McGarrity, 1993:167). Finally, McGarrity (1993) notes that PLMRs with employment or regular social activities exhibit less anxiety than those who are unemployed or lead boring lives.

As this chapter illustrates, group members experienced a variety of types of anxiety for different reasons. Yet unlike Edgerton's study, none named nerves as a reason. With the exception of Marcia being concerned about her problem with her temper and occasional self-abuse, group members either attributed their anxiety to being overworked or pushed, not feeling well, being misunderstood or abused. In any case, the tendency was to blame other people.

Some of the anxiety experienced by group members in this study was due to changes in schedule, content of the play, or their roles, what could be called "situations that are typically stressful to the general population."

However, the extent to which they reacted to these stresses raises the question as to how much of their anger was based not only on failing, but a "nagging self-doubt" that they were failing because of their cognitive impairments:

> They usually give the appearance of being successful in their efforts to answer their own questions about themselves, but at the same time they give indication that, fundamentally, they either know or strongly suspect that they are mentally retarded. Probably the most accurate understanding of the expatients in their struggle for denial is to see them as participants in a self-instructive dialogue that is in a constantly changing balance between highly rationalized denial and gnawing self-doubt (Edgerton, 1967:170).

This "gnawing self doubt" was most evident to me when George feared that he would forget his lines. He wasn't only embarrassed and afraid of blowing his scene in the play; he was in pain because he was reminding himself (and others) of the very thing he was doing this play to overcome - his inherent inability and consequent feeling of inferiority. He feared looking stupid, thereby reinforcing his deepest fear - that he is stupid. Of course, he never said this, but rumblings of this type of fear occurred throughout this project amongst all group members.

For this reason, I believe that issues with memory, dynamics of activities, and conflicting logics were difficult not only because they were more difficult for this group than they might have been for normals, but because they were also painful reminders that perhaps part of their difficulties were due to their cognitive impairments.

Yet unlike Edgerton's study, even though group members experienced this pain, they did not seem intent, at least with me, on passing and denial. As Goldschmidt points out,

> These difficulties are compounded by the fact that their incompetence itself hampers their ability to manage their public life so as not only to hide from others the reality of their stigma but - even more important, in my belief - to receive confirmation of their own competence. It is this inadequacy and the valiant subterfuges by which they endeavor to overcome it that give pathos to the story of their behavior (p. viii).

While group members did engage in some passing and denial, their more explicit need, it seemed, was "to receive confirmation of their own competence." This, it seems to me, is related more to their need for affirmation and acceptance, and use of urgent behavior to get it, than to a need to hide their identity. The reasons for the differences between Edgerton's study and this one are unclear, though no doubt being involved in the production of a play, along with being involved with an ongoing, support-oriented group, had an influence on group members' behavior in this study.

The findings in this chapter illustrate one additional dynamic that claimed much of my attention throughout the project - the group's volatility. The prominent feature of this group's chronic problem orientation was not the fact that it was chronic in the sense of being continuous, without interruption. It was the fact that this group was given at times to singing, dancing, and expressing themselves unabashedly, as I will talk about in Chapter 7, while at other times they would lapse into outbreaks of anger and fighting. What was perhaps most difficult for me to deal with as a director, as a researcher, and as a friend was not the group's chronic problem orientation, but the unpredictability of their moods and their actions. For as this study points out, their chronic problem orientation was only one of many facets of their "personality."

I also realize that one danger in assessing certain types of behavior as "chronic problem orientation" is that their behavior itself might appear to be a problem, when in fact their behavior is taking care of a problem. It is important to note that discussing problems usually seemed to help group members, even if we didn't bring them up again in subsequent meetings, or take action to solve them. So were these discussions a manifestation of their chronic problem orientation, or an example of a problem-solving orientation? To what extent were the things I observed as problems really attempts to work problems out? And how could I find this out? This question as to whether problem manifestations might actually be problem solving strategies warrants further study.

Finally, the problem of ambiguity has implications for educators' attempts to build democracy or conduct collective inquiry processes such as participatory research. The night we tried to make a collective decision about where to do the play was a fiasco. What does this mean about shared decision making? When should the group make a decision, and when should a single person make that decision? That is, when does involving everyone in a decision actually cause problems? And how is this question different when working with PLMRs? While these questions must for the moment go unanswered, they do suggest a level of thought addressed in the next chapter of this study.

Conclusion

This chapter has presented the first of three major findings of this study: that group members showed a proclivity toward discussing, attempting to deal with, and even creating problems - what I call a chronic problem orientation. Problems included dealing with interpersonal conflicts; dealing with feelings of loneliness, loss and unrequited love; dealing with the fact that others are in pain or potentially in pain; getting basic needs met; physical and health problems; dealing with systems and/or their personnel; and keeping up with normals. Reasons cited for these problems included group dynamics, dynamics of the activity, need for attention, my own ignorance, conflicting logics, the memory problem, and the congregation effect. Group members used a variety of techniques to face these problems: confrontation, empathy, identity change, consolation, levelling, avoidance, and rarely, collective action.

In light of the research mentioned in the Discussion section above, the problems of gnawing self-doubt and volatility on the part of group members, and the problem of degree of participation to be encouraged by the facilitator, stand out as unresolved issues to be explored by future research. What these and other issues discussed in this chapter also suggest, however, is the possibility that group members' problem orientation might in fact increase their sensitivity to issues of justice - the second major finding of this study to be discussed in the next chapter.

CHAPTER 6

JUSTICE ORIENTATION

Introduction

The second major finding of this study is that throughout this project, group members exhibited what I shall call a justice orientation, or proclivity toward showing their concern that all people, especially the disabled, should be treated with respect and care. Unlike the previous chapter, I will not attempt to separate emic and etic perspectives, but I will mix them. My reason for this is because of the level of interpolation necessary at some points in this analysis. That is, perhaps because the word justice was not used by group members, I often struggled with group members' meanings, not sure whether they understood a situation as justice or injustice or something else. Consequently, my analysis at times includes their perspective as well as my own in an effort to discern what is happening.

In the first section, I will inductively define justice according to group members' experiences, then present several patterns that illustrate the nature and reasons for their concern about justice. After discussing these patterns, I will examine what these patterns mean. I will conclude with a summary and thoughts about issues that these two perspectives raise.

Justice defined

Mark: Do you ever use the word justice?

Kim: No.

Mark: Have you ever heard anyone use it? What do you think it means?

Kim: Justice for all. Or give me justice. Something like that.

Mark: What do you think it means in those examples?

Kim: Means give me peace.

Mark: Hm. So justice for all means peace for all?

Kim: Yeah.

Mark: In this book (dissertation) that I'm writing, I've said that you guys talk about respect and care a lot, that everyone should be respected and cared for, that that's justice. What do you think? I don't want to put words in your mouth.

Kim: That sounds good. (pause) So what time are we rehearsing tomorrow?

One of the dominant concerns of this group was the fact that people should be treated with respect and with care. Yet as the above passage suggests, group members never used the word justice, nor did they really care to. In fact, one of the greatest difficulties of this study has been dealing with the gap between phenomena as I understand them vs. the way group members describe them. Group members tend to talk about experiences directly, not by using representative words such as problems, justice, or oppression. Moreover, trying to verify these words with them is basically fruitless because as the disclosure above suggests, it becomes more of a vocabulary lesson than a verification process.

Yet they talked constantly about rights, respect, choices, freedom, "let people do what they want," unfortunate situations, prejudice, "it's not nice," "he can't do that," "people should have the right to . . . " and "that's a type of prejudice." And they repeatedly recounted stories in which they had been treated unfairly, and how they should have been treated instead.

Marcia: As I was walking down the street one day and I heard somebody saying to me, "Oh, hello handicapped." And I didn't (clears throat), I didn't like it what that person said that.

Mark: And what did you say?

Marcia: I didn't say nothing.

Mark: You just kept walking.

Mark: How would you rather that person talked to you? What should they say?

Marcia: They should be polite.

Mark: So instead of saying hi handicap, they should say hi . . .

Sam: Her real name.

Mark: Well if they know her real name, right?

Marcia: This, person does know my name. He could have said, "I shouldn't have said that Marcia."

Mark: So it was a put down.

Marcia: Yep. . . . He died of cancer, (or a) heart attack. I don't like that.

It is interesting to contrast Marcia's story with a standard definition of justice as taken from the American Heritage Dictionary (1982):

> 1. a. the principle of moral rightness; equity. b. conformity to moral rightness in action or attitude; righteousness 2. the upholding of what is just, esp. fair treatment and due reward in accordance to honor, standards, or law; fairness.

This definition reflects the spirit of the group's view of justice - moral rightness, equity, righteousness. As with Marcia's story, group members could give numerous examples of these principles, and constantly reaffirmed the need for all people to incorporate these principles into their lives. Yet the American Heritage definition does not quite capture group members' way of talking about justice. They would have never used "principle" or "moral rightness" - a significant point, because for group members, justice was not a principle, it was a way of life. Moreover, it is a necessary way of life. Marcia's ability to articulate how she should have been treated, as well as her ability to sympathize with her tormenter, exemplifies what I have identified as the core of the group's sense of justice - an insistence on treating all people, even those who mistreat others, with respect and care.

Based on stories and incidents like Marcia's, then, I have derived a definition: for group members, justice consists of recognizing the inherent goodness of all people, and treating them with respect and care. Of course, this definition fails to take into account the view that some people perhaps should not be viewed as inherently good, such as people who are cruel. However, as the example with Marcia illustrates, there is evidence that at least one group member believes even cruel people should be treated with compassion, respect and care.

Two areas of difficulty

In the following pages, I will describe two areas of difficulty and pain out of which group members' sense of justice arose: experiencing difficulty due to misunderstanding, mistreatment, or abuse, usually by would-be friends; and experiencing difficulty over the use of labels.

Misunderstanding, mistreatment and abuse

Group members' sense of justice arose, in part, from experiences of misunderstanding, mistreatment and abuse, usually by would-be friends. When group members spoke of the necessity to respect and care for people, their observations were often born out of their own stories of misunderstanding, mistreatment or abuse.

Can you see the real me? Some of these stories emerged during an exercise in which we sang "Can You See the Real

Me?" by The Who, substituting our own lyrics about how people often didn't see "the real us." Then we would go around the circle recounting times when someone had not seen the real us. Group members' stories, some of which appear below, indicated that when someone had not seen the real them, they experienced some difficulty with people more powerful than they were and, as a result, they got hurt. Quite often, group members attributed the mistreatment or abuse they received to misunderstanding on the part of the person hurting them.

Interestingly, no one ever interpreted the question "who has not seen the real me?" in a positive or neutral fashion, as "someone didn't realize I worked at that store, so they were surprised." Instead, they always said things like "someone underestimated me" or "someone hurt me" or "someone made my life more difficult because they couldn't accept me for who I am."

Mark: Bruce, when has someone not seen the real you?

Bruce: My dad hurt me when a small boy.

Mark: He hurt you when you were a small boy?

Bruce: Yeah. To the stove, me stayed home, (not) go out.

Mark: What did he do? He tied you to the stove?

Bruce: Yeah. Ah be, me stayed home a lot. Ah be, no friends.

Mark: M hm.

Bruce: Ah be, no boy scout,

Mark: Mm

Bruce: and tell me be in group home. No listen.

Mark: He sent you to a group home?

Bruce: I might. . . .

Bruce's language is difficult to understand, but based on his accounts at other times as well, his story is one in which his father tied him to the stove, refused to let him go to boy scouts, and even threatened to send him to a group home. This represents one kind of story group members told in which family members rejected, mistreated and hurt them. Others reported similar events: one was frequently denied dinner, one was regularly whipped with a belt, one was burned once with a hot iron when his father was "under the weather" (presumably drunk). One reported that his mother did not tell him when his two brothers passed away. Another group member's mother failed to tell him when his father passed away; he found out when someone told him on the street a year later! One group member spent her childhood in foster care where every Sunday her foster parents would tell her and her siblings to go up the hill and have peanut butter sandwiches while the parents had guests over for Sunday dinner, after which the children could return. One group member was taken aback by these stories, saying "Ooh, God, we wouldn't do that to our kids, would we Mark?" Yet he was the exception; of the eight group members, two did not have such stories.

Another type of story was one in which group members had been mistreated because the people mistreating them, usually family members, "didn't know what else to do," but nonetheless caused a great deal of pain for the group member. Charles' story is an example.

> I always liked stayin' at home and helpin' around the house there. I always went out and feed the chickens, and I can remember when I was a little kid, when I used to go down and count the trains, as the trains go by. And I used to take a stick and use it as a baseball bat. I used to throw a stone up in the air and hit it with a stick (chuckles). So I had some good times there, but (my mother) just didn't see the real me there. She shouldn't put me in Glenview, I think I was doing ok. I wanted to stay there longer. She could have done something else. But she couldn't know what else to do there, so she ended up puttin' me at Glenview.

Still another type of story concerned mistreatment by institutional staff. Paul, who lives in a group home, recounts how one of his house staff refused to help him.

> I asked for a favor one day. I asked if I could have my suspenders done. Barry Hack said, "No. It's against my religion to help you out." I says, "Too bad you can't help me out." I says, "You get paid to help me out." He says, "No I don't get paid for that." He says, "I get paid just to work here." And I was getting dressed up for my mother's memorial . . . I mean for a tribute to my mother. . . . I says, "Well,"

> I says, "man, you are a jerk, aren't you?" I says, "All's you care about is your God, your darn religion." He said, "That's right Paul. He says uh, "My religion stops me from doing things for you." And so right away I got into a yelling match with him, I got, I got mad.

Charles' life in Glenview made Paul's group home story look mild:

> When people take showers, when you come out of the shower the staff people would be out there waiting for you and you would get a strap across the back for no reason there. I think it was because you took too long in the shower, or taking a bath there, so they strapped you. And whenever they punished people, they put you in a dog house, which is called seclusion. And you only get bread and water. . . . We had to put our hands on the table, and they used to take a label spoons and whack us on the hand for no reason. None of us didn't know how to fight back, or, we couldn't do anything about it. . . . Also, they wouldn't let us stay up late. They would make us go to bed by ten o'clock. People want to stay up, watch movie or just talk with a friend, they wouldn't let you do it. They'd say, "Ten o'clock! Time to go to bed!" And then everybody had to get up in the morning by six o'clock. If you're not up, you got water dumped on you, or they pulled the covers off if you tried to cover your head up and go back to sleep, they yank your covers right off. Then

> they'd take a pitcher of water and dump it right on you. "Time to get up!" That's how mean they were, I mean. At the cafeterias, they wouldn't let us take seconds on helpings there. One slice of toast, one glass of juice, and one cereal. But they didn't listen. People took two toasts, two glasses of juice and two cereals. They didn't listen to staff people like that.

In all these cases, the line between misunderstanding, mistreatment and abuse is unclear. All of them were arguably cases of abuse, defined by The American Heritage Dictionary (1982) as "to use wrongly or improperly; misuse" and "to hurt or injure by maltreatment." To be sure, all group members maintained that "not seeing the real me" constituted a type of misunderstanding that usually led to their getting "hurt or injured by maltreatment." Whether they would call this abuse is uncertain; what is important here, however, is the causal connection they saw between being misunderstood and being mistreated and hurt.

The bus incident. The following case provides an example of being misunderstood and, as a result, being hurt. Kim is telling audience members after one of our performances about the origin of the bus idea in the play. Kim:

> As you already know, the way we came out about doing this (play) is that this friend of ours, Bill Keown,

> said that people who take the . . . bus that says Special Transportation[1] on it who are disabled and are under the classify of D.M.H. or D.M.R. that would take that bus would stigmatize them and I tried to bring out a point to say that this is a good way to get transportation. If you don't have any other way to do it and the bus is actually for anybody, I mean, . . . people who are elderly can take this bus, too. And I asked him whether or not the elderly people who take this bus, does it stigmatize them too? And he said yes.

In this case, Kim, a group member, maintains that her friend doesn't "understand" her position. Considering the fact that Bill never offered Kim any alternatives, she has a point. But at issue here is not whether Bill understood or not, but what their disagreement meant to Kim.

When a disabled person has a relationship with a "normal," it usually goes beyond friendship to include moral, financial and/or professional support as well. Kim spent holidays at Bill's house, he visited her in the hospital. She baby sat his children, he provided her with employment, leads for job training, rides, advice on how to get services, even moral support whenever she (not

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[1] The Special Transportation Bus is a public bus that provides free transportation for people who are mobility impaired, including the elderly. Because Kim wears a leg brace, she qualifies to ride on the bus.

infrequently) had to appear in court. He had even been instrumental in getting her released from a group home.

Because of Kim's reliance on Bill for so many things in her life, both emotional and material, his position that she should stay off the bus in fact put her in a bind. If she rode the bus, she risked losing Bill's friendship and support; if she didn't ride the bus, she would have to pay for a taxi whenever she wanted to go somewhere, which she couldn't afford to do. If this had been a "normal" friendship, she might have felt free to simply disagree. As it turned out, she chose to forego the bus, which clearly made her life more difficult, and those of others around her. For a period of time, she was calling me for rides to the store, to the hospital, to appointments. Because I always felt like saying no was adding yet another layer of oppression from a "normal," I too was in a bind.

So what this misunderstanding meant to Kim was losing access to free transportation rather than losing Bill's friendship. But it went further. By insisting that riding the bus would stigmatize her, Bill had in effect taken away Kim's ability to define her world for herself. In the final analysis, she was the one with a handicap and must decide what constituted mistreatment for her, but because of the status differential, she feared doing this. Admittedly, one of Kim's big problems in life was her fear of what others think of her, a subject often taken up by the group. Of concern here, however, is Kim's perception of the problem, however justifiable. Whether Bill would in fact withdraw his friendship and support if she rode the bus is beside the point, for Kim believed that he might, and because of this belief, she chose not to ride it. Thus for Kim, the causal link between misunderstanding and mistreatment was very real. For me as an observer and a "normal," this case illustrates another point: that if justice for the group means that people should be treated with the respect and care they deserve, then disagreements between "unequals" must be worked out in such a way that the person in a "one down" position feels free to do whatever he/she believes is right, without fear of loss or punishment. Otherwise, misunderstanding might constitute mistreatment and, consequently, result in injustice being done.

<u>Labels</u>

Group members' sense of justice was evident in their struggle over the use of labels.

<u>Labels defined</u>. One of group members' greatest sources of pain was the way people labeled them. Group members defined labels as: (1) words that are hurtful and that are attached to people (e.g., "retarded," at times "handicapped," at times "disabled," sometimes client); and (2) situations that put people in degrading positions, as Sam describes:

> Like (in) sheltered workshops that put people in training . . . labels were still at hand. Sometimes people would be in the same thing, day in and day out, day in and day out, day in and day out. And I think that's a label itself, when people just treat people like, you know, they gotta go in and just sit in one area . . . . You know really people don't have to label with words. People can label in other ways, too. You don't have to come out and say, "Wow, you're sick," or uh, uh, you know, "you can't do anything." People can show it with an action.

Labels objectify people. Kim often said, "A sign on our office door (for a self-advocacy group) reads 'Label Jars, Not People.'" According to Sam, labels do not reflect reality; they reflect people's prejudices about reality. Sam also believes that labels are dangerous because they freeze a person's image, rather than acknowledging that "most things that happen to people can be overcome."

Unanimous rejection of "retarded." The only point of unanimity I found on any subject in this entire project was group members' universal condemnation of the word retarded. In the only potentially disconfirming case I could find, Sam argued for its conditional use, then reversed his position.

> They don't have lead paint any more, but when they used to have lead paint, uh, my mother was the one that told me that if a real small child ever got ahold of a lead

> paint and ate a very very small dose of it, it can make him or her become retarded which means very slow learning. . . . A small dose of it. So that's only (time) you ever use a label, is stuff like that . . . sparingly only, you know, . . . to prevent it. Otherwise it should never be used.

But, he continues, the meaning of the word has changed.

> People have labeled these words so that it becomes a nasty word, and the nasty word now I think is uh, retarded, which I'm sure you've heard some people say retard, which is a very very awful insult, you know, retarded, sick, mental . . . .

In this case, then, retarded does not mean "very slow learning" but subhuman - "sick, mental" - a notion so demeaning that in spite of Sam's prior acceptance of the "clinical" definition, he changed his position, and in fact never used the word again during the course of this project other than to denounce it. At one time or another, all group members verbally rejected retarded as necessarily degrading.

Kim: I'm mad when anyone calls me retarded!

Paul: There was a guy named Glen that used to work on Center Street. And uh, I couldn't exactly cook, cause I never did it, and so I refused to cook. And uh, Glen says alright, if you don't do your house jobs, you can't go outside. And I says, "Why not?" He says, "Because," he says "you are

. . . acting like a retard." So I got so mad, I took his hair and I pulled it.

Charles: Another thing I don't like is using the word retarded. We're not retarded. I think we're all really normal people like everybody else.

This sentiment that "we're not retarded" was echoed by several group members - that everyone is the same, that no one is retarded. It is difficult to know what this means. Are group members denying that they have a mental impairment? Or are they accepting that they have a mental impairment, but rejecting the word retarded because it means subhuman? Several times, Charles said he had done this play to show that "we can do plays as well as anyone else." Again, did this mean that like other members of the community, developmentally disabled people can create and perform a respectable theater production, which *Special* proved, or that disabled people could create theater as well as any group of normals, including professionals? This, of course, is a claim that only other professionals could make. What he means here is unclear, though I believe he meant the former, referring to Sam's observation that retarded has come to mean sick, and that "we're not retarded" (i.e., sick). This comment also illustrates two important issue raised by this project: the issue of passing and denial, discussed in greater length throughout Chapters 7 and 8; and the question of standards for theater, discussed in A question of standards, Chapter 8.

Other labels. Whereas group members were unanimous in their rejection of the word "retarded," they differed on the use of other words. Some maintained that handicapped was acceptable, others did not. More accepted the word client. Disabled received the least resistance. Charles accepted the word client, but refused to say he was disabled or handicapped, opting for "we have a disability or handicap (emphasis mine)." What also appeared to be important was not just which word was used, but how it was used, as George explained:

> You can say words so long as you don't hurt the feelings for other people are around you. You make 'em feel more comfortable. . . . I take an example (to Fred, a group member). If I'm introducing you to, um, "This is my friend, disabled Fred," I don't think you would like that, you know? So I would put him as just my friend Fred. See it's hard to describe people to other people if they're not there. This is what I was trying to get (across) to Dean. . . .

I call myself handicapped! In the following passage, George "tries to get across to Dean" what many members were trying to get across to the audience as the main point of *Special*: to give them credit for being able to think, which includes being able to decide what is right for them, what words are appropriate for them. George is interviewing Dean, a friend and associate who had had a son in Glenview

State School and had since formed an organization which successfully advocated for the school's closure. George, who self-identified as handicapped, stated that he enjoyed working with handicapped people because it made them happy.

Dean: You used the word handicapped.

George: What?

Dean: You used that word. Stop! Stop! Stop!

George: But if you describe something to somebody, you have to have things straight so people understand them, Dean. What would you say if you're gonna describe a person to somebody if that person wasn't here?

Dean: I'd say I was going to go with Mary somewhere, or Phil, or Paul, to get services.

George: My brother Joe, right, is handicapped, right? More than me, right?

Dean: Maybe he is.

George: Dean, be sensible, will you please?

Dean: I am. But he's your brother first.

George: Yeah, but I explain that he's that way 'cause people will know. That's why I say handicapped people. Like you say like mental health, things like that, that explains what office it is, right?

Dean: I can't change your mind. I'm just saying that you don't need to say it as often as you probably do . . .

George: The reason I said handicapped, it's better than saying retarded.

Dean: I agree with that. But I'm saying think about it, not even using the term. Try, try it. . . . It's gonna take a little while, because you're so used to putting labels on people. . . .

George: I'm not labelling people. You think I am, but I'm not.

Dean: I think you are.

George: I'm not. I'm not going to change my mind about this.

Dean: I know people like that, George. You know what they say? My mind is made up. Don't confuse me with the facts. You're gonna change your mind.

George: No I'm not.

Dean: You are. You're too nice a guy.

George: Would you change your mind back again?

Dean: To what?

George: To handicapped people? No you wouldn't.

Dean: I try to use it as little as possible.

George: Well, I do too, Dean!

Dean's comments illustrate yet again the tendency for some advocates to define disabled people's words and situations for them, even to the point of arrogance. Dean is assuming that George uses the word handicapped frequently ("as often as you probably do") and that George is not sensible enough to determine whether to introduce someone by name or by handicap. Ironically, even though he has called George's sensibility into question, he appeals to his sensibility as proof that he will change his mind and see things "correctly" ("you're too nice a guy"). He reinforced this position at other points in the interview: "I think he should have been a lawyer! He's good, he's good, this guy."

Nevertheless, George's comments reveal a nuanced understanding of labels - that some words (e.g., retarded) are taboo, whereas others (e.g., handicapped) are not necessarily. For him, the use of the word handicapped is appropriate in some contexts and not in others, and he specifies the conditions under which he would choose not to say it - a distinction Dean did not make in the interview, even though at one point Dean had used the word "retardation" and then enjoined against the use of the word retarded.

In another case, an "advocate" tried to convince Sam of one of Wolf Wolfensberger's tenets - that "you can't be friends with somebody if you're getting a salary for it, that's another lie" to which Sam responded "Gee! That's interesting because up at Maple Street it happens now with Alex . . . ." As in the case of Kim and Bill above, these cases provide examples of how friends and advocates are often the biggest offenders when it came to using labels - in this case, by attempting to define disabled people's world for them, often over their protestations. These examples also illustrate the tendency for "normals" to define disabled people based on normals' beliefs about disabled people at that time. Over time, of course, these words change. The word for the disabled persons living in institutions, for example, has changed from patients to clients to consumers to residents, the current official designation.

Don't call me client! Sometimes group members ended up agreeing with normals. In one case, Kim appeared to be disagreeing with Dean about the use of the word client.

Dean: Never use the word client.

Kim: Well, D.M.R.'s person . . .

Dean: Well no no no you're not. You're a person. Stop the D.M.R. stuff.

Kim: Well I've been saying it because I'm not . . .

Dean: No you're not. You're a person.

Kim: I'm a D.M.H. client. I mean . . .

Dean: No you're not. You're not anything of that type. You're a person. . . . See, that's the great putdown. Don't call me client.

Kim: But how do you, how do you tell this, how do you tell this to people, because you turn, you say it and then you turn in . . .

Dean: Sometimes you have to embarrass people and I do and I tell them Don't use the word client. You insult me.

Kim: Well.

Dean: You hurt me. Don't hurt me. Just, if you just say please don't hurt me, please don't insult me, I'll bet they'd stop immediately. I'll bet they would.

Kim: Well I asked one place where I went today and the other day, they say well you're client's here, I'm like don't say that, and, but the thing is, they said, they said, "We have to, it's our policy."

Dean: Oh, that's a bunch of nonsense. What policy? Ask them to show you the policy in writing. There's no such thing as a policy. That's a joke. That's from uncaring and unthinking people. We're gonna win that fight entirely. You're gonna help us win it.

Kim: Ok. Whatever.

In this interview, Kim's struggle with Dean was like George's: Dean was trying to convince her how she should self-identify as a disabled person. Dean says Kim is not a D.M.R. client, but in common parlance, she is. Even if the word is objectionable and should be changed, it was in current usage at the time of the interview, it was Kim's understanding of her relationship with D.M.R., and therefore it had meaning for her.

But unlike George, she considered Dean's position and, in time, changed hers. Since performing the play, she had informed the staff at her agency to call her by name when she came in. They said if she reminded them each time, they would. She did. Of course, this change is not as surprising as choosing to ride the Special Bus might have been since in this case she is agreeing with the normal and therefore need not fear losing his friendship or support.

Responses to difficulty

In the next section, I will present examples of group members' responses to the kinds of difficulties described above: showing respect and care for others; and additional recommendations about how people should be treated.

Treating others with respect and care

Group members' sense of justice was reflected in the way they respected and cared for others. Throughout this project, when group members recounted experiences of being mistreated, they usually accompanied these stories with statements about how people should treat one another - with respect and care. This position appeared to go beyond any individual's concern about living free of mistreatment. Rather, it suggested a vision about how the world should be, a distinction which leads me to believe that their concern about being treated with respect and care was also a concern about justice.

He saw the real me

I have argued that group members equated "not seeing the real me" with being abused - i.e., being misunderstood and as a result, getting hurt. Conversely, when group members spoke of someone "seeing the real me," it meant being understood, accepted, and treated with respect and care.

Charles: My father sees the real me.

Mark: Your father sees the real you?

Charles: He's not livin' now. He passed away, so but when he was livin' he saw the real me.

Mark: What did he do that showed that he saw the real you?

Charles: Well he let me go down there, fly down to Texas to see 'im (sniffs) and spend some time with 'im.

Mark: Huh.

Charles: That shows that he saw the real me. Way down there.

This account reflects group members' personal experiences of being understood, accepted, and treated with respect and care. Yet one of the major themes of this project was the urgency with which group members felt this kind of treatment should be extended to all people.

Sam's 6 tenets of respect and care

In the following passage, Sam gives Kim advice about how to respond to a difficult situation - advice that group members enacted in various ways throughout the project. Because I will use Sam's advice as a heuristic for examining other examples of respect and care in the group, I will quote him at length. He is responding to Kim, who shared how she "felt like crap" when a friend had told her

> "We don't think this (job) is good for you, we don't think you can do it," but that really bugs me, particularly when you're close friends to this one person, and you just wanna go up and say "Come on, give me the benefit of the doubt, that I can do what I wanna do" . . . .

Sam's response:

> I'm a veteran of that same thing over at H.E.A.[2] And from what I see from what you're tellin' us in the group, I think you're trying to do your best speaking up, I think that all the things that everybody has in this group are legitimate, you know which is the reason why we have this thing, which is the reason why we do the play. But from what I see, and I'm just tellin you as a friend, I think you tend to worry a bit too much of what other people think. I mean I know that we live in a world that you know we have to do it but I think that you kinda have to kind of overcome it. You can't always worry about losing friends, whatever it is about the Special Bus, you know, unless you feel that you don't really don't wanna do it. . . . Meg Smith told me something one time - that people will respect you for being your own person, other than to just not speak up,

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[2] Hampshire Employment Associates is a pseudonym for a "sheltered workshop" for people with disabilities where Sam worked.

> to like go along. I mean, you know we live in a world where people are different, and even people that are best friends disagree. . . . I mean so many times people worry about what other are going to think and they don't look into what they can really do, I mean you know, you don't have that person's body, you know I mean, not everybody's the same, you know, people are good with different things.

In this passage, Sam lays out six elements of respect and care:

a) empathy ("I'm a veteran of the same thing over at ICE");

b) appreciating others ("I think you're trying to do your best speaking up, I think that all the things that everybody has in this group are legitimate");

c) helpfulness, in this case, with supportive advice ("I think you tend to worry a bit too much of what other people think . . . I think that you kinda have to kind of overcome it");

d) tolerance ("I mean I know that we live in a world that you know we have to do it");

e) affirmation of people's dignity ("Meg Smith told me something one time - that people will respect you for being your own person, other than to just not speak up, to like go along"); and

f) appreciation of diversity ("even people that are best friends disagree," "not everybody's the same, people are good at different things").

Throughout this project, group members exemplified, to varying degrees and in different ways, their belief in the importance of respect and care as identified in these six tenets, illustrations of which follow.

Empathy. A dominant theme in this study was empathy, characterized by group members' propensity, and arguably their skill, for feeling with others. Empathy was usually manifested in the form of care and consideration for friends and acquaintances:

Sam: I just wanna make sure Janet's comfortable (during a rehearsal). Are you ok, Janet?

Marcia: I saw Randy today. He is doing so well!

Sometimes group members were concerned about the pain of others, even to the point of despair:

Fred: My mother was paralyzed both legs.

Marcia: And she's been married 13 years.

Fred: 13 years.

Marcia: It was better that she went 'cause she was paralyzed both hands . . . .

Fred: Both legs.

Marcia: She was suffering. And she couldn't suffer any more.

Fred: And I said, I told my brother, I said, "I wanna go down in a hole with my mother."

This passage reflects not only Fred's extraordinary attachment to his mother, but his empathic ability as well - so much so that he was ready to share even her experience of being buried. On other occasions in the group, I observed Fred comforting Marcia, his wife, in truly empathic ways as well. At times, she would start crying, and almost instantaneously, he was crying too (though I'm not sure he always knew why).

Group members often showed their concern about the feelings of other people by consoling them when they felt bad, or by helping them out with advice and support (see Helpfulness below). When conducting interviews, group members frequently strayed from our preset questions, showing their concern about the feelings of interviewees:

Charles: (When I was living in the group home, they were) pokin' through my things there . . . . I didn't like it either. So I couldn't move out on my own, I had to stay there. Though the staff called Glenview, says they didn't want me living there any more so they sent me back to Glenview. Then I got out again July 7.

Kim: How'd that make you feel? When they called Glenview back up and asked, you don't want you to live there at the group home any more. How'd that make you feel?

Charles: Well I know that the place where I was working, I was working in a factory. People at the factory missed me. They were, they were very sad, sad when they found out I had to go back to Glenview. That was in like December, I went back, of that year. So I got out earlier in that year, and December came and I went back to the state school there.

George: But it makes you feel good when you're um, lookin' for company or something, you go in somewhere and your workers feel sad about it. It makes you feel good, doesn't it?

Charles: Yeah, I mean they said I did a nice job at, in the factory there . . . .

Sometimes group members exhibited their empathy for people they had never met.

Dennis: If you go back before let's say 1970, many times residents who worked on campus (at Glenview) weren't paid at all.

Marcia: Well I did!

Sam: Oh it was terrible, the way they treat, even even if they did get paid, it was just something the way they treated (them) back then . . . .

At times group members even strove to make others more empathetic.

Bob: Think, think if it, what it would be like if you were in an institution and you haven't had the freedom to make your own choices. And this is another point I wanna bring up: people that are wards of the state in institutions don't have choices on who they wanna have relationships with. People on the outside have that choice.

Sam: I think that there should be an end to the prejudice once and for all. We have a long ways to go, and I think it could move a lot quicker than it has been . . . . I think (the purpose of the play is) to get a message across to people that they could be perfectly fine one day, and disabled the next, and that they really should start thinking.

Appreciating others. Group members regularly showed unsolicited appreciation of me, each other, interviewees, and people who had helped them. Their appreciation came in the form of phone calls, cards and gifts to me (though I must confess I've only had the nerve to wear my Elvis T-shirt once), and unsolicited statements to me and others about their ability, efforts, attitudes, and knowledge.

More than appreciating people's ability and attitudes, however, group members regularly paid homage to those who had understood them, taken their side, helped them get work, and enabled them to live more rewarding lives.

Bob: Now I live in my own apartment. I work at Hampshire Employment, I have a good job thanks to

Mitch Albert, is a receptionist, it was him and Tom Osborne that came and asked me if I wanted the job. If it hadn't a been for them I wouldn't of taken it because I used to work at one of their sheltered segregated sites where I used to get a check for like 60 cents or two pennies . . . .

Susan: I appreciate all the things that Mark and Marcia and Fred does for me, but I don't need it sometimes, but I think Marcia, Marcia is a good friend of mine, so is Mark. And, the day my husband died, that we had that funeral, and I was glad to see Mark and Kim and Fred there.

Helpfulness. Group members constantly gave each other advice and support, as in the case with Sam talking to Kim above. Sometimes they helped each other physically, like helping Sam find a chair, or helping him find a green shirt in his house for a performance. At times Susan would make sure that if we were bringing food to a rehearsal, or someone would bring lemonade for Charles, who was on a restricted diet because of dialysis. Sometimes their willingness to help others took the form of prayer (though not always to God):

Susan (in a role play with Sam): Santa, would you like to send some presents to the little ones, to the homeless, Santa Clause? Oh Santa, would you like to send some to the handicaps, to some people in the nursing home, too, and to some people in the men's home?

Fred: I look up to heaven, I take care of him, my father, my grandfather, my sister. . . . I hope you take care of them, Amen.

For half the group, the main motivation for doing the play was to help people. Bruce said he wanted "to help the community out." Marcia and Susan wanted a chance to make people happy, especially the disadvantaged.

Susan: That we gonna put it on for some other places too, like the Soldiers' Home . . . and the state hospital. And Glenview.

Marcia: What's that other place, where people can't. . . ?

Susan: Jones School. For the deaf.

Marcia: Jones school don't get nothin'.

For Fred, the play was an example of how he helped people out in daily life:

Mark: Hm, yeah. Fred, how about you? Why are you doing this play?

Fred: Well, to help people having seizures and stuff like that.

Mark: Hm.

Fred: And everybody (will) be right there. And so this our boss where I work, he had this seizure and I just called the ambulance, helped him out . . . . And Russ says "thank you very much."

Mark: M hm.

Fred: So I like to help every people all like that.

Perhaps the most prevalent form of assistance group members gave was moral support in the form of comforting and advice like: "Don't worry about it. Next time he touches you, he goes to jail. He can't hit anyone."

Susan: The other day I was walking around the corner waiting for my friend Marcia. And then Robbie says, "Oh you're crazy." I says, "Well you should talk, Robbie." I says, "I'm not bothering you so just leave me alone, I'm not bothering you." I says, "I'm just minding my own p's and q's so just go on a way home." I said, "You didn't have to call me crazy," and I shut up and I walked away.

Marcia: He said handicapped!

Susan: He didn't call me a handicap . . .

Marcia: And that wasn't right, to her . . .

Mark: Why do you think he did that?

Susan: Just to be, just to be a rat about it.

Marcia: Walk on the other side of the street Susan.

George: No, no, you don't. You don't owe respect for anybody. I mean if the guy's gonna clair (?) something you don't like, you've got a right to respond to it.

Marcia: You can't, you can't go around calling her like a handicapped people, thing. 'N he said, "Oh you belong in Glenview with the handicapped people." No she does not. She's not doing anything to him, and he can't go around calling her names like that.

George: Well, respond to it, just don't say nothing to him.

Marcia: She tried it. It's hard, George, right now. Just ignore that guy.

Tolerance. Perhaps Marcia's advice to "just ignore that guy" is acceptance of the fact that people are prejudiced and, to some extent, we all must learn to live with it. Nevertheless, group members did exhibit an understanding of the importance of tolerance when it comes to dealing with people's prejudices against disabled people. Sometimes tolerance bordered on forgiveness. Bob:

> My mother hurt her back, and I was diagnosed with cerebral palsy at the age of nine months old and she couldn't get any help out in the community at the time so she told me she had to put me there for a little while so she could have me back home to take care of me. Back in those days, if a parent had a child with a disability, they were told by doctors if you want any relief from your son or daughter, to put them in an institution. But that wasn't the case in my parents' case; my mother did what she had to do because my father was workin' at the time and she was laid up with her back bothering her and she couldn't give me the

> care at home I needed. So she had to put me in Glenview.

Charles also forgave his mother for putting him in Glenview. In spite of his concession that "(My mother) shouldn't put me in Glenview, I think I was doing ok," he goes on to acknowledge her reasoning:

> But she couldn't know what, what else to do there, so she ended up puttin' me at Glenview. . . . she couldn't take care of me any more. . . . Cause she had too many other kids to take care of and she had to let somebody go.

This is not to say that all group members advocated tolerance of abuse and labelling, or that they were able to tolerate it themselves, only that a prevalent theme in this project was the desire, voiced by most, to try to accept this behavior, "not worry about it, it's not his fault" as Marcia would frequently say, and in certain cases, acknowledge why it was happening.

Affirmation of people's dignity. Throughout the project, group members signalled their belief in people's dignity and respect in a variety of ways. One prominent behavior was "floor giving," in which all group members frequently showed concern about letting others speak. Another was the kind of caretaking and support described in Helpfulness above. However, group members' appreciation for people's dignity and respect was perhaps most conspicuous in the recommendations they made about how people should be treated, and allowed to live.

Appreciation of diversity. This point was the most problematic of the six for group members. They did at times indicate an interest in exploring the issue of diversity, particularly in terms of "how different people are treated in the world" as the subject of their research project. But their interest rarely went beyond investigating the fate of people leaving Glenview, or living in group homes. In fact, on two occasions, Janet heard Fred and Marcia use the word nigger. Marcia also used the word Pollacks on several occasions.

Their limited interest in diversity might be attributable to two other facts. One is the fact that, for anyone, appreciation of diversity is a function of one's understanding of the existence of diversity. However, people with developmental disabilities tend to live impoverished lives, deprived of the kinds of experiences that might introduce them to diversity, and this group is no exception. Until we took a field trip to Toronto some years ago, no group members had ever been outside the US. Few can distinguish between French, Spanish and Polish (though they love learning songs in any language). They rarely go to movies, plays, or concerts, most have had limited school experience, and few have been exposed to work situations beyond a restaurant kitchens, nursing home laundry rooms, or sheltered workshops. Worse, half of the group spent many years - up to 17 in at least two cases - sequestered in Glenview State School.

The other impediment to their appreciation of diversity, it seems, is the problematic nature of difference. One of the dominant themes in this project was disagreement around the meaning of "different." To be sure, it was most often used in its conventional sense, signifying the idea that identities of things or ideas varied, as in "I have a lot of different tapes" or "I'm making a different point." But while writing the Special Bus scene, George came out as SuperGeorge and proclaimed, "We're all the same. No one is different." A lively discussion ensued in which it became obvious that for some group members, different often meant inferior, as in "the way people see it when people are disabled makes other people think (we) are different." In our discussion, the "normals," including myself, tried to convince the group members that different did not have to mean inferior, and that in fact claiming that everyone was the same obscured one very important message of the play - that we need to appreciate all people for who they are, which means appreciating their uniqueness, their difference.

In reviewing the data I now realize that our point overlooks two important realities of disabled people. The first is that their experience of being different is not the same as mine because in our society, the kind of difference they exhibit is one of being mentally deficient, and therefore personally defective. George:

> What bothers me that is that I'm in society what you call a disabled person. It's like I can't read very good, I can't spell very good, and I can't do rithmetic very good. It's like on the outside I'm a normal, happy-go-lucky, but inside of me, it just is different. It's like you know, you can't read and write very good, it makes me feel uncomfortable that way, you know what I mean?

The other reality that our point overlooked is the fact that because of the status differential between normals and disabled people as discussed above, any discussion of difference is inherently problematic. That is, when normals see something as different, they (we) do not necessarily mean inferior, yet whatever we mean, some disabled people will undoubtedly fear that different does mean inferior, and that because we are "normal," our meaning will prevail. The disabled person will therefore lose, as in the bus case cited above. Thus, because some disabled people do not feel able to define the world before normals, the notion of difference becomes doubly problematic. For these reasons, group members' understanding of this word is (if I may use the word) different from mine, and because of our life situations probably always will be. In writing this section I realize that in some ways, I too have fallen into the trap of trying to define their world for them, that I do have a certain understanding of the word different, but that theirs arises out of their experience, and that for them, like retarded, the word different has taken on a meaning which diverges from its ordinary use - a fact that I must understand and accept.

Other recommendations

Besides treating others with care and respect, group members' sense of justice included other recommendations about how people should be treated. Each recommendation always came with numerous stories from personal experience and the experiences of those close to them. And when group members told stories of mistreatment or abuse, they were almost always followed by some sort of rule or recommendation. Broadly speaking, group members made two recommendations:

No more abuse. All people have the right to live free of abuse. Group members' stories of abuse included everything from "not being given credit where it's due" to assault, ridicule, and physical abuse. Based on these experiences, group members claimed that:

- People should be able to live peacefully, without fear of harassment.
- People should be able to live without fear of being labelled, or compared to other people.

- Group home staff should respect residents. In particular, they should tell residents who is being hired or fired and when, what staff schedules are, and what changes are upcoming (e.g., if the house is to be worked on or sold, etc.).
- Community members should befriend people leaving institutions, invite them into their homes, and introduce them to the community. (One group member does this as a part-time consultant.)
- Disabled people should be integrated into community life as much as possible, and should not be segregated into institutions such as state schools or sheltered workshops.
- Deinstitutionalization and independent living should be supported, and disabled people should receive support in order to get access to basic life opportunities such as employment and education.

Give people choices. People should have the right to choose how they want to live. Group members' stories highlighted their beliefs that:

- People leaving state institutions should be able to decide where to live, and who they wanted to live with. If feasible, they should be able to choose to live on their own.
- People should be able to be with and marry whomever they choose.

- Group home residents should be able to choose their staff workers.
- Institutional workers need not be stripped of their power; rights and responsibilities should be shared reasonably between institutional workers and residents.

Discussion

Several issues raised in this chapter have been touched on in the literature on PLMRs as well. I will discuss two here. The first is the issue of labels. In general, the literature on this subject (Mercer, 1973; Bogdan and Taylor, 1983, 1990) points out the arbitrariness with which labels are assigned, the fact that they serve the labelers for the purposes of control more than people being labeled, and the question as to what mental retardation actually is, arguing that at the very least, a different, nondegrading name needs to be found (e.g., Edgerton, 1967). One point on which most people agree is that the word "retarded" is unacceptable. Numerous studies (e.g., Edgerton, 1967; Szivos and Griffiths, 1990) report that their subjects rejected the word completely. Edgerton’s subjects employed "almost any other excuse, from epilepsy to "craziness" - excuses that are themselves highly stigmatizing. Never is mental retardation admitted" (p. 207). This study is consistent with those findings.

It seems that there are two main points of contention on the subject of labeling PLMRs. The first, discussed in

Chapter 4, centers on the debate between whether mental retardation is an objective fact or a misunderstanding of reality, a myth. This debate is irrelevant to this study insofar as group members did not contest the meaning of the word retarded, they simply rejected it. The second main point of contention, however, is relevant - whether rejecting the word retarded implies a rejection of one's condition as mentally impaired. Bogdan and Taylor considered this issue with two subjects in one of their studies, Ed and Pat. They are responding to the argument that:

> . . . when people who are labeled retarded do not agree with their designation, they are denying the reality of their being - that they can't face the truth of their condition. This view is based on the premise - the official view - that everyone in an institution or anyone below a certain test score is objectively retarded - that retardation itself is a fact. Ed and Pat are saying something more profound - at least, to those who can regard their denial that they are "retarded" as more than just a defense mechanism. Essentially, their claim is not that they personally have been misdiagnosed "retarded" but that the system that is used to classify people as either "retarded" or "normal" is wrong and misleading. It is erroneous to classify people as retarded" because it doe not produce the kinds of services that it is in their best interests to receive. Moreover, having lived among the "retarded" and been so labeled themselves, they have come to look for and see the intelligence in themselves and in their friends, not the "retardation" (Bogdan & Taylor, 1982:216-217).

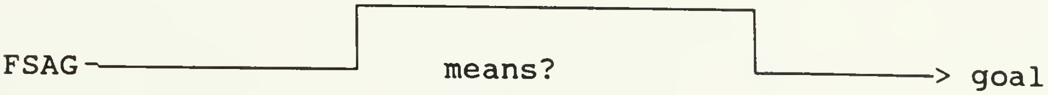
Ed and Pat's efforts to "see the intelligence in themselves and their friends" is consistent with Sam's suggestions to appreciate others, to be tolerant, and to treat others with dignity. The spirit of Ed and Pat's claim is also consistent with Charles' claim that "we (PLMRs) can do plays like anyone else." That is, the system used to classify PLMRs - in this case, people's faulty perceptions about PLMRs' inability to do things that normals do - is wrong and needs to be corrected. For Charles, doing the play is one way to do this. Of course, this does not settle the issue of passing: could it be that by rejecting the word retarded, Charles is simultaneously critiquing the system and denying his own condition? To some extent, I believe that this is what is happening, a subject which I will continue to discuss as an issue of pride and identity in Chapter 7.

The second issue raised in this chapter is the issue of PLMRs discussing justice at all. Because of the gross absence of literature which includes the voices and perspectives of PLMRs, perhaps it should come as no surprise that while references are made to justice statements in various parts of the literature, no books, articles or studies discuss PLMRs' perspectives on justice as a central theme, much less their orientation toward justice in their behavior or in their lives. This study, then, points to a much-needed area for further research.

Third, the bus incident illustrated the problem of the interpretation of events between people of different social status. Even the best intentions can result in what is perceived as control, misunderstanding, or even abuse by a person who is in a "one down" position. Accordingly, people engaged in relationships of different social status must continually be involved in dialogue in order to understand each other's position and, to the greatest extent possible, allow the other person to exercise their will even if it appears to violate a principle we hold near and dear to us (unless it is morally questionable).

Finally, without defining justice, group members intuitively and naturally subscribe to an understanding of justice that knows no distinction between public and private, personal and political. To them, they are all the same. Justice is not an abstract "principle of moral rightness," or "fair treatment and due reward in accordance to honor, standards, or law." Rather, it consists of continual acts of respect and caring that start with the individual and continue beyond the group. In this way, I believe that they are radical visionaries.

However, the fact that justice is not an abstract "principle of moral rightness" for group members also has its limitations, for if they know what should be done, they are often unable to determine how. The fact that they did not exhibit and inability in this study to go beyond the immediate has implications for implementing any policy of justice that they might advocate. For it is by invoking abstract concepts that we can find areas of commonality, then work backward again to the particulars - for example, the U.N. Declaration on Human Rights. But if we cannot talk about common principles, how can we work for justice between disparate groups? If they know what should be done, they are often unable to determine how. I do not know how to answer this question, except that it might be that we can look to groups such as the Friends Support and Action Group for guidance on what the end goals of justice should be, then leave it to the administrators, policy makers, and legislators to figure out the means:



Conclusion

In this chapter I have argued that throughout this project, group members exhibited a justice orientation rooted in a belief in the inherent goodness of all people, and the necessity to of treating all people with respect and care. This understanding appears to have arisen from experiences of difficulty, mistreatment, or abuse, usually by would-be friends, including the use of labels. Experiences of abuse seem to have spurred a belief that all people should show respect and care for others as elaborated by Sam's six tenets: empathy, appreciating others' position and ability, willingness to assist others, tolerance, affirmation of people's dignity and respect, and appreciation of diversity. Group members' understanding of respect and care also led to recommendations about how people should be treated.

The first two major findings, group members' chronic problem orientation and justice orientation, provide a base from which to critically examine reasons for group members' behavior. As I argued in Chapter 3, the design of this research is to first attempt to understand group members' experiences as much as possible from their perspective, then to invoke a critical framework based on that understanding which can illuminate reasons for the kinds of problems group members face. This is the subject of the next chapter, in which I invoke the framework of internalized oppression in order to better understand why group members' chronic problems persist, as well as to "unpack" the volatility of the group and what this means in the larger context of people struggling with the kind of oppression they face as PLMRs.

CHAPTER 7

THE DRIVE TO VISIBILITY: IMPLICATIONS FOR PRIDE AND INTERNALIZED OPPRESSION

Introduction

Can you see the real me, can you? Can you?
Roger Daltry, The Who (British rock'n'roll music group)

Can you see the real me, normals? Normals?
Sam Moore, group member

In Scene 2 of *Special*, a "normal" interviews Sam, a blind person, for a job as a telephone receptionist. The prospective employer asks Sam to indulge him in a role play to test his receptionist skills, whereupon Sam performs so poorly that the normal admonishes him, "Don't call us, we'll call you." SuperGeorge (dressed as Superman) then comes out and reverses the situation, putting Sam in charge of interviewing a musician, "Microtone Magic," for a job. When Microtone sings off key, Sam says, "I'm sorry, you normals don't have as good a hearing as us blind folks, so you don't get the job," upon which Microtone screams "Normal! I don't get a job because I'm normal! I've worked all my life not to be normal!"

While this scene usually gets a lot of laughs, there is a certain irony here. For "normals," being different means being unusual, unique, exceptional. For many PLMRs, being different has come to mean being less, incapable, unfit. And because of their perceived "difference," their daily fear, and often their daily experience, is that they will be treated as less, incapable, unfit because of their difference. Theirs is not a difference that makes them great violinists or famous inventors; theirs is a difference that makes them unable to read or remember their address or understand the 6:00 news or drive a car or hold a checking account. Theirs is a difference that makes people "size them up" and reject them, or worse, that causes people to just look the other way. In fact, for many PLMRs, the greatest scourge is not being seen as different, but not being seen at all.

Perhaps nothing counteracts the experience of invisibility more forcefully than theater. In this project, I have observed eight adults who have been labeled "retarded" repeatedly hone their experiences into dramatic statements, then stand before audiences and tell their stories in their own ways, with their own words and gestures, the spotlight on them alone, the theater silent, everyone's attention riveted, for once, on them. For these brief, precious moments, their differences were both noticeable and o.k. For a few brief moments, they were visible.

Group members' interest in visibility was evident in numerous ways throughout this project - in their incessant desire to do these plays; in their readiness to jump up, sing, dance, and act; in their constantly vying for my attention (as discussed in Chapter 5); even in their language which is studded with visual imagery, from Sam (who is blind) frequently saying "you see what I mean?" to George stating "outside I look normal, but inside I'm different" to Kim confessing that she went to bed at night singing "Can you see the real me?" to herself.

At the same time, while group members are driven to express who they are, one of the most striking phenomena I have observed has been group members' tendency to also slip into fighting, confusion, even self-destructiveness, sometimes only seconds after a joyful moment. I discussed some aspects of this phenomenon in Chapter 5 as a chronic problem orientation. Here I am referring to the group's volatility, or tension I have observed between their spontaneity and their hostility. How does one account for their tendency at one moment to be expressing themselves so jubilantly, then in the next moment to be blaming each other for what appear to be petty problems, hitting each other or stomping out of the room? What is going on here?

One possible explanation can be found in their need to be seen - what I will call their drive to visibility. As discussed in Chapter 3. identification of this drive was made possible by inductive analysis through which I derived five general categories of experience: identity issues, fear, values, problems, and norms. Chapter 5 dealt with the problems category, and Chapter 6 dealt with norms. The values category will not receive separate treatment, though I believe some of these issues are covered throughout this study.

In this chapter I will consider how group members dealt with identity issues and issues of fear by explaining what I mean by the drive to visibility. First, I will draw on group members' understanding of the idea, then I will situate it in a larger framework of internalized oppression as articulated by Gail Pheterson. After describing this framework, I will explore two related claims: 1) that group members' drive to visibility is an attempt for them to battle oppression and internalized oppression; and 2) that when group members' drive to visibility is frustrated, internalized oppression or internalized domination often results.

Six hypotheses

These claims derive from the following hypotheses:

1) The drive to visibility constitutes a major behavior pattern and concern amongst group members.
2) When group members exhibit hostile behavior, it is a result, at least in part, a function of their invisibility.
3) Visibility and pride are cogenerative.
4) When group members exhibit hostile behavior, it is also a result, at least in part, of a lack of pride on their part.
5) Lack of visibility and lack of pride in this group both result in and are an effect of internalized oppression and internalized domination.

6) Providing opportunities for group members to be visible contradicts internalized oppression and internalized domination.

After examining each of these hypotheses, I will analyze examples of group member's ideas and behavior, particularly examples of their volatility, in light of this framework. I will conclude with a discussion of these ideas based on my findings and relevant literature.

Internalized oppression framework

Gail Pheterson, who has studied problems with alliance building amongst women's groups in the Netherlands, has developed a framework for analyzing internalized oppression and internalized domination. Drawing on the work of Sartre, Fanon, Memmi, Freire and others, Pheterson (1986) defines internalized oppression as

> the incorporation and acceptance by individuals within an oppressed group of the prejudices against them within the dominant society. Internalized oppression is likely to consist of self-hatred, self-concealment, fear of violence and feelings of inferiority, resignation, isolation, powerlessness, and gratefulness for being allowed to survive. Internalized oppression is the mechanism within an oppressive system for perpetuating domination not only by external control but also by building subservience into the minds of oppressed groups (p. 148).

Pheterson defines the counterpart for internalized oppression within the dominant group as internalized domination, or the

> incorporation and acceptance by individuals within a dominant group of prejudices against others. Internalized domination is likely to consist of feelings of superiority, normalcy, and self-

> righteousness, together with guilt, fear, projection, denial of reality, and alienation from one's body and from nature. Internalized domination perpetuates oppression of others and alienation from oneself either by denying or degrading all but a narrow range of human possibilities. One's own humanity is thus internally restricted and one's qualities of empathy, trust, love, and openness to others and to life-enhancing work become rigid and repressed (p. 148).

While internalized domination, according to this formulation, is primarily the domain of the oppressor, I will invoke the concept later in my analysis of group members' behavior as it is manifested in "horizontal violence" as described in Chapter 4.

In Pheterson's framework, internalized oppression and internalized domination are contradicted by two characteristics of people who have <u>not</u> internalized their oppression (i.e., empowered persons): visibility and pride. She defines visibility as

> being oneself fully, openly, undefensively, and expressively. Visibility of the oppressed group contradicts self-concealment, isolation, subservience, and dominant denial or avoidance of oppressed persons (p. 148).[1]

Like visibility, pride contradicts internalized oppression and internalized domination. Pheterson defines pride as

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[1] Of course, this definition implies that a person can be called "oneself" - that is, that each of us has only one self, an assumption increasingly challenged in the postmodernist literature. Pheterson's definition also implies that "one" is stable, centered, a certain way all the time - yet another set of assumptions increasingly challenged in the postmodern literature. In response to both of these concerns, I would only argue that, as with all Pheterson's definitions, the implication is that people are generally capable of exhibiting these characteristics, but not necessarily in all circumstances. Moreover, each of us goes backward and forward depending on the issue at hand, at which times we might be drawing on "other selves."

> self-acceptance and self-respect, in particular, respect for one's identity, one's heritage, and one's right to self-determination. Pride carries with it an indignation against the abuse of any human being, including oneself, and a vast resource for perseverance and righteous struggle. Most fundamentally, pride derives from deep love for oneself and for life (p. 148).

Finally, Pheterson's framework includes two types of action that contradict the internalized oppression process: solidarity and alliance building. She defines solidarity as

> knowledge of, respect for, and unity with persons whose identities are in certain essential ways common with one's own. . . . Internalized oppression isolates people from one another, especially from others like themselves, and thereby prevents solidarity. . . . Solidarity is essential to oppressed groups for liberation and to dominant groups for collective alliance (p. 149).

On the basis of an oppressed group's ability to build solidarity, alliance becomes not only possible, but essential if change is to occur. Alliance is

> knowledge of, respect for, and commitment between persons who are in essential ways different but whose interests are in essential ways akin. For dominant groups, alliance is a process of sharing power and resources with others in society in order to create structures equally responsive to the needs and interests of all people. . . . For oppressed groups, alliance is a readiness to struggle with dominant groups for one's right to an equal share of power and resources . . . (p. 149).[2]

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[2] Pheterson (1986) used these definitions as guides to developing questions which would be discussed by women over in order to determine how women's attitudes might be helping or hindering the formation of alliances. The research design covered four stages over a five-month period: 1) telling, and sometimes writing, life stories (visibility), 2) expressing feelings, both positive and negative, about oneself, one's identity, and one's history (pride), 3) exploring feelings and experiences in relation to other women who share one's group status (solidarity), and 4) exploring feelings and experiences in relation to women with different group status (alliance)(p. 149).

I will return to the notions of solidarity and alliance in Chapter 8. In the next section, I will examine the six hypotheses posited at the beginning of this chapter by focusing on Pheterson's notions of visibility and pride, and in particular, what occurs when visibility and pride are absent.

Analysis

In this section, I will examine the six hypotheses presented in the introduction of this chapter in the context of Pheterson's internalized oppression framework. The first hypothesis, that the drive to visibility constitutes a major behavior pattern and concern amongst group members (Hypothesis 1), will be illustrated by a discussion of visibility - what it means, and how group members found it important.

Visibility

As noted above, Pheterson defines visibility as "being oneself fully, openly, undefensively, and expressively" (p. 148). This definition captures the "spontaneity" aspect of this group. However, it fails to address the types of experiences voiced by group members concerning visibility - in particular, the fact that to them, visibility means being seen, understood and accepted for "who they really are." Again, though group members never used the word, they frequently alluded to the concept of visibility in exercises like "Can you see the real me?" and in accounts about how they had been treated. When they alluded to visibility, they did not mean showing who they are, but being seen. Kim:

> Sometimes I feel like they don't take my word for what I say. For example where I took someone else to a doctor's appointment, they would look at the other person, instead of asking <u>me</u> the question, they would go ask <u>them</u> the question, and I feel like they think I'm too stupid to say anything.

Here, Kim felt invisible both in body and in spirit; the doctor would both ignore her presence and her intelligence. To her, then, visibility meant both being noticed and being recognized for what one is able to do.

<u>Visibility defined</u>

Because group members exhibited both dimensions of visibility, I will combine Pheterson's definition with group members' experiences to define visibility as 1) being oneself fully, openly, undefensively, and expressively, or what I shall call "expressive visibility," and 2) being seen, understood and accepted for who one really is, or what I shall call "acceptance visibility." I have identified four characteristics of expressive visibility and three characteristics of acceptance visibility as enacted by group members throughout this project. They are identified in the following table:

Table 1
Characteristics of expressive and acceptance visibility

TYPE	DEFINITION	CHARACTERISTICS
EXPRESSIVE VISIBILITY	being oneself fully, openly, undefensively	1. Unabashedness: being ready to play, sing, dance, engage in discussions, ask questions, act something out, be blunt 2. Openness: being willing to self-disclose, tell stories from the heart 3. Self-acceptance: recognizing one's own strengths and limitations; acknowledging when one is wrong 4. Self-assertion: asserting one's presence, will, identity; asserting one's own understandings, even when others might disagree
ACCEPTANCE	being seen, understood and accepted for who one really is	1. Being noticed, acknowledged, appreciated 2. Being understood 3. Being accepted, respected, liked, cared for

This table illustrates the relationship between visibility as something acted out (expressive visibility) and visibility as reflected in others' behavior (acceptance visibility). That is, visibility is not only something one does, as in Pheterson's definition, it is also something one experiences or does not experience, as the group understands it. The first comes from within, from the actor, and the second comes from without, from the world. This table also serves as a model for the behavior of empowered people - people who exhibit traits that contradict internalized oppression. It suggests that visibility is one way empowered people enact their empowerment, through unabashedness, openness, self-acceptance, self-assertion, and boldness.

Expressive visibility

As Table 1 indicates, expressive visibility consists of unabashedness, openness, self-acceptance, and self-assertion.

Unabashedness. More than is typical of "normals," group members were unabashed in their readiness to play, sing, dance, engage in discussions, ask questions, act something out, and simply be blunt. Of course, the context of bringing a group together to write a play provided a safe and conducive environment for this kind of behavior. And because members had self-selected for this project, the group no doubt consisted of people interested in expressing themselves in theatrical ways. Whatever the reason, Janet and I rarely felt a need to draw people out in meetings or rehearsals. In fact, sometimes achieving calm was a problem, though usually a good one. In particular, certain activities and songs seemed to unleash an exuberant spirit in the group, motivating them to get up and parade around the room, even after a long rehearsal.

Group members' unabashedness did not always serve them well, however. It is one thing to want to act something out in the context of developing a play. But in looking for jobs Sam sometimes had difficulty, as noted in a report filed by Sam's agency worker:

> Sam gets very nervous during interviews which affects his listening skills. Also, he tends to do impersonations during the interview. Recommended: Interview skills training (from "Progress Notes," Sam's Confidential File, Western Mass Associates).

Group members were sometimes unabashed to the point of being blunt in their assessment of certain people, situations, and systems. Charles claimed that Glenview staff had been "feebleminded," Sam proclaimed that Governor "Dingbat" Weld should get his priorities straight, Kim insisted that people working in group homes should either do what the residents want or get fired. Bob, an "extended group member," reported that

> Institutions haven't changed all that much. The people don't have total control over what they want, and they're afraid to tell 'em what their legal rights are because they'll lose the control they have over 'em. I'm being frank. You may not agree with all this, but that's the truth. . . . Matter of fact, the day I left Glenview State School, they were glad to see me leave cause I was so vocal. I used to speak out about the abuse there, I was given thorazine . . . .

<u>Openness</u>. Group members frequently exhibited a willingness to disclose delicate feelings or stories about

painful life events.[2] Of course, this definition implies that a person can be called "oneself" - that is, that we each have only one self, an assumption increasingly challenged in the postmodernist literature. This definition also implies that "one" is stable, centered, a certain way all the time - yet another set of assumptions increasingly challenged in the postmodern literature. In response to both of these concerns, I would only argue that, as with all Pheterson's definitions, the implication is that people are generally capable of exhibiting these characteristics, not in all circumstances. Moreover, each of us goes backward and forward depending on the issue at hand, at which times we might be drawing on "other selves." Group members' stories bear this out. In spite of Bruce's generally quiet nature, for example, he showed on a number of occasions that he felt safe enough to talk about painful issues with the group:

> Last summer me worry about me robbed, take all my money, Chuck saw me with Kim . . . Kim's life, she's in

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[2] In this context, openness is seen as a sign that people are at ease with themselves, and are not repressing their feelings because of their sense of unworthiness or inadequacy. This kind of openness, as manifested by the practice of self-disclosure, is culture-specific and within cultures, domain-specific. That is, each culture has places where such practices are appropriate, and places where they are not. In U.S. culture(s), this kind of self-disclosure is sometimes called sharing, defined by Carbaugh (1988) as incidents in which (1) a person who (is) making resources of self available to others, (2) speaking as an act of expressiveness, generally expressing feelings and experiences, and (3) support of one another by orienting to common purposes (p. 144).

> the hospital, cut her with a knife, her body, that me worry about.

Marcia often felt inclined to share her difficulties with the group, so much so that many of her problems could be viewed as chronic (as described in Chapter 3). Nevertheless, her openness at times signalled an ability on her part to share what for many might be too painful to share. One example was her account of being fired from a nursing home:

> I had a job at Pleasantville Nursing Home and I got fired and I don't think that's right. And I ain't worked for over a year now. They shouldn't a done that. And I ain't had a job since.

Marcia's confession was particularly moving for two reasons. First, according to written reports from case workers, she had been wrongfully fired, having been accused of hitting someone when in fact she reported that she had been hit by another staff member, which no one believed until an eyewitness stepped forward and corroborated her story. Second, Marcia shared this story on several occasions, including the Friends Support and Action Group scene in *Special* in which group members shared "how they were doing that day." Her candor was noticed by one audience member who commented in a group discussion we held with the audience after one of our performances:

> Part of the play for me, the fact that all of you shared a very intimate and personal part of your life

> with us brought you closer. I mean I'm fortunate enough to know some of you that were in it, some better than others and it really touched me real closely to be able to share what I mean with people that I know that I see in Pleasantville because I live in Pleasantville.

Self-acceptance. In this project, group members showed that they accepted themselves by recognizing their strengths and limitations, and by acknowledging when they were wrong. This analysis considers two types of self-acceptance. In the context of expressive visibility, self-acceptance is an attribute that enables someone to say "I'm comfortable with who I am, warts and all." This kind of self-acceptance knows of no false-modesty, but is a frank acknowledgement of who one is and what one is able to do. This kind of self-acceptance also exhibits a maturity in one's ability to admit when he or she has done wrong, and in such cases, to be contrite without becoming self-deprecating. The following passage illustrates this idea. In an interview I conducted with the group, Sam is remembering when he, too, had trouble "seeing the real person":

> When I was at the Center for Blind Children, there used to be this guy. Granted, he would have problems, you know, with tantrums and stuff like that, yelling and sometimes stealing goodies from the kitchen. If you didn't keep the kitchen locked and he'd steal like sweet stuff, you know. His name was Tom Schwartz,

> called Tommy Schwartz. . . . Anyway about 29 years ago, I'd be sitting at a table and I'd be hearing this guy saying "Tommy, Tommy, Tommy," you know, just repeating it, and of course that would set him off. You know, he would go "Wow!" and it was awful. I mean, I guess, to see sometimes kids you know labeling or hurting each other. And one of the things that was so horrifying I think back then was when people would actually like to see other people cry or hear other people yell. I mean it was really biza, I mean, and stupidly enough, I feel bad now because I used to sometimes get a kick out of it in my younger days at 10 or 11 years old, and now when I think back on it, I think "God how stupid!" I mean, you know, I can talk about now seeing the real me, but why didn't I see the real person themselves?

In addition to self-acceptance as "I'm comfortable with who I am," group members at times exhibited a type of self-acceptance that suggested a level of pride in who they were or what they could do.

Self-assertion. In this project, group members' ability to assert themselves was evidenced in the ways they asserted their presence, will, and identity, and by the way they asserted their understanding of certain situations, even when others might disagree. One of the most compelling efforts to assert one's identity was made by Charles who, after his release from Glenview, had moved into his own apartment, begun working as a consultant to human services workers interested in issues of deinstitutionalization, and occasionally hired out as a contractor to show newly-released people how to shop, open a bank account, and integrate into the community. (We video-taped Charles doing some of these activities and included them as part of the play.) Nevertheless, Charles' mother believed Glenview should have remained open, and that her son still belonged inside. Charles:

> Only if I can get my mother to listen to me, get her to see, see how I'm doing out here, what's in the spring time, I'm gonna have, she already agreed that she would come out here and talk to people out here, in the spring, and hopefully that people can, when she leaves Pleasantville, goes back to Boston that she'll have a better idea like how good I'm doing out here. She, there's a lot of things she doesn't know what I'm doin'.

Compared to Charles, other group members were vociferous in asserting their wills, as when Paul reported, "I keep saying to Paula (my group home staff), I says, 'You cannot take money away from me.' I says, 'Don't even try it.'" Even more overt was Kim's response to her employer at a grocery store. After she was fired, she said

> He wasn't even gonna let me back in the store, and then I had a lawyer that most of us in here know, Jeff

> Cipiti, go and talk to him, say, "Hey she has every right to go in there. . . . So I mean telling me because I was trying to fight for my own right and saying I wasn't allowed back in the store I think was kind of stupid.

While the above examples illustrate group members' need and ability to assert themselves, they also raise an important question: What moved group members to assert their visibility? I believe there are several reasons why group members exhibit this drive to visibility to begin with. First, doing a play created a context that made it "safe" to assert themselves, to be visible. This safety, no doubt, was reinforced by the fact that since its base community days, the group had established a "tradition" of being supportive of one another, of feeling free to express themselves however they chose in the group, of singing, dancing, of acting just about however they wanted without reproach. Though we were now doing a play, the group still consisted primarily of original members, so the "ethos" of sharing, caring and playing remained. I certainly had a strong influence on this ethos, forever with guitar in hand, ready to do whatever the group wanted (within reason).

Second, group members exhibited an undeniable need for attention, mostly mine, but also each others', and particularly the attention of "normals."

Third, group members asserted their visibility because of a general need to be included, to belong. When asked why they were doing the play, they would say because it is fun, because it is something to do ("better than sitting at home and watching TV"), because they got public visibility (including their pictures in the newspaper and on T.V.), because they could form friendships with other cast members and assistants, and because they were doing something nice for the community. Yet their need to be included and to belong did not appear only to be a case of loneliness. By their accounts, it was evident that they led isolated, impoverished, and boring lives, no doubt because they had been ostracized from mainstream society. Few group members could name many "normals," other than paid staff, as friends. The only way they ever got a chance to travel, to study, to take part in cultural events, or to be a part of an integrated community was if someone invited them in, which rarely happened. By creating theater, they were finally getting a chance to participate. For once, interaction with normals happened automatically and regularly.

The fourth and perhaps most important reason this group exhibited a drive to visibility can be found in their need to be taken seriously, to set the record straight about who they are and how they should be treated. Kim:

> My point of doing these plays is, particularly with the one song, the one song I hope that people get the real feeling out of is, "Can You See the Real Me?" for who I am. I don't feel that people see us that way and

> accept us for who we are, and that's one reason why I'm hoping out of this play that people accept us for who we are . . . I mean, we are who we are, and that's the way life's supposed to be.

Time and again, group members claimed that they were doing this play for similar reasons: "to show others we can do a play like anyone else," to "educate people," and "to put an end to prejudice once and for all."

The above examples are intended to illustrate how group members assert their visibility. That is, they are examples of expressive visibility - i.e., their need to show who they are, or to "be themselves fully, openly, undefensively, and expressively." In the next section, I will discuss the other side of visibility: acceptance visibility, or "being seen, understood and accepted for who one really is." Group members' stories of being seen and not being seen provided insight into their view of justice. Here I am using these examples to further illustrate my first hypothesis by showing how visibility itself constitutes a major behavior pattern and concern amongst group members.

Acceptance visibility

As Table 1 indicates, acceptance visibility consists of being noticed, acknowledged, and appreciated; being understood; and being accepted, respected, liked, cared for.

Being noticed, acknowledged, appreciated. As noted in Table 1, acceptance visibility was enacted in this project in three principal ways. The first, being noticed, acknowledged or appreciated, consists at one level of simple acknowledgement, in this case of what someone has. When the group went to Glenview to interview Dennis, their public relations officer, Marcia began describing her new-found life outside of Glenview, where she had been a resident.

Marcia: I have like two T.V.s, two big stereos, and plus my walkman and tape and plus what else?

Dennis: Excellent.[3]

At another level, being noticed means being acknowledged or appreciated for what one is able to do:

Marcia: At (the local state university) I had a bunch of people that were there. I was like this, when I was gratuatin'(from food service training). There

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[3] The first time I ever visited Marcia and Fred, who had lived at Glenview, I was stunned by the clutter in their house - clothes, stuffed animals, records, three record players (two didn't work). I later learned that this is not unusual. In his study of formerly institutionalized people who were labeled mentally retarded, Edgerton (1967) noted: "They enter the outside world without any of the large or small possessions which normal persons accumulate. Many normal folk may come to regard these possessions as impedimenta, but the released retardate sees the as the essential symbols of being normal in the outside world" (p. 156-7). Interestingly, he also noted that "the automobile represents perhaps the most enticing yet unattainable of commodities to the expatient. . . . (F)or the expatient the automobile is the ultimate symbol of success" (pp. 158-62). Only one group member in this study ever mentioned an interest in having a car. Having a job, a peaceful home life, and food and clothing seemed to be of greater concern.

was a bunch of us were there. Nat Simone and everybody else. (laughs)

Fred: And I graduated from Makework Industries. Gotta have awards. Everybody was all (in our) class and everything else.

Marcia: And I was there when Fred got (his) award, and you should hear him. Oh was he . . . and some people went up to him, and went (spitting sound).

Fred: I was nervous like this (shows his hand shaking).

As will be discussed in the next section, one of the greatest transgressions group members reported was someone simply ignoring them, walking by them, or failing to comment when they had done something worthy. Such actions were often read as contemptuous, even occasionally sparking hostility. Needless to say, one of group members' favorite people in the whole world was Wil, the minister at the church where we performed the play, who doted on group members, advertised the play from the pulpit, attended every performance he could, went out with the group after every performance, and made the following speech to the group in front of audience members:

> You combine everything, you combine music with humor, you reveal the pain, but you show the enormous potential . . . . You make us realize that we all have disabilities and we all transcend those disabilities. You make us part of one family, you know, you're so

> proud to be part of one family in that play, you bring us all together, and it's very moving . . . .

Being understood. Being noticed, acknowledged and appreciated is only one level of being seen; being understood requires greater effort. For Bob, being understood requires looking beyond one's disability and seeing what is on the inside:

Bob: (People leaving Glenview) must be made to feel like part of the community, and they must be thought of as individuals, their disabilities or their differences must come last. Sometimes people place too much emphasis in this society on the way someone looks. Beauty comes within someone's heart, not always in the way they look.

Kim: (laughs) I love that one. Mark, let's remember that one now.

To Sam, being understood involved "treating people like individuals," which had the effect of making him more open:

> In terms of the community living, I mean, we had it pretty good at Crescent Street, at least for the most part because I mean staff treated people like individuals . . . . They knew that if certain people needed more supervision, you know ok that's it, but the ones that didn't need it, you know they never, you know, it wasn't like treating us discriminatory. . . .

> You know, it was treating people equal, but, and that's how I got to be open more.

In general, however, being understood was problematic throughout this project not only because outsiders did not understand group members, but because group members often did not understand outsiders, and group members often did not understand one other. An inadvertent snicker or push on the arm could immediately lead to harsh words, even fighting. On a cognitive level, I often did not understand what group members meant when they spoke, and group members often did not understand me. In one of the interviews conducted by the group, the interviewee, a long-time trainer and evaluator for the state D.M.R. and other groups, used a 40-word sentence filled with polysyllabic words basically to say that the human services system watches out for itself first (see Critical pedagogy, Chapter 2). While we were analyzing this statement on video tape, George asked, "Why do people speak like that?" and said that he had no idea what the interviewee meant. I explained what I thought he meant, whereupon George and Kim both said, "Oh, of course," and proceeded to give numerous examples from their own personal experience to illustrate the point.

Given everyone's general difficulty in understanding others, perhaps it is no wonder that group members often felt misunderstood. Still, it is difficult to say how much misunderstanding was born out of prejudice or ignorance, how much resulted from cognitive or physical difficulties (indecipherable pronunciation, conceptual lapses, memory loss, mistaken identity, etc.), and how much can be attributed to simple, everyday misunderstandings that would happen with anybody.

<u>Being accepted, respected, liked, cared for</u>. Beyond being understood, group members indicated that being seen included actually being accepted - as humans, as equals, as people deserving respect just like anyone else. Kim expressed this feeling when the group was interviewing Dennis, the public relations man at Glenview:

Kim: There's a real song that we're trying to bring out to people: Can you see the real me instead of uh . . .

Dennis: Beautiful.

Sam: Yeah.

Kim: That's the point we're sayin'. . .

Dennis: And that's still the struggle.

Kim: Ok this is us . . .

Dennis: That's right.

Kim: Can't you accept us for who we are?

The need to be "accepted for who we are" seemed to be a unanimous sentiment amongst group members, though it was expressed in different ways. In some cases it simply meant being liked:

Mark: Who in your life has seen who you really are?

Susan: All my friends, my two friends right there, and my other friend that is sittin' up there in the window over there . . . .

Marcia: My friends.

After one of our interviews, Dean, the interviewee, shook George's hand and congratulated him on being "like a lawyer."

George: See he likes me cause I give his stuff back to him. That's why . . .

Dean: That' right. That's right, I do.

For some, being seen or accepted meant being loved or cared for.

Mark: Who do you think in your life does see the real you? Does anybody right now?

Charles: My father sees the real me.

Mark: Your father sees the real you?

Charles: He's not livin' now. He passed away, so but when he was livin' he saw the real me.

Mark: What did he do that showed that he saw the real you?

Charles: Well he let me go down there, fly down to Texas to see 'im (sniffs) and spend some time with 'im.

The above examples illustrate two important points. First, acceptance visibility reinforces group members' expressive visibility. For example, being understood and treated as equal was how Sam "got to be open more." George was more exuberant when he realized that Dean liked him.

Kim laughed and proclaimed "let's remember that one now" when told that for all people, including the disabled, beauty comes from within.

Second, the above examples suggest that acceptance visibility is important not just because of group members' need for attention, but because it demonstrates that "normals" have seen - or understood and accepted as equal - disabled people for what they really are - people.

Finally, these examples illustrate how the drive to visibility constitutes a major behavior pattern and concern amongst group members (Hypothesis 1). In the next section, I will discuss Hypothesis 2, that when group members exhibit hostile behavior, it is a result, at least in part, of visibility unattained. This hypothesis will be examined by looking at what group members meant by invisibility, and why it was important to them.

Invisibility

It might stand to reason that if group members valued visibility because it confirms their humanity, then they might become hostile when visibility was not attained. In fact, the data in this project bear this out: when group members felt invisible, they often became hostile. However, not all acts of hostility were caused by lack of visibility alone; some were clearly attributable to other factors, most notably physical pain, fatigue, the perception of a threat. Nor did invisibility always lead to acts of hostility;

sometimes, group members became withdrawn, or threatened to leave, or dropped out altogether. What this study suggests is that when group members became upset or hostile, sometimes it was because of a sense of invisibility.

In this section I will first explore the meaning of invisibility, then examine the types of responses group members exhibited or reported given the different types of invisibility. Before I do, however, it is important to make several points.

First, invisibility here means perceived invisibility. No attempt has been made to verify that in fact group members' stories were "true" in the sense that they in fact happened, or that "normals" really did or intended what group members perceived them to do. Rather, the point here is to understand how group members understood the reality of invisibility, and the effect that it had on them.

Second, if a person does not feel that he or she is visible, then functionally speaking, visibility is not occurring. That is, the positive effects that derive from visibility - acting in an empowered way - do not occur when a person feels invisible. Therefore, by this definition, a person must feel visible in order for visibility to occur. This is not to say that simply feeling visible constitutes visibility either; the visibility act must be authentic, lest the person has "false knowledge" of visibility, as in the case of tokenism (see also <u>Visibility and the problem of "false knowledge</u>," Chapter 8).

Third, invisibility is a complex concept because it is manifested differently for expressive and acceptance visibility. In the case of acceptance visibility, invisibility consists of visibility unattained because of not being seen by others. These visibility/invisibility oppositions are summarized in the following table, which repeats the definition of and characteristics of acceptance visibility from Table 1, but adds the category "not being seen":

Table 2
Acceptance visibility and invisibility[4]

TYPE	BEING SEEN	NOT BEING SEEN
ACCEPTANCE VISIBILITY	1. Being noticed, acknowledged 2. Being understood 3. Being accepted, respected, liked, cared for	1. Being ignored, neglected, excluded 2. Being misunderstood, underestimated 3. Being mistreated, abused

Invisibility defined

As Table 2 suggests, invisibility is the opposite of acceptance visibility, defined as not being seen, understood and accepted for who one really is. There are two reasons

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[4] As this table shows, invisibility means not being seen - the opposite of acceptance visibility. However, what is the opposite of expressive visibility? The end result might be invisibility, but what does not being oneself fully, openly and expressively mean? When a person does not self-disclose or jump into an activity, is it because they are disempowered or ashamed? Or is it because they simply don't know how, or it is not their style, or they are having a bad day, or they object to something that has been said or done? What is happening, then, when expressive visibility does not occur? In order to answer this question, examples of expressive visibility and its absence must examined closely, which will be done with Hypotheses 3, 4, 5 and 6 of this analysis.

that visibility can be unattained. It can be unattained because someone has made a bona fide effort to be seen, yet others still do not "see" that person, either because of choice or because of their genuine inability to "see" that person. It can also be unattained because someone has failed to make a bona fide effort to be seen, so it is unreasonable to expect others to "see" that person. Next, I will present a description of invisibility as experienced by group members.

Being ignored, neglected, excluded. In one of the group's interviews, Kim asked an evaluator of human services programs how she could "get seen" in cases where human services staff simply "ignore you."

Kim: When people work . . . for you, they're not actually working, I mean doing what you asked them to do, they're basically doing something else.

Dean: That's right. They're doing what they think is best.

Kim: Right. And then when you tell em that it's not right, they still ignore you. I mean how would you try to get somebody to um

George: Get attention?

Kim: (Nods.)

For Sam, being ignored was like being labelled:

Sam: I don't think I was labeled in words, I think it was just when I would have trouble concentrating before, I would even get hurt more, because people just never bothered with me there too much years ago when I was at a school . . .

Mark: So they wouldn't call you names, they would just ignore you.

Sam: Yeah.

For some group members, being ignored was tantamount to being neglected and excluded. Charles:

> Oh it was awful at Main Street Group Home. . . . There was one night a week, on Saturday nights, everybody had to be out of the house. Nobody could stay home, you had to go out, go somewhere, find something to do. And every time I asked other people there, could I go with them, they wouldn't wanna take me. So I ended up going home most of the time there.

For group members, then, being ignored rarely meant simply "not being seen." For them, it carried with it a feeling of being disregarded, labelled, excluded - more a sense of mistreatment than neglect.

Being misunderstood, underestimated. Like being ignored, group members reported experiences of not being seen as being misunderstood or underestimated, often by family members. Charles:

> (My mother) shouldn't put me in Glenview, I think I was doing ok. I wanted to stay there longer. She could have done something else. But she couldn't know what

> else to do there, so she ended up puttin' me at Glenview.

Bob:

> I know a lot of the parents and guardians at Glenview were, weren't very happy that it was closing down. I have an aunt that wasn't very happy about it and she <u>still</u> isn't. She thinks that I don't know what I'm talkin' about, that I'm being programmed by the state, that I don't have a mind of my own, and that's what some of the guardians think of some of the people that they're in charge of looking after.

In some cases, when group members felt they were being misunderstood or mistreated, they made bona fide efforts to "be seen," as in Sam's account in which he tried "with open arms" to do a job correctly.

> People didn't try me on enough jobs to see what I could do. You know, like for an example, uh every job that I would do, people would make statements that I wasn't concentrating on my job. Uh, I remember having talks with Penny from Joe's Grocery where maybe I didn't uh concentrate enough and it was like, "Sam, I don't think you can work on a real job, we're having, you know, trouble." And even at Makework Industries when I was doing work, people didn't have the proper, or sometimes wouldn't want to have the proper system you know of having me do the job and stuff and of course I, much as I didn't care for those jobs, like mailing jobs, I did

> it with open arms, thinking that I could make a paycheck. And it made me think of that when I finally found that I could do the work at the South End News (a newspaper in a nearby town where Sam eventually found work).

Some group members' attempts to be seen were more pointed, though they still resulted in being misunderstood. Kim:

> When I started to get angry with the program and told 'em what to do finally, and I wrote a letter knowing that they thought the staff wrote the letter for me, and they fired two staff, and I became close friends with one of 'em, Pat, but my point also is that they didn't think I could live on my own. And where I think that my point is where, when they decide to put people in group homes and stuff, they don't really give 'em credit where it's due.

For many group members, this sense of not being seen traced back to their childhoods.

George: You know how you have 25 students in a class and you tryin' to get a one on one and you can't quite do it? My teacher was kinda, like this (shakes his hand). Tight teacher, know? I give an example. If you have a row of tiny kids in class, I think you should treat as kinda differently like we were like kids, like human being. That we couldn't talk, we couldn't um, get up and walk around like that in classroom, you know?

Mark: Mm, m hm

George: But I uh, of course we were real little, so we . . . gotta get real nice with the teacher, huh? (laughs)

Mark: So you did. You obeyed the teacher.

George: Right, yeah, but they were strict son of a guns.

George's comments about how he was treated as a school child summarize group members' feelings about being misunderstood and underestimated: all people, whether they are kids, elderly folks, or disabled, should be treated like human beings. Of course, their definition of what it meant to be treated like a human being was no doubt a point of contention with their employers, their group home staff, their parents. Yet whatever the definition, the result was the same for group members - feeling mistreated and abused.

Being mistreated, abused. In some cases, group members actually reported explicit cases of mistreatment and abuse, not just feeling that way, such as Bruce's account of being tied to the stove, or Fred's account of being burned with a hot pan. In the following excerpt, Paul recounts one of many cases where staff used demeaning language. The excerpt was shown in video format in the play as an example of group members naming problems.

> There was a guy named Shawn that used to work on Center Street. And I couldn't exactly cook, cause I never did it and so I refused to cook. And uh, Shawn says

> "Alright, you can't go out," he says "you can't go out then. If you don't do your house jobs, you can't go outside." And I says "Why not?" He says, "because," he says, "you are acting like a retard." So I got so mad I took his hair and I pulled it. And uh ... I finally went down to the area office, not this one but at the state hospital, and I uh told them, I says this guy named Allen is not working out very good, he's acting like uh, he's acting like I'm a retard. And then this woman named Kate thought that I was a retard too, I just thought I cannot uh, I just thought oh, so I cannot work with him. And then they had another one named Mike, and in the middle of a party, Maria broke the window. At a party. And I got so angry with that, uh, what she was doing to the other staff, I took 12 glasses of beer and drank it right down so I wouldn't know what was goin' on. I was so mad that I was ready to move to uh, Crescent Street . . . .

Again, these examples confirm that group members experienced invisibility as not only "not being seen," but as mistreatment and abuse - "old hurts" as Sam calls them. Perhaps it is these "old hurts" that move group members to react in hostile ways - thus supporting the hypothesis that group members' hostility can be attributed, at least in part, to visibility unattained.

The above examples also illustrate a range of responses, from writing a letter to trying to get the teacher's attention, from speaking out to the point of being given thorazine, to pulling someone else's hair and getting drunk. The range and nature of these responses raises an important question: When invisibility occurs, is it because "normals" are prejudiced or ignorant? Or might it be because group members have failed to make a bona fide effort to be "seen for who they are" - i.e., deserving of respect and care. Who could blame Shawn for having trouble "seeing" Paul after having his hair pulled? Perhaps a distinction can be made between making a bona fide effort to be seen - what we might call "acting up" - and "acting out," or reacting in an extreme, unhealthy or destructive manner to a perceived wrongdoing or danger. Judging by group members' accounts and behavior, none of them would advocate pulling hair to right a wrong, understandable as it might seem at the time.

The point here is not to cast judgment on group members' behavior, but to argue that by group members' definition, some responses to invisibility are acceptable (i.e., those that preserve people's dignity and respect) whereas others are not (i.e., those that are disrespectful, violent, etc.). Based on this logic, group members' invisibility might sometimes be due to their acting out, thereby blocking normals' ability to see "the real them." Invisibility is not only a function of how normals see PLMRs. It is also a function of how PLMRs represent themselves and, as a consequence, are seen. That is, the nature of their expressive visibility has implications for the type of acceptance visibility they experience.

This section has also been an attempt to examine what invisibility means to group members as a way of developing Hypothesis 2: that when group members exhibit hostile behavior, it is a result, at least in part, a function of their invisibility. In the next section, I will examine what pride means to group members, and its relationship to visibility, as a way of examining Hypothesis 3: that visibility and pride are cogenerative.

Pride

As the previous discussion illustrates, expressive visibility consists not only of showing who one is, but making a bona fide effort to show who one is. Otherwise it can become destructive behavior, or "acting out." In examining group members' behavior throughout this project it becomes clear that when they are acting in a way that they want to be seen, and when others are acting in ways that they applaud, they are acting with a certain degree of self-acceptance or belief in their own self-worth. That is, when they assert their visibility, they are exhibiting a certain level of pride.

Pride defined

Pride is the alter ego of visibility. Where visibility is found, so is pride, and vice versa. Expressive and acceptance visibility include an element of respect. Visibility, then, is rooted in pride. Table 3 lists the six key characteristics of pride as defined by Pheterson. I have posited certain types of behavior that exemplify each of these characteristics as enacted by group members in this project.

Table 3
Characteristics of pride and proud behavior

CHARACTERISTIC	BEHAVIOR
1. Self-acceptance	- respect for oneself: who one is and what one is able to do
2. Respect for one's identity	- respect for the type of person one is
3. Respect for one's heritage	- respect for oneself as a member of a group with history, purpose, and value
4. Respect for one's right to self-determination	- insistence on freedom to choose, to express oneself, to act
5. Indignation against the abuse of any human being, including oneself	- actively advocating for justice and respect for all people
6. Vast resource for perseverance and righteous struggle	- readiness to advocate for self and others

Tables 2 and 3 show how people act to contradict internalized oppression through visibility and pride. This study argues that visibility and pride in fact are cogenerative - that is, they create each other. When one feels a sense of pride, he/she is willing and able to assert her visibility. And conversely, when one <u>feels</u> visible, this has a reinforcing effect on that person's ability to feel proud.

Self-acceptance. Group members exhibited self-acceptance in two ways: first, by recognizing their strengths and limitations, and by acknowledging when they were wrong; and second, by taking pride in who they were as individuals: who they were, what they could do, even what they owned. The list of things they were proud of was long. In fact, each group member had a little "routine" for expressing something about which they took pride in themselves: George saying "God, I'm good at this" whenever he summarized someone else's point, Bruce holding his fist triumphantly in the air when he succeeded in learning a difficult phrase or gesture; Susan recapping "When we (she and Marcia) did the harmonizing of the Old Silent Night" in our first 5-minute community play; Fred showing us his biceps after lifting me up or telling a story of carrying a heavy pot for someone at work; Marcia reminding us how fast she learned things ("I pick songs up fast, just like that"); Kim amusing herself, then saying, "I like the way I said that." Sam had trouble limiting the number of his gifts:

> It's hard to say what my gifts are, because I have so many. I guess I'd have to say a lot of imagination. . . . I'm also musically inclined, and just because I'm at an advantage that way, it doesn't mean others in our group should be left in the dark. Even if I was a

> business person, I would still feel I want to help others. These skills like music, you know they say "the mind is a terrible thing to waste," well skill is a terrible thing to waste, too.

Respect for one's identity. On several occasions, group members showed not only acceptance of who they were, but respect for the type of person they were. This was most evident in incidents where they described themselves as an "us." Sometimes "us" meant members of the group, as when Sam spoke proudly to audience members after a performance:

> I'd like to especially say about us people, the members of the group, I think we've come a long ways uh, you know when we talk about now how we like to be treated equal, I think we do it to each other, I think for the most part. I think there was a time where we used to, mind you and I say used to have trouble with that, and I think we've come a long ways where we support each other, so I think aside from what the play really means, uh I think we've shown each other, you know that we appreciate what we do. Last night as a matter of fact, we helped and prayed and showed somebody our support, we were right there for them whenever they were down, and I think this is an example too. I mean it's been known that while you, we complain about the establishment which is good, I mean there's lot of work

> that needs to be done. We also have to set an example, and I think we've done it.

As this comment shows, group identification was strong throughout this project. One of the most energizing moments in rehearsals and in the play was when the group sang the FSAG song, our curtain call: "We are Sam and Marcia and Fred . . . we hang out together and call ourselves the Friends Support and Action Group."

Group members also identified with other groups they belonged to. Paul, for example, sat on a human rights committee set up by the mayor of Pleasantville:

> I keep saying to (my house worker) in a nice way, I say, "You cannot take my money away from me," I say, "Don't even," I says, "Don't even try it. Uh, because I'm part of the human rights committee." I says, "Anybody that tries to take these things away from me," I says, "they could (lose) their job. 'Cause I'm part of the human rights committee, and uh human rights keeps tellin' me that I have got a right to press charges any time I think something's wrong at the house, I could just press charges against them. If I think they're doing wrong."

When introducing herself to an assistant in the play, Kim identified herself as a member of two advocacy groups:

> . . . the Open Door Club, that's people with disabilities who get together and try to fight for their rights and have people stick up for their rights

> when they don't think things are going right, and I'm also part of the Side by Side which is a one-on-one relationship for people who don't have advocates, to stick up for them and, who can't speak for them.

Kim's use of the word "they" is telling in that it disassociates her from the disabled community, although at other times she self-identifies as disabled. On rare occasions, group members did identify themselves as members of the disabled community. Sam, identifying as a member, said "we all have feelings." George once referred to other disabled people as "more disabled than we (group members) are." Kim indirectly referred to herself as a member of the disabled population when she would say, "Accept us for who we are."

Nevertheless, group members usually resisted the labels that placed them in the disabled category, sometimes even to the point of denying that they were disabled. This pattern raises an important question: To what extent do group members respect themselves as members of the disabled population? This remains unclear.

Moreover, on a number of occasions, group members signalled a confused sense of identity, ranging from jocularity to outright identity crisis. Some examples:

- Sam would call and leave a message on my answer machine impersonating Maggie Thatcher, saying that she had "seen the light" and wanted to withdraw her troops form the Gulf.

- At least half the time group members laughed, it was related to identity issues: normals being put down or disabled (in one scene, SuperGeorge turns the tables and magically cripples Janet and me so we can see what it is like to be disabled, upon which we waddled off stage - one of cast members' favorite moments in the show); normals' world being put down (e.g., interviewees often drew laughs by saying things like, "Well the whole D.M.R. system is messed up"); and group members being exalted (e.g., One interviewee drew a laugh when he asked George: "Who are you, the next Johnny Carson?").
- On more than one occasion, Kim, tired of her problem related to the brace on her leg, her shunt, and her persistent bladder infections which required a catheter, asked if she could have my body.
- Bruce wanted to change his last name to Kim's last name, presumably because he was madly in love with her, but also perhaps because of his painful family history and consequent desire to disown that and become someone else.

What do these examples suggest about group members' sense of identity? One explanation is that they were simply having fun, trying to make their lives (and mine) easier, or at least more enjoyable by making jokes. Sam's imitations would fit this explanation. But why did Kim and Bruce talk about an identity change? By their own account, the reason was because they did not like their own bodies, their own places in life, and they wanted a change. This might be called self-hatred, a characteristic of internalized oppression discussed in greater detail below.

Respect for one's heritage. People ordinarily indicate that they have respect for their heritage when they accept themselves as members of a group, and when they show respect for their group as one with history, purpose, and value. _This kind of behavior was the least evident of all behaviors identified in this analysis_. The reasons for this are unclear, though I attempted to discern them on several occasions with group members. In one discussion in which I was attempting to verify my coding scheme with George and Kim, I asked them point blank whether, as disabled people, they were proud:

Kim: Do you mean as an individual, or as a group?

Mark: Both.

Kim: I guess I'm proud of who I am, but I just get frustrated when I go for something and I don't get it. (pause) I'm just being honest.

Mark: I know. I know.

George: Like I can't read and write very good. But I'm not afraid to say it. If I'm not at a meeting, people can call me, when they describe me, they can call me disabled. I don't mind that. (pause) It's better than calling me retard.

When I pushed Kim and George on whether they considered themselves part of a group - e.g., of disabled people, of handicapped people, whatever - Kim said, "I work with the Open Door Club. They do advocacy for disabled people. Is that what you mean?" I explained that the Open Door Club is an organization, but I was asking whether they identified with a specific group. Kim again responded, "Well the Department of Mental Retardation will only give money to one agency for job training, so that's a kind of label because they put you all in one place."

It seems that for Kim, having a history of being congregated with other disabled people has come to mean something negative, something to be avoided, a type of labelling. When I asked her if she would ever choose to live with disabled people in a group home again, she replied,

Kim: No, not unless I ran it. But I want my independence. I'd like to help other disabled people, but living with them, I would end up feeling more disabled than I am now.

Mark: Why?

Kim: Because if I wasn't able to help the disabled person, I'd feel more disabled than they are.

Mark: So you'd be afraid you couldn't help them, and you'd feel more disabled?

Kim: Yeah.

Interestingly, Kim never expressed an aversion to being with disabled people. In fact, with one exception, no one in the group ever indicated that they would prefer not to hang out with disabled people.

The one exception was when Kim read the letter from the friend of the group criticizing our effort for not including nondisabled people (see Appendix B). This criticism derives from the normalization principle that people at risk of being devalued should not be segregated, but mixed with people of the "normal" population. Charles responded, "I agree. Having normals in it would have made it a better play." Was Charles also of the opinion that the only way to reverse the oppression of disabled people is to include them in every aspect of community life, which means never to do things in a segregated fashion? Or had Charles internalized the belief that normals are better, and that therefore their inclusion would have improved the play? Perhaps he felt, as Janet, the co-director did, that the play would have been more effective as an advocacy tool if more normals had been involved. I will return to this last point in <u>A question of standards</u>, Chapter 8.

Without launching another study, it is difficult to know what comments like Charles' meant. My point here, however, is to show that for this group, the meaning of being disabled, and the meaning of being a member of the disabled population, is to some extent undesirable - a problem if empowerment is contingent on the kind of pride that includes respect for one's heritage.

Respect for one's right to self-determination. This point recalls the theme that group members exhibited an ongoing justice orientation, or drive to show that all people should have the freedom to choose, to express themselves, and to act. The following passage provides an example in which Paul exercises these rights to the point of holding his landlady accountable - to his peril:

> One day Mrs. Munroe called me on the phone. She says, "What do you need?" I says, "What do I need?" I says, "I need, I need a new floor from you." "Well," she says, "it's none of my business," she says, "it's the state's." I says, "What are you some kind of a," I says, "What are you, some kind of a jerk?" I says, "You are not, you're not living up to your responsibility of the house, you're not doing the responsibility of the house," I say, "You're not doing a very good job." I says, "When you moved in, when you said we were going to move into South Street, you didn't say that it's in bad condition." I says, "You didn't say one word at all." I said, "You just had us move in today." I said, "You don't uh care what we live in at all." I said, "You are an unfit landlord." And so she came up one day and she put a For Sale sign with one day's notice. She was leaving (believing?) me

> when I said, to her I guess. She put a For Sale sign up. And I said to her, I said, "Boy, you're making me," I said, "You're making me pissed." I says, "Vicki, this makes me very very pissed off." I says, "I don't really like the way she put the sign up," I says, "inlegally." I said, "She shouldn't a done that." And uh, Vickie says, "Well Paul, it is her house. But it's the way you talked to her. No wonder she did it!" But I thought that it was my job to talk to her. Uh, cause I thought that it was my house and I thought that it was my duty as a client to bring up things that I didn't like. So I was uh, I was very much exposed (opposed to?) the way she put the sign up.

In this example, Paul acknowledges and asserts his identity as a citizen with rights and duties: "I thought that it was my job to talk to her." He also exhibits signs of expressive visibility, particularly unabashedness ("You are not, you're not living up to your responsibility of the house, you're not doing the responsibility of the house, you're not doing a very good job"), and self-assertion ("What do I need? I need a new floor from you"). This example, then, shows Paul exhibiting characteristics of both visibility and pride. Moreover, this example shows how visibility and pride work together: because Paul is a citizen with rights ("I thought that it was my duty as a client to bring up things that I didn't like"), he feels justified in asserting his will with his landlady and staff worker.

But something else is going on here. Because of Paul's understanding of his role, he even pushes his point to the level of accusation, calling Mrs. Munroe "a jerk" and "an unfit landlord." By invoking visibility as a heuristic, Paul's behavior can be explained in terms of invisibility; as before when he had pulled staff workers' hair or downed 12 beers, he is feeling "unseen" and, as a result, we can see why he feels justified in acting the way he does. By invoking pride as a heuristic, the distinction between acting up and acting out becomes clearer, for while Paul might have felt justified in his behavior, and felt that his assertiveness was arising out of his sense of pride in who he was and his right to self-determination, his pride did not seem to include a concern for other people's dignity. Given the idea that pride includes both self-respect and concern for other people's dignity, Paul's behavior can be seen as "acting out" - a point that I will now develop more fully.

Indignation against the abuse of any human being, including oneself. As discussed in Chapter 5, group members frequently voiced an interest in actively advocating for justice and respect for all people - in their words, so that all people could live free of mistreatment and abuse, and so that people could be free to choose how to live. Here I am focussing on the link between this justice perspective and pride, arguing that this kind of justice orientation is born out of group members' sense of pride, evidenced by the fact that they often rooted their indignation in their concept of what it meant to be human. When Sam heard Kim tell her story about being fired from a grocery store job in part because her employer "brought up Bruce's name in the middle of the picture and said that the two of us make a good pair," he reacted:

> They say sticks and stones may break my bones but words will never hurt me. But I have to kind of disagree with it because I think in some cases we all have feelings . . . and unless we're really taught to deal with it, I mean there's no human beings that just can know how to ignore things that, when people say things, you know we, it hurts our feelings. And I think that by saying those things . . . it's kinda like what we call old hurts . . . I think that's just as violent as violence themselves, is comparing people, bringing up names, you know . . . That's the worst thing anybody can ever do.

Sam's indignation is born out of something more than simply having experienced this kind of treatment himself. By saying that "there's no human beings that just can know how to ignore things that . . . when people say things, you know we, it hurts our feelings," he is implying that since we are all human beings, we deserve to be treated with equal respect, which in this case means being judged on our own merits, not on the basis of similarities to other people. This kind of understanding extended beyond individuals and beyond the group to include all people. What this analysis fails to take into account is the fact that if Bruce had been fired, and his employer was equating his action with the fact that Bruce was disabled, that also was an injustice - of a different sort to be sure, but no less wrong than comparing Kim to Bruce. Yet in the discussion between Kim and Sam, Bruce's case was not taken into account, even though he was present.

Again, I am arguing that visibility has implications for the kind of pride Sam is discussing. By comparing Kim to Bruce, Kim's employer has rendered her invisible; he is not "seeing the real her." According to Sam's analysis, this is a disrespectful act, causing feelings so hurtful that he equates it to an act of violence. More importantly, Sam's analysis implies that he himself is self-respecting. Otherwise he would not understand or feel so passionately the standard he is invoking to judge the employer's action as wrong. Thus, understanding people's beliefs about invisibility is a key to understanding the pride with which they understand themselves and the world.

<u>Vast resource for perseverance and righteous struggle</u>. After respect for one's heritage, this characteristic was the least evident of all behaviors identified in this

analysis. All group members exhibited an interest in creating a more just world, from wanting to do the play for the benefit of the community to insisting that "group home staff should respect residents or be fired." However, group members' willingness and ability to persevere in their struggle against the oppression of other PLMRs, or against the oppression of people in general, was much more limited, and it varied from person to person. Some never spoke of trying to help anyone outside family and friends. Bob, on the other hand, spoke inspiringly about a life of perseverance:

> To be in the community, people have to have total control over their life, and if they can't, they should have a responsible person making the decisions with em, you can do it in this way. You would say, "What would I want for myself that I want for this person?" And that's where your role comes in, as members of the Open Door Club, when people get out there, you know, wait a while cause they're gonna have to get used to being out there, go around and talk to them and ask them what they hope to get out of the community. Just don't cram things down their throat like the state is famous for doing. . . . I work in the system, but I don't agree with everything the system does. I've been battling the system for years and one, the one thing that they need are people in their life that are not connected with the system. . . . I mean, one thing that I did

> that I'll always be grateful for, I got my friend Richard Roy out. Took several letters to the Department and took me over five years. Richard Roy's a young man who has a slight speech impairment, but he's very smart, and he walks with quite a.... he's very, he's very intelligent.

Bob's respect for people with impairments and his commitment to struggling against ablism was echoed by other cast members. Sam:

> I like doing these plays because I think it shows how we feel about handicappism. It also builds cast members' confidence, so when something happens to them, they can respond in a positive way, a nonviolent way.

Nevertheless, in most cases, group members' justice orientation rarely went further than expressing their views on the subject, taking individual action to improve their own lives, or being of support to family or friends. Sam had occasionally attended rallies in Boston to protest funding cuts for social services; Sam, Marcia and Fred had written letters in support of closing Glenview. All had voted occasionally. In the case of *Get a Job!*, our previous play, a number of us attended a meeting with Kim and confronted a DMH official, resulting in the release of job training money for Kim in the agency of her choice. But other than the play, the group never took any form of collective action. Nor did any group member ever work individually or with others for a cause outside of the group, other than the cases mentioned above.

What are the reasons for this? This issue is discussed further in Participatory research as a means moving to action with PLMRs: What group members did, Chapter 8. This analysis aims to highlight the relationship between pride and visibility and, as stated in Hypothesis 3, that the two are cogenerative. This analysis also suggests that when pride is lacking, certain behavior can be expected as well. This idea will be developed further in the next section as we look at Hypothesis 4: that when group members exhibit hostile behavior, it is also a result, at least in part, of a lack of pride on their part.

Lack of pride

In this project there were numerous instances when group members would talk about how powerful they felt: when Marcia told an abusive ex-lover to bug off and slammed the phone down on him - "CLUNK!" - when Kim finally won job training monies, when Sam found he was able to work at the South End News after being told he couldn't work at Joe's Grocery because of his "concentration problems."

It is interesting to note that for group members, feeling powerful often consisted not of being able to control other people or the environment, but simply feeling capable - of saying no, of exacting services from bureaucrats, of being able to do a job. It is also interesting to note that for group members, feeling powerless felt not like being incapable, but being controlled. For example, once in a while a group member would become hostile, but instead of dealing with it, other group members would try to ignore it, even if the hostile person was absent. Of course, the problem would escalate until one of two things would happen: either someone would delegate the responsibility to someone else (often me) to confront the perpetrator, or a group member would start acting out. Usually, it was the latter and came in a variety of forms: hitting, name calling, leaving the room, and screaming from outside the door. One night Marcia took me to the police station (which was right next door to our rehearsal space) and reported me to a kind young officer who spoke softly, acknowledged her griefs, called her by name, and wrote down everything she said. Calmed, she took my hand and we walked back to the rehearsal.

This group's tendency to try to avoid dealing directly with conflict is, of course, a common group dynamic, and at one level, not necessarily a bad one. In some cases, indirect methods are more culturally appropriate and, strategically, are sometimes preferable since they can allow everyone to "save face." However, in many cases throughout this project, group members reached an impasse where they did not know what to do, at which point there was a palpable sense of fear - of getting hurt, making someone angry, of someone making <u>me</u> angry, of the hostility ruining the entire project. At times like this, there was a certain "out-of-controlness" to the group that was truly frightening.

The following analysis is aimed at determining what this out-of-controlness is about, arguing that a lack of pride is one explanation. The following table includes the same categories found in Table 3 but extends these categories with examples of what I have constituted as lack of pride taken from group members' behavior and from Pheterson's definition of internalized oppression. This study argues that group members' hostility, or fear, or "out-of-controlness," is rooted, in part, in their lack of pride. Moreover, this study argues that one manifestation of lack of pride is internalized oppression. This is not to say that all internalized oppression can be reduced to a lack of pride, but that the characteristics of lack of pride are the same as the characteristics of internalized oppression.

Table 4
Characteristics of pride and lack of pride

CHARACTERISTIC	BEHAVIOR OF SOMEONE WHO HAS PRIDE	BEHAVIOR OF SOMEONE WHO LACKS PRIDE
1. Self-acceptance	- respect for oneself: who one is and what one is able to do	- feelings of inferiority, self-hatred: putting oneself down, apologizing for reasonable behavior, accepting others' negative views of oneself
2. Respect for one's identity	- respect for the type of person one is	- feelings of inferiority, self-hatred: tolerating misrepresentations or putdowns
3. Respect for one's heritage	- respect for oneself as a member of a group with history, purpose, and value	- feelings of inferiority, self-concealment: hiding one's identity as member of devalued group; tolerating misrepresentations or putdowns of one's group
4. Respect for one's right to self-determination	- insistence on freedom to choose, to express oneself, to act	- feelings of powerlessness, resignation: accepting will of others
5. Indignation against the abuse of any human being, including oneself	- actively advocating for justice and respect for all people	- feelings of powerlessness, resignation: allowing abuse to occur either in one's presence or outside one's immediate circle
6. Vast resource for perseverance and righteous struggle	- readiness to advocate for self and others	- resignation: giving up

<u>Lack of pride defined</u>

As this table illustrates, lack of pride is based on fear that manifests as (1) feelings of inferiority/self-hatred; (2) feelings of inferiority/self-concealment; and (3) feelings of powerlessness/resignation. I will not attempt to probe the meaning of fear for group members, or speculate on what kinds of fears they experienced in this project. To do so would require a separate study using a phenomenological design - clearly not my intent here. Rather, I will briefly discuss each of the three categories of internalized oppression as group members experienced them in order to understand the relationship between hostile behavior and lack of pride.

Feelings of inferiority/self-hatred. These feelings consist of putting oneself down, apologizing for reasonable behavior, accepting others' negative views of oneself, and tolerating misrepresentations or putdowns of oneself as a member of a devalued group (#1 and #2 in Table 4). Perhaps nobody typified these characteristics more than Kim, whose very language was studded with asides (e.g., "You're gonna hit me for saying this but...") in which she constantly admonished herself for mispronouncing words, or misusing them, or forgetting them altogether, or not being clear, or misunderstanding a situation. Kim also constantly struggled with other people's negative opinions of her to the point where a regular topic of conversation in the group was to convince her that it didn't matter what other people thought, that she could do what she wanted. At times, the extent to which she internalized other people's negative views of her was explicit:

> They call you when you go to your appointments when you work with case workers and stuff, they call you a

> client and you sit there and say, say to yourself, I don't care if people know who I am. And then they can say "Kim's here" . . . instead of saying "client." Then you sit there and say they're like you're, think you're a dog or something when they say client (laughs) or you're a piece of dirt.

Feelings of inferiority are sometimes explicit, as in Kim's statement. At other times, they are less obvious.

<u>Feelings of inferiority/self-concealment</u>. These feelings consist of hiding one's identity as a member of a devalued group, and tolerating misrepresentations or putdowns of one's group. As noted before, some group members openly acknowledged their disability. Kim never overtly expressed feelings of inferiority on the basis of being developmentally disabled, yet her experiences with employers had taught her to try to hide her condition as a person with physical problems.

> I'm actually kinda scared right now to get a job now cause I'm afraid if I go and tell 'em about the medical stuff, that they're not gonna wanna hire me or want to do anything with me.

Charles' way of talking about being developmentally disabled was perplexing. At one time he said, "Another word I don't like is retarded. We're not retarded. I think we're normal like everyone else." Yet on other occasions he acknowledged the fact that group members had disabilities, but that they were hidden:

> I think the reason why we're puttin' on the play is because um, I have to say that us, we have a, we we we, I know we don't like to use the word but we have a disability. It's somewhere hidden, so no one can see it, and we have to show them that us people can put on plays as well as anybody else can.

Charles' notion that "we're not retarded - I think we're normal like everyone else" has interesting implications for both pride and visibility. First, if Charles is placing his hope in the possibility of feeling proud because he is able to perform "just like normals," then his long-term chances to feel proud are not good since PLMRs by definition have certain impairments. Second, if Charles is trying to portray PLMRs as no different than normals, then he is attempting not to become more visible, but to hide his disability and only show that part which can be credibly compared to normals. In both cases, it seems that self-concealment is occurring - in the first case, that he is perhaps hiding something from himself (that maybe disabled people can't do everything normals can), and in the second case, that he is choosing to reveal only that part which looks normal, and to conceal the rest. In both cases, then, he is failing to explicitly accept himself as a PLMR in a way that can, in the long run, make him feel both visible and proud.

Feelings of powerlessness/resignation. These feelings consist of accepting the will of others over one's own, allowing abuse to occur either in one's presence or outside one's immediate circle, and giving up. Of the three characteristics of lack of pride, this seems to be the least evident in group members' behavior. Perhaps owing as much to their general feistiness as anything else, group members' lives are filled with stories in which they had said "fuck you" to employers, walked out of courtrooms, kicked police officers, filed reports, and complained to whatever authorities they could find who would listen.

Still, several examples illustrate how group members accepted the will of others over their own, such as the incident in which Kim refused to ride the Special Transportation bus because her friend said it would label her. While we were developing *Get a Job!* Susan reported that her husband said she was "good for nothing" and that he refused to give her permission to leave the house for rehearsals, much as she wanted to. After producing *Get a Job!* Susan's husband died, and she immediately called me, asking when we were going to do the next play. In terms of resignation, perhaps there is no example more striking than the one cited above in which Paul drank 12 glasses of beer the night Maria broke the window. He even concedes he drank them "so I wouldn't know what was goin' on. I was so mad that I was ready to move to uh, Main Street (group home)."

Though none of the above examples is conclusive in themselves, all raise important questions about the relationship between group members' pride and behavior. If Kim, Charles, Susan and Paul were acting out of a feeling of powerlessness or inferiority in the examples cited above, whether this means feeling self-hatred or simply feeling trapped, then there is reason to believe, as stated in Hypothesis 4, that the absence of pride was at times a significant factor in explaining some of the hostile behavior exhibited by group members in this project.

Cogenerative elements of internalized oppression

The first four hypotheses claim (1) that visibility is important for group members, (2) that they behave in hostile ways when visibility is unattained, (3) that visibility and pride are cogenerative, and (4) that hostile behavior is sometimes due to lack of pride. This section will examine Hypothesis 5: that the lack of visibility and lack of pride in this group both result in and are an effect of internalized oppression and internalized domination. This hypothesis is based on the notion that invisibility and lack of pride are also cogenerative, and that internalized oppression and internalized domination are also cogenerative. Moreover, the invisibility/lack of pride dynamic and internalized oppression/domination dynamic are also cogenerative of each other, as illustrated in Figure 3:

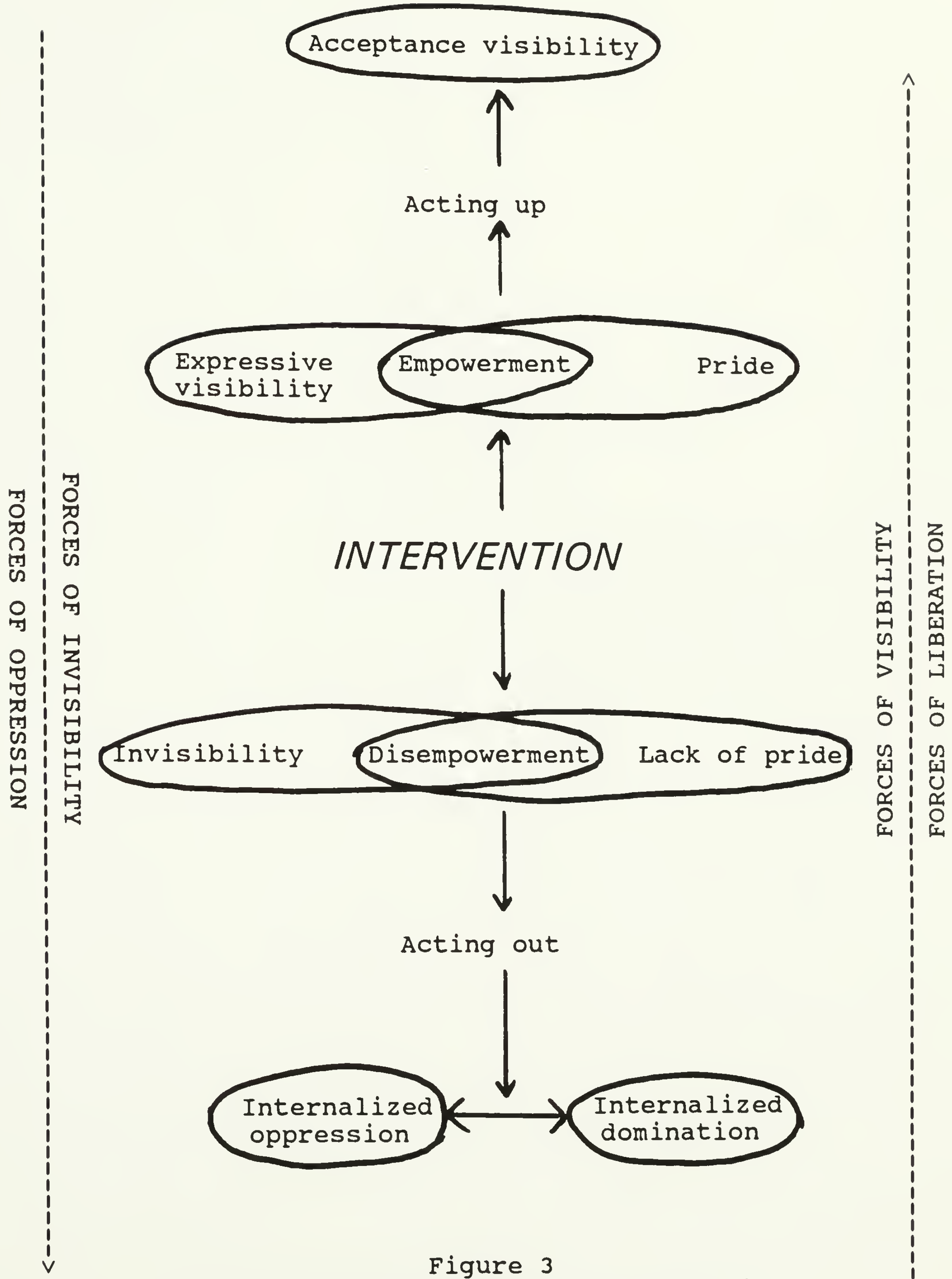

Figure 3
Relationships between pride, visibility, and internalized oppression

What does it mean to say that invisibility and lack of pride are cogenerative? When people feel invisible, they can do one of two things: act up, or assert their visibility in a positive way, or they can act out and assert their visibility as hostility, anger, or destructiveness. Acting out is sometimes the result of a convergence of invisibility and lack of pride which, in turn, lead to internalized oppression or internalized domination. Conversely, when people act out in these ways, they are reinforcing their invisibility and lack of pride. Similarly, when cast members feel oppressed, they "reach out and dominate someone else," a form of horizontal violence. And when group members dominate others without being resisted, others are being both oppressed and are internally oppressed since they are also tolerating this behavior. Hence, internalized oppression spurs internalized domination, and internalized domination, when it goes unchecked, spurs internalized oppression. The following transcript illustrates this concept. Kim, Sam and George are interviewing Bob, a former resident of Glenview. They are talking about the practice within human services agencies in which service receivers are referred to as clients.

Transcript of discussion on internalized oppression

	Kim: Well I also know how, which I don’t care if people know me, but...
(1) Visibility: being noticed	Bob: (1) Well your name is Kim Sanders, I...
	Kim: (laughing) No no no no, the reason I’m saying that Bob is, they call you when you go to your appointments when you work with case workers and stuff, they call you a client
(2) Internalized oppression: powerlessness	(2) and you sit there and say, say to yourself,
(3) Invisibility: being misunderstood	(3) I don’t care if people know who I am. And then they can say "Kim’s here" instead of saying...
	Bob: Yeah well the thing is, people need, people need jobs, and you don’t really need an agency to do that, you just gotta take them to employers that have the right attitude. The system gets too mu, they use the money to control people.
(4) Internalized oppression: self-hatred	Kim: (4) Then you sit there and say they’re like you’re, think you’re a dog or something when they say client (laughs) or you’re a piece of dirt...

	Bob: Well client was...exactly used for cus...
	Sam: Law cases
	Bob: Customer, but, the thing is, or a lawyer, lawyer,
	Sam: A lawyer
	Bob: a lawyer's client, but it gets overused in the department.
	Kim: Yeah see that's what I say and... I tell people, I don't care if they know my, who I am.
	Bob: I mean Dean Popper deserves a lot of credit for what he did . . . I mean,
(5) Pride: vast resource for perseverance and righteous struggle	(5) one thing that I did that I'll always be grateful for, I got my friend Scott Bohr out. Took several letters to the Department and took me over five years.
(6) Pride: respect for one's identity of any human being, including oneself	(6) Scott Bohr's a young man who has a slight speech impairment, but he's very smart, and he walks with quite a.... he's very, he's very intelligent.
(7) Internalized domination: horizontal oppression	(7) (Kim tells George not to leave a cup on table.)

(8) Pride: indignation against the abuse	Bob: (8) Kim, you don’t have to be like that. George knows what to do. That’s annoying. Kim: He was gonna leave it there for you. Bob: So? I would have had somebody wash it. You, you gotta learn not to boss people around.
(9) Internalized domination: horizontal oppression	(9) Kim: He does the same thing at my house. Bob: I know, but respect people.
(10) Pride: respect for one’s right to self-determination	(10) That’s what this video’s all about. Treat them like you would wanna be treated. You can’t expect them to treat you like you w, you wanna be treated, if you don’t treat them the way they (you?) wanna be treated.
(11) Pride: self-respect	(11) George: Let Bob tell me to do that, not you.

This transcript highlights several relationships. First, the relationship between internalized oppression and internalized domination is clear in the interaction between Bob, Kim and George when Kim tells George not to leave a cup on the table, to which Bob responds: "Kim, you don’t have to be like that. George knows what to do. That’s annoying."

Here, Bob is refusing to allow abusive behavior, even on the level of "bossing someone around," to be enacted in his presence. Yet Kim retorts, "He was gonna leave it there for you," further justifying her position and attempting to assert her control over George.

This is not just a simple incident of someone bossing someone around but a case where, at one moment, Kim reports feeling like "a dog or a piece of dirt," and in the next moment, is asserting what little control she has in someone else's house over someone else whom she is obviously used to controlling in her own house. Of course it must be mentioned that Kim and George have a "routine" where she regularly picks on him, shuts him up, hits him, etc., and he often plays along. This case, however, is different because George does not play along, as he sometimes does, but defends himself: "Let Bob tell me to do that, not you."

I showed this transcript to Kim and George and explained the various words in the analysis as follows:

1) Pride: When someone respects your identity, heritage, or right to choose
2) Visibility: When you're free to express yourself, and when people see the real you
3) Invisibility: When someone doesn't see the real you, or you're treated badly
4) Internalized oppression: When others say you're bad, and you believe it and accept it

5) Internalized domination: When you feel picked on, so you pick on others (i.e., horizontal violence)
6) Oppression: Power + prejudice.

After discussing these words, I asked Kim and George what they thought of my assessments of their behavior. George agreed that Kim had been picking on him, and that he really didn't like it. Kim conceded, which she often did throughout the project, often accompanied with an apology, though it did not stop the behavior. The relationship between internalized oppression and internalized domination, then, consists of Kim's feeling oppressed and simultaneously oppressing others, suggesting that they are cogenerative.

This example also illustrates the cogenerative relationship between expressive visibility and pride. George responds to Kim's behavior _after_ Bob says "Kim, don't be like that." This in contrast to numerous other times throughout the project in which Kim would badger George and others without any resistance from them. The difference, I believe, is visibility. Bob is "seeing" George, which emboldens George to say "Let Bob tell me to do that, not you." Just as Sam reported that group home staff treating him like an individual "had opened him up more," Bob's treating George like someone who shouldn't be bossed around encourages George to affirm his rights as a person who should not be harassed. And, emboldened, George speaks and asserts his visibility. This example, then, shows one way in which providing opportunities for group members to be visible contradicts internalized oppression and internalized oppression.

Discussion

My analysis of the six hypotheses proposed at the beginning of this chapter has been aimed at ultimately defending my two original claims:

1) that group members' drive to visibility is an attempt for them to battle oppression and internalized oppression; and
2) that when group members' drive to visibility is frustrated, internalized oppression or internalized domination often results.

These two claims suggest two different directions that group members took in this project - toward greater visibility and pride, or toward internalized oppression and internalized domination.

Pheterson's contribution

In order to summarize these two directions, I would like to offer a complete table that includes all of Pheterson's elements considered in this chapter, characteristics incorporated from this project, and ideas I have posited on a continuum, the endpoints being subjugation and liberation.

TABLE 5
FROM SUBJUGATION TO LIBERATION: A CONTINUUM

UNIT OF ANALYSIS	DEFINITION	CHARACTERISTICS
SUBJUGATION	Living a dehumanized existence	- servility to others - servility to a distorted view of oneself
INTERNALIZED DOMINATION	The incorporation and acceptance by individuals within a dominant group of prejudices against others.*	- feelings of superiority - horizontal oppression
INTERNALIZED OPPRESSION	The incorporation and acceptance by individuals within an oppressed group of the prejudices against them within the dominant society.*	- self-hatred - self-concealment - feelings of inferiority - feelings of powerlessness - resignation
INVISIBILITY	not being seen, heard or understood for who one really is	- being ignored, neglected, excluded - being misunderstood, underestimated - being mistreated, abused
VISIBILITY	1. Expressive visibility: being oneself fully, openly, undefensively*	- unabashedness - openness - self-acceptance - self-assertion
	2. Acceptance visibility: being seen, heard or understood for who one really is	- being noticed, acknowledged, appreciated - being understood - being accepted, respected, liked, cared for
PRIDE	Self-acceptance and self-respect, in particular, respect for one's identity, one's heritage, and one's right to self-determination. Pride carries with it an indignation against the abuse of any human being, including oneself, and a vast resource for perseverance and righteous struggle. *	- respect for who one is and what one is able to do - respect for the type of person one is - respect for oneself as a member of a group with history, purpose, and value - insistence on freedom to choose, to express oneself, to act - actively advocating for justice and respect for all people - readiness to advocate for self and others
SOLIDARITY	Knowledge of, respect for, and unity with persons whose identities are in certain essential ways common with one's own.*	- ability to understand commonalities and work with others with similar issues
ALLIANCE	Knowledge of, respect for, and commitment between persons who are in essential ways different but whose interests are in essential ways akin.*	- readiness to struggle with dominant groups for one's right to an equal share of power and resources
LIBERATION	Living a "fully human" existence	- autonomy - self-determination - leading a "dignified lifestyle" - critical consciousness

* Source: Pheterson (1986). All other items derived from group members or the author.

The previous discussion aims to do two things: first, to identify various components of internalized oppression and analyze them on the basis of data generated in this project; and second, to use the internalized oppression framework with visibility as an entry point to explore possible reasons for the volatility of this group. Thus, there were two subjects of concern here: the content and usefulness of the internalized oppression framework as adapted from Pheterson, and what the model revealed about group members' experience.

Reflections on Pheterson's framework. Pheterson's framework is unique for several reasons. First, it distills the key elements of oppression and internalized oppression as represented in a disparate literature. Second, the ideas it identifies are expressed succinctly enough to be useable for analyzing how certain groups understand the world, and what these understandings mean in terms of those groups' readiness or ability to move toward greater levels of pride, solidarity and alliance. In this study, her framework was particularly helpful in analyzing the role visibility plays in the overall movement toward liberation. Finally, her definition of visibility offers a new understanding of the term in the context of stigma theory. Before her, the term had only been used in reference to stigmatized people by Goffman (1963) in which he claimed that visibility was a negative thing, something to be avoided, tantamount to detection. If a stigmatized person was visible, Goffman argued, then that person had failed to "pass," or "conceal discreditable facts" (p. 42):

> Traditionally, the question of passing has raised the issue of the "visibility" of a particular stigma, that is, how well or how badly the stigma is adapted to provide means of communicating that the individual possess it. For example, ex-mental patients and expectant unmarried fathers are similar in that their failing is not readily visible; the blind, however, are easily seen. . . . Since it is through our sense of sight that the stigma of others most frequently becomes evident, the term visibility is perhaps not too misleading. Actually, the more general term, "perceptibility" would be more accurate, and "evidentness" more accurate still. A stammer, after all, is a very "visible" defect, but in the first instance because of sound, not sight (p. p. 48).

Pheterson's definition of visibility is just the opposite - a positive thing, tantamount to recognition of who one really is inside, more in keeping with group members' use of the word in this study. In the context of stigma theory, then, Pheterson's definition, and group members' experiences in this study, raise an important and thorny question: what exactly should the stigmatized person want others to see? Is there something that the stigmatized person should, or even can, feel proud of? This subject will be taken up in detail in Chapter 8.

Pheterson's framework, then, provides both the tools and conceptual aids in considering the question of visibility from a new vantage point. However, her framework is limited in three ways:

1) It does not take into account oppressed people's perceptions of oppression. As a result, certain

dimensions are missed - as this study pointed out, the distinction between expressive and acceptance visibility.

2) It tends to be individualistic; no allowances are made for group phenomena such as self-hatred on a collective level, and its natural outcome, horizontal violence.

3) It does not deal with the relationship between acceptance invisibility and internalized oppression, leaving unclear the question about how society should change in order to accept oppressed people and treat them justly.

This study expands Pheterson's framework, thereby suggesting that it can and in some cases perhaps should be expanded, in the following ways:

1) It expands the idea of visibility to include both expressive and acceptance visibility.

2) It includes the idea of invisibility, and examining how it relates to lack of pride and internalized oppression, particularly the extent to which acceptance of invisibility constitutes a type of internalized oppression.

3) It considers the nature of group phenomena as well - e.g., horizontal violence, acting up and acting out.

4) It locates Pheterson's definitions as points on a continuum between subjugation and liberation, with oppression as a subjugating force, and caring as a liberating one.

Perhaps the most significant characteristic of this analysis has been the use of visibility both as an entry point for understanding group members' volatility, and as an entry point for reversing their sense of internalized oppression. That is, the centrality of visibility has been a dominant feature of this analysis.

What the framework revealed about group members' experience. In addition to the relationships discussed previously and illustrated in Figure 3, two additional insights come out of this framework. The first is the context within which visibility and pride are situated. Pushed in one direction, they can turn into internalized oppression and domination, whereas pushed in the other, they provide the groundwork for building solidarity and alliance building. The chances of the latter happening, however, are questionable given the problem of lack of pride, particularly group members' resistance to identifying as members of a group with a heritage and a purpose.

The second insight to come out of using this model was the fact that there seem to be helping and hindering forces that moved group members toward greater pride and solidarity on the one hand, and higher levels of internalized oppression and domination on the other. These forces can be summed up as forces of caring on the one hand, and forces of oppression on the other. Since the focus of this study was not on the specific nature of these forces, but their manifestation as described by group members, a more thorough examination of them would be a worthwhile next step. The focus on visibility in this study, however, suggests what some of these forces might be. Caring forces include efforts to enable group members to be seen - i.e., feeling accepted, cared for, appreciated and respected. Oppressing forces include efforts that make group members feel invisible - i.e., ignored, excluded, mistreated and abused.

<u>Internalized oppression and functioning levels</u>. Given the descriptions of higher and lower functioning levels posited in <u>Overview of the project: Two groups</u>, Chapter 2, I observed that functioning levels correlated positively with views of justice as articulated in this project. That is, those whom I designated "higher functioning" were more articulate about what justice meant. However, I saw no clear correlation between functioning level and level of internalized oppression or internalized domination. <u>While higher functioning members were more articulate about their experiences of oppression, pride or visibility, they did not necessarily exhibit higher levels of pride and visibility, or lower levels of internalized oppression and internalized domination</u>. All exhibited high levels of pride frequently, and all acted out on occasion.

Reflections based on the literature

The importance group members placed on visibility can, of course, be explained in various ways. In this chapter, I have presented it in the context of internalized oppression and their drive to combat oppression. Others (e.g., Schulman, cited in Schalock, 1983) have argued that the need to be seen can be understood as a larger need for affection and attention, which in turn is often due to social deprivation. In general, the disabilities literature talks of PLMRs' intense interest in friendship, in their desire to belong, and their eagerness to socialize, even to the point of unusual avidity (Edgerton, 1967) - all of which might be interpreted as types of expressive visibility: unabashedness, openness, self-acceptance, and self-assertion. Group members' expressive visibility is no doubt rooted in their desire to belong, and the nature and intensity of that desire is turn rooted in the types of backgrounds they have, their current social situations, the difficulty they typically have as PLMRs making and keeping friends, etc. This study suggests that another factor to be considered in assessing PLMRs' openness and need to be seen is the fact that they are members of an oppressed group, that they have to some extent internalized their oppression, and that their need to be seen can either be worked positively to build their pride and overcome their internalized oppression, or it can be "managed," which might only serve to allow the internalized oppression, and the hostility it provokes, to continue.

The literature on PLMRs' need for affection suggests an even more important point, however. As with the absence of literature on PLMRs' perspectives on justice, there is a virtual absence of literature on PLMRs and visibility, invisibility, and internalized oppression. There are related literatures. For example, on the subject of invisibility, some claim that disabled people in general are underrepresented in the media and in the literature (Ruffner, 1984), and that PLMRs in particular are misrepresented as deviants, weak, dependent, etc. (Bogdan et al, 1982; Brolley & Anderson, 1986). On the issue of internalized oppression, some writers argue that PLMRs often fall victim to "self-fulfilling prophecy" by believing the labels and therefore becoming disempowered. Yet none of the literature directly deals with the issues of visibility, invisibility, pride, lack of pride, internalized oppression, or internalized domination - either as they affect PLMRs, or as PLMRs experience these phenomena themselves. Nor does any literature identify these phenomena as part of a larger picture of the oppression of PLMRs, or the possible advantages of accepting a social identity around which PLMRs can feel proud and organize. <u>This study is significant in that it represents the first step in that direction</u>.

Conclusion

The drive to be seen is a basic human motivation. Responses to invisibility vary from person to person and group to group, however. When the response is hostility, the question arises: Are these just the rantings of a frustrated and neurotic person? Or is something deeper happening? This chapter has argued that group members' tendency to act out can be viewed as an effort on their part to be seen and understood, or at least to express the frustration they feel when they are invisible. This finding carries two important implications: (1) that research is needed in which these ideas explored, especially a close examination of the conditions under which PLMRs routinely feel invisible, coping strategies they employ, the effect of these strategies on people around them, and ultimately, the effect of these strategies on PLMRs' ability to control their environment; and (2) that those who work with and advocate for PLMRs might interpret the drive to visibility as a bugle call to action, signalling the importance of creating and enhancing opportunities for visibility for PLMRs.

CHAPTER 8

SUMMARY OF FINDINGS, DISCUSSION AND CONCLUSION

Introduction

In this chapter, I summarize the findings from this study from the perspectives of what group members revealed about themselves, then from the perspectives I developed based on the use of the internalized oppression framework. I then discuss criticisms of Special and additional issues to come out of the project. I conclude with some final thoughts on the meaning of visibility, and what I learned throughout this process.

Summary of findings: What group members revealed about themselves

Three main findings emerged from this study: that group members had a chronic problem orientation, that they shared a justice orientation, and that their engagement in the play was largely motivated by their drive to visibility. These findings are summarized in this section, as are three additional observations about themes that were woven throughout this study: that group members were "hardwired for joy"; that deprived of visibility, they "acted out," exhibiting varying levels of internalized oppression; and that evidence of internalized oppression signalled a reluctance for group members to accept an identity of impairment, much less take pride in it.

A world of happiness: "Hardwired for joy"

In this study, group members frequently revealed what made them happy: being able to do things, having things, especially things they had previously been denied, the ability to be productive, the ability to belong to a group such as the Friends Support and Action Group, being able to live in a community and have friends there. They revealed that being happy consisted of being seen, understood and appreciated, and doing things they enjoyed such as singing, dancing, celebrating birthdays, anniversaries, people's accomplishments. Their predominant value was being in relationship with others and their socially active lives bore this out. The most frequent response of newcomers and visitors to the group was astonishment at how upbeat, fun and funny they were.

A world of pain: Chronic problem orientation

One of the prominent findings of this study was group members' proclivity toward discussing, attempting to deal with, and even creating problems - what I call a chronic problem orientation. Problems included dealing with interpersonal conflicts; dealing with feelings of loneliness, loss and unrequited love; dealing with the fact that others are in pain or potentially in pain; getting basic needs met; physical and health problems; dealing with systems and/or their personnel; and keeping up with normals. Reasons cited for these problems included group dynamics,

dynamics of the activity, researcher influence, my own ignorance, conflicting logics, the memory problem, and the congregation effect. Group members used a variety of techniques to face these problems: confrontation, empathy, identity change, consolation, levelling, avoidance, and rarely, collective action.

An imperfect world: Justice orientation

Another key finding of this study was that group members had a justice orientation, or a proclivity toward showing their concern that all people, especially the disabled, should be treated with respect and care. Group members' understanding of justice, and practice of it to varying degrees, was summarized in Sam's six tenets: empathy, appreciating others' position and ability, willingness to assist others, tolerance, affirmation of people's dignity and respect, and appreciation of diversity. In general, group members spoke of choice as the most important indicator of justice, though group members were split on their understanding of understanding justice, half of them viewing it as a matter of being polite, the other half seeing it as being fair.

An unseeing world: What visibility means

One of group members' dominant traits was the need to be seen, or what I call the drive to visibility. Visibility is defined as both expressive - being oneself fully, openly, and undefensively - and as an act of acceptance - being seen, understood and accepted for who one really is. Group members exhibited four kinds of expressive visibility: unabashedness, openness, self-acceptance and self-assertion. They also exhibited four kinds of acceptance visibility: being noticed, acknowledged, appreciated; being understood; being accepted; and being respected, liked and cared for. Group members experienced invisibility as being ignored, neglected or excluded; being misunderstood or underestimated; being neglected or excluded; and being mistreated or abused. Finally, group members' behavior revealed three different cogenerative relationships: (1) between invisibility and lack of pride, (2) between internalized oppression and internalized domination; and (3) between the invisibility/lack of pride dynamic and the internalized oppression/domination dynamic, as illustrated in Figure 3, Chapter 7.

Discussion of related literature

Explanations for human behavior can be found in the literature for every possible group. However, the literature on PLMRs' behavior is, in the main, restricted to explanations of how PLMRs behave as individuals, either on their own (e.g., self-abusive behavior) or in groups (e.g., families, work situations). Individual and social reasons are given for the causes of their behavior (e.g., family relationships, cultural norms), and analyses exist which explain the social causes of our attitudes toward PLMRs, particularly the work of Goffman, Wolfensberger and others who examine stigma theory and social role devaluation. Explanations are also proffered regarding how PLMRs "absorb" society's negative attitudes toward them through processes such as self-fulfilling prophecy (e.g., Bogdan and Taylor, 1982; Taylor et al, 1992). Finally, there are theories concerning how PLMRs have come to deal with negative attitudes, the two most prominent being the notions of passing (concealing discreditable facts about their identity) and denial (refusing to acknowledge their condition at all) as elaborated by Goffman, Edgerton, and others.

Internalized oppression and social identity

To date there is no literature on the internalized oppression PLMRs experience, or how they experience their oppression as a group. In fact, some writers have noted that PLMRs understandably do not want to be identified with one another and in fact they should be encouraged to pass. For example Edgerton (1967) justifies passing and denial "as much a life and death matter as are the deceptions of a spy behind enemy lines," but that at least benefactors will help them succeed in these stratagems (p. 208).

Hence, the question of how PLMRs think and behave as a group, or what they can do as a group to fight the oppression that they face, is absent. Studies have been done on how PLMRs self-identify as individuals, how they deal with their condition, and how they view other PLMRs (see Social identity theory below). The findings of this study support the positions of other authors that PLMRs are stigmatized (Goffman) and devalued (Wolfensberger), and that measures should be taken to ensure that they are treated with dignity; that to the greatest extent possible they should be given choices about the important areas of their lives such as housing, health, employment, and relationships; and that structures should be changed to ensure that the greatest level of community living and normal, unrestricted environments be made available to them.

However, this study also claims that PLMRs have unique characteristics, however acquired, named, or devalued, and that because they have these characteristics, PLMRs are discriminated against, which, as with other oppressed groups, leads to internalized oppression. Moreover, this study identifies internalized oppression as a powerful motivating force in PLMRs' negative self-concept, and a primary reason they behave the way they do, especially when they act out. Finally, this study isolates the role visibility plays in enabling PLMRs overcome oppression, and the role invisibility plays in causing and reinforcing internalized oppression, especially the fear of being perceived as stupid, the tendency to abuse others ("horizontal violence"), the frequent denial of their mental impairments, their occasional resistance to associating with other people with impairments, and their rejection of a social identity of mental impairment. By understanding their behavior through the lens of internalized oppression, this study shows that they are not only behaving because of some psychological feeling of sadness, inability, or shyness, but also because of internalized feelings of worthlessness and rejection of a positive social identity of impairment, resulting in their inability to accept, feel o.k. about, or even be proud of being a member of the community of PLMRs.

Most of all, this study shows the effectiveness of internalized oppression as an analytical concept as a means of understanding the relationship between group members' understandings and the oppression they experience. This viewpoint highlights the problem of rejection of a social identity of mental impairment, thereby prompting a discussion about what this problem means, and what needs to be done to resolve it.

Visibility

The literature on PLMRs is almost as spare on the subject of visibility as it is on internalized oppression. In the main, as noted in the previous chapter, the subject of visibility refers either to the absence of PLMRs from our view in the media or in public life (e.g., Ruffner, 1984), or their negative portrayal when they are in view (e.g., Gliedman and Roth, 1980; Brolley & Anderson, 1986). This section describes the gap which this study begins to fill concerning PLMRs and visibility.

Visibility as an explanation for positive behavior. This study claims that when group members felt visible, they flourished, or spoke as empowered people and acted proudly, responsibly, and respectfully. Group members flourished when someone recognized something good they had done, when they were being interviewed, especially by audiences and the press, when they were performing the play, and when they felt a sense of belonging (e.g., working, participating in groups or organizations). When these kinds of activities occurred, group members exhibited an increased ability to interact harmoniously with others, to work together and be productive, to associate with people outside the group, to talk about and "own" their situation and condition, to name oppressive realities in the world for PLMRs, and to identify courses of action for change.

The types of activities that made group members flourish can be understood in one of two ways. First, they can be seen as opportunities for integration, an interpretation which the dominates the disabilities literature. According to this interpretation, a variety of services should be proffered to facilitate this integration: job training support, assistance with receiving basic services, access to "normal" community events, help in developing relationships, and the like. While these approaches aim to improve PLMRs' actual living conditions by respecting their individual rights, they ignore the larger issue of what it means to be labeled retarded, and how to deal with this reality.

Alternatively, the above activities can be viewed as opportunities for visibility, suggesting that group members not only had a need to be recognized, but they also had a right to be recognized. This interpretation helps explain why they were so motivated to do the play and tell their story - not just to be included, but to be recognized. This is just the opposite of what Edgerton found in his study - that the two dominant concerns of "expatients" were passing and denial. While group members in this study did engage in passing and denial, some of them frequently, my observation was that in the main, group members seemed more concerned about proclaiming that they had a right to be treated equally, and that they were tired of the kinds of abuse and mistreatment they and other PLMRs had received. Moreover, for some group members, the play was viewed as a way to get this message out. They did not want to pretend they were the same as everyone else; they insisted they were the same as everyone else even though they had handicaps.

The reasons for the discrepancy between Edgerton's study and this one are unclear, though differences between the two studies and the two groups are obvious. First, all of Edgerton's subjects had lived in an institution, whereas only half of this group had. Second, there were no doubt differences between the two institutions that resulted in differences of opinion about treatment there, though the similarities are undoubtedly greater. Third, Edgerton and his team interviewed and observed their subjects; I not only interviewed and observed mine, but also worked with them to develop a musical theater production that gave expression to their views about who they were. I had also worked with them for several years on similar activities, including the Manna Base Community and *Get a Job!*, and I had clearly pushed a critical line of thinking in which reasons for problems and solutions were required as part of the discussion. Finally, in terms of group identities, it is interesting to note that none of Edgerton's subjects reported being religious or going to church. All members of the Friends Support and Action Group (except Janet and me) go to church, a fact that could have implications for their normative view of themselves and the world.

Invisibility as an explanation for negative behavior. This study argues that visibility is a reason for group members' development of a positive self-concept and consequently, positive behavior. Likewise, this study argues that invisibility is one reason for negative or destructive behavior (what I have called acting out). Again, the literature on PLMRs does not identify reasons for negative behavior on the basis of invisibility, but as a result of personal idiosyncracies of group members, physiological reasons (e.g., medical conditions), lack of choice group members experienced in their lives, ostracism, difficult situations that PLMRs perceive to be threatening or unmanageable, mistreatment or abuse they have received at home, in the community, or in institutions, and the like. Group members' explanations and behavior in this study corroborated all these factors. In particular, it seemed that group members most often acted out in response to facilitators'' mistakes: when Janet and I had insufficiently prepared for a meeting or rehearsal, when handled a difficult situation in the group poorly, or when we attempted to do something that was too threatening or difficult.

However, many examples group members gave of times they had acted out, as well as incidents I observed in this project, clearly illustrated the fact that when group members felt invisible, their behavior usually took a turn for the worse.

This study also illustrates the link between invisibility and lack of pride, and how a feeling of invisibility could lead to a feeling of lack of pride or self-worth (internalized oppression) which in turn at times led to internalized domination (horizontal violence). This formulation differs from traditional explanations of PLMRs' negative behavior, summarized in Table 6:

Table 6
Traditional problem/solution strategies for PLMRs

PROBLEM	SOLUTION
1. Individual personality traits	- various techniques: behavior modification, normalization, etc.
2. Retarded people are naturally given to outbreaks	- various techniques: behavior modification, normalization, etc.
3. Inappropriate treatment or medication	- change the treatment
4. Congregation effect (too many PLMRs in one setting)	- community integration; mixing with normals for modeling, friendship
5. Restrictive/abusive environments	- least restrictive environment legislation, deinstitutionalization, community integration, legislation to outlaw abuse

This study offers a sixth formulation: if PLMRs are feeling invisible, then provide opportunities for visibility by establishing and maintaining an atmosphere of safety, support and caring, and by structuring opportunities to be seen. In this way, forces of caring can be seen as forces of visibility and, as a corollary, forces of liberation (see Figure 3, Chapter 7).

Social identity

Perhaps the biggest conclusion to come out of this study is the fact that group members' manifestation of internalized oppression points to the deeper problem of stigma attached to PLMRs. That is, for both individual and social reasons, it is extremely difficult, if not impossible, to embrace the fact that one has a mental impairment, much less feel o.k. about it. This bind leaves PLMRs with the following problems.

Retardation and identity crisis.

> For most parents, the day they learn the diagnosis of mental retardation for their infant or toddler is probably one of the most devastating days of their lives (McGarrity, 1993:77).

What is it about mental retardation that makes it so horrible, so unspeakable, so stigmatizing? Will people with mental impairments ever be able to accept their condition? This, my view, is the most important question to come out of this study. Perhaps the best way to answer this question is to first consider the impediments to having a healthy sense of self as a PLMR.

First, the definition of people with mental retardation has made it all but impossible for them to accept that designation. People involved in studies by Edgerton and Gibbons, as well as this study, have justifiably repudiated the label "retarded."

Second, PLMR live with a constant fear that somehow their condition will "spread," either by their being identified with other PLMRs, which will result in their devaluation, or in their being unable to help other PLMRs, making them feel more disabled themselves. Goffman described both of these phenomena as typical of stigmatized people: "In general, the tendency for a stigma to spread from the stigmatized individual to his close connections provides a reason why such relations tend either to be avoided or to be terminated, where existing" (p. 31). In this study, Kim reported having both feelings, and others suggested the same. However, group members never exhibited an unwillingness to work with members of this group, or to be associated with them. To whom this phenomenon applies, then, is based on particular conditions.

Third, PLMRs are often encouraged to pass or deny their condition. This encouragement most often comes from what Edgerton calls "benefactors" (Edgerton, 1967), or people on whom PLMRs rely in order to pass, as well as to receive help with transportation, communication with agencies, reading pertinent documents, etc. Benefactors can be agency workers, friends, family members, employers. While these relationships are a source of great joy for many PLMRs, as well as their benefactors, these relationships also reinforce the fact that because of their condition, PLMRs are and will always be dependent on others.

Finally, PLMRs are suffering an identity crisis: at best, they are confused about their identity and at worst, they truly believe that they are worthless. This should come as no surprise given treatment most PLMRs have endured. In this study, Charles once commented that living at Glenview had been like living in a prison - a sentence for a crime he never committed. Kim said having to live by rigid rules in a group home, such as the requirement to get permission from house staff before friends could come over, made her feel "stupid." Edgerton notes that the experience of institutionalization left the expatients in his study "without privacy, without clear identity, without autonomy of action, without relatives, friends, or family, in a regimented and impersonal institution where everything combines to inform him that he is, in fact, mentally inadequate" (p. 146). Unfortunately, the sources of this identity confusion go beyond institutionalization. Even if they are not institutionalized, people who are labeled retarded are reminded throughout their lives that they are people, yet should not expect access to the same basic opportunities as everyone else. Friends and family members often downplay their differences, yet cannot really treat them as normals. Normalization/SRV, the dominant theory guiding human services practices for PLMRs in the U.S., makes no provision for retarded people to deal with their retardation and, in fact, by encouraging them to "walk with a gait," is in effect asking them to "buy into" the dominant view of mental retardation rather than develop their own understanding of their experience.[1] In community life, at work, on television and in movies, PLMRs see people falling in love, raising families, buying houses, driving cars, yet are discouraged or even prevented from doing these things themselves. No wonder one researcher involved in sex counseling for the developmentally disabled at York Central Hospital commented: "Many individuals show a disturbance in

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[1] See Chapter 4 for a discussion of the parallels between liberal feminism and normalization/SRV.

their self-concept. We find that clients reveal not so much a poor self-concept, but a confused concept" (cited in McGarrity 1993:179).

Of course, self-concept is not only a matter of individual identity, but group identity as well. Yet PLMRs in the main do not identify as members of the disabled community, much less a community of mentally impaired people. Nor are they encouraged to. The system is designed to treat them not as members of a group, but as individuals. PLMRs have individual case workers, Individual Service Plans, for those in school, Individual Educational Plans. When they are being referred to in the third person, the term of choice is "these individuals." They are given individual choices, receive benefits as individuals, have individual Confidential Files in their agencies. In the interest of community integration, it almost seems that the system has atomized the PLMR population, sending them out into the community as so many individuals forever severed from those with whom many of them have grown up, with whom they have lived, worked, even identified. They are constantly encouraged to become involved with community activities, even to become members of self-advocacy groups and other PLMR-specific organizations. Yet the emphasis is clearly to integrate them with normals, which often means to separate them from one another.

The tendency of the system to treat PLMRs as individuals carries an additional danger. In Blaming the victim (1976), Ryan explains that reality is systematically distorted when "exceptionalistic" solutions are applied to "universalistic" problems. By implying that the problems of PLMRs are unique, the system justifies a division between people. "Inequality can be justified when we insist that human beings are internally different and that these internal differences justify differential rewards to individuals deemed superior" (p. 303). Mead (1934) argues, on the other hand, that if we applied universalistic solutions to problems, humankind would be perceived as a social entity responding to the material world around them. In effect, people would recognize the role of systems in the creation and maintenance of individual problems (Barry, 1987:36). The individualistic focus of the system, then, not only separates PLMRs from one another and discourages them from identifying individually or socially as impaired, it also hinders their ability to view the system as a whole, and their problem not as exceptional but universal, shared in some ways by normals as well, thereby justifying an inequitable system of treatment.

Social identity theory. In response to the identity crisis faced by PLMRs, some researchers have set out to discover how retarded people experience their retardation, how they deal with it, and what the chances are of their accepting it. Szivos and Griffiths, for example, have made an effort to explore "the subjective quality of the individual's experience or, indeed, to the individual as a feeling, sensate, being" (Szivos & Griffiths, 1990:334). Their research, based on the premise of social identity theory as elaborated by Tajfel (1981), proposes that

> disadvantaged group members have two main options when they cannot leave the group that is the source of the disadvantage. The first is to assimilate or to pass into the mainstream group, which has several unpleasant psychological consequences, such as disaffiliation from one's group, guilt, and derogation . . . . The second opinion is to attempt to construct a positive identity based on being different (Szivos and Griffiths 1990:333).

In their study of seven retarded adults over a 13-week period, Szivos and Griffiths used a self-esteem group model to explore the ways in which the ideas of consciousness raising (following the ideas of the feminist consciousness-raising movement) and loss (following the ideas of Kubler-Ross) are applicable to mental retardation. In particular, they wanted to find out whether it is possible, on the one hand, to forge a positive group identity and on the other, to "accept" the handicap. They found that the closest group members had come to acceptance was what they called "compensatory acceptance" (e.g., "At least one person loved me better for being as I am") or "comparative acceptance" (e.g., "I could have been worse, like some others")(p. 338). In terms of group identity, Szivos and Griffiths found that group members shared a "strong in-group affiliation" with other members, but this affiliation was limited, as evidenced by the fact that some group members took the opportunity to make downward comparisons: "handicapped people," or those with visible physical disabilities or severe cognitive deficits, were rejected by some group members. This last finding led Szivos and Griffiths to conclude that "the goal of the consciousness raising paradigm has questionable relevance to this group as they were not able to generate a strong and positive group identity," raising the question of what practitioners working with clients with mental retardation should aim for when addressing the problem of stigma management (p. 340).

These findings parallel Gibbons' findings that retarded people both in the community and institutions had a negative group concept, and that downward comparison might be a part of that negative concept. He concluded that their negative group concept "interferes with normal social interaction and inhibit romantic relationships among retarded persons, then it is likely to make adjustment to their environments - no matter how independent or nonrestrictive - much more difficult" (Gibbons, 1985:106).

These two studies illustrate two points that had previously been unaddressed in the literature. First, the self-concept of retarded people (as with all people) is directly related to their group concept - that if their group concept is negative, so most likely is their concept of themselves, or at least confused. Second, people's negative views about their groups indicate that developing a positive group identity might be difficult, if not impossible, and that even the most nonrestrictive environments cannot overcome the social and psychological barriers to acceptance of self and other.

<u>The case for a positive identity for retarded people</u>. The studies of Szivos and Griffiths, and Gibbons, as well as this study, raise important questions about how positive identity, both individual and group, is built, how it is built, whether it even can be built, and what the consequences of negative identity might be. Throughout the literature, the assumption around the identity of mentally retarded people is overwhelmingly negative. Edgerton (1967) maintains that expecting retarded people to have a positive identity, to be proud of who they are, is impossible since their condition is so undesirable, and that society's role should be to help them pass as a way of dealing with their condition. Szivos and Griffiths (1990) are not optimistic, either. Noting that no one as yet has devised a suitable analogy to the "Black is Beautiful" or "It's great to be gay" slogans, they ask whether "acceptance" is every completely possible for anyone with mental retardation, at least anyone who understands the stigma attached to the description.

This group's experience of developing <u>Special</u> seems to take this discussion in a different direction. Among their many motivations was an abiding interest to become visible, to present themselves to the world with the message, as Kim puts it, "This is who we are, accept us for who we are."

In contrast to Szivos and Griffiths' study, group members in this study never engaged in downward comparison; nor did they ever reject someone because they perceived that person to be inferior.

On the other hand, group members in this study never, in my opinion, fully accepted any designation of their mental impairment. Nor did they ever identify with a larger group, other than occasionally talking about the rights of disabled people in general, or groups they belonged to such as the Open Door Club.

What, then, are the prospects of group members' developing a positive social identity of mental retardation? Perhaps another way to put this is: What's so great about being mentally retarded (not just being labeled retarded, but having cognitive impairments)? I believe a case can be made that a positive identity, both personal and group, can be achieved amongst people with disabilities, including people with mental impairments. For I have observed several reasons for group members to be proud: their ability to care for one another, the value they place on friendship and community, their exuberance and ability to enjoy one another and the world, their ability to survive in the face of traumatic life experiences, their ability to learn, change and grow in the face of formidable obstacles, and their ability to name injustices and articulate how the world should be.

Of course, only PLMRs can decide what's so great about being a PLMR. In the end, however, if they decide, as Edgerton and others have, that it is only stigmatizing and the best that can be hoped for is successful passing and denial, then the question arises: Will they ever be able to work toward solidarity with one another and alliance with other groups? This question, of course, implies an antecedent question: Is pride in one's social identity, one's group, one's heritage, necessary in order to overcome oppression?

PLMRs and oppression theory: What role pride? Most oppression theories and identity-development theories require that people pass through a stage of pride - in themselves as individuals, in their identity as part of a group, and in the case of oppressed people, in the heritage of their group as valid and noble - in order to become mature, happy or empowered. It appears that with the case of mental retardation, the expectation that oppressed people feel a sense of pride in their group and their heritage is problematic, perhaps impossible, even cruel.

I asked group members if they were proud to be disabled. They looked at me like I had three eyes. I invoked the example of the Civil Rights Movement and the importance of blacks defining themselves as black and beautiful. Without this kind of identification, I argued, African Americans would not have had a group to identify with and therefore gain power, nor would they have had the possibility of becoming proud of who they were - a necessary ingredient, I thought, in the movement toward gaining power. "Well, disabled people have marched in Washington, too," George responded. "And President Bush just signed that big bill, what was it called?"

"The American Disabilities Act of 1991," I said.

"Yeah, that's it."

George and other group members were not ignorant of events that have helped the cause of disabled people. Yet the parallels between the efforts of disabled groups and other oppressed groups is unclear to them, and seems problematic to me as well.

Disability is inherently undesirable. Unlike other oppressed groups, there are no ethnic markings which make it easy to identify disabled people. There is no unifying historical phenomenon such as slavery upon which to build a group identity. Most of all, for PLMRs, there is no chance that they can learn the dominant discourse, as members of other oppressed groups can. As a consequence, PLMRs will never be able to successfully compete in the "normal" games of capitalist production, bureaucratic administration, or intellectual persuasion. Hence the Special Olympics, Special Education, sheltered workshops, etc.

Is it possible for PLMRs to sidestep the usual patterns of empowerment and find a more direct way to get recognition regardless of what mainstream society thinks of them? And should pride play a role in this process? Sadly, the literature offers few reasons to celebrate being a PLMR. The issue of pride seems a distant one; the implication is that everyone agrees being a PLMR is unfortunate because mental retardation is unfortunate. Consequently, our task is not to try to appreciate being a PLMR, but to make the best of it.

Proud because of, or in spite of? In the case of PLMRs, it seems that if there is any hope in trying to gain a sense of pride, it is pride in spite of who one is, not because of who one is. This study shows that these PLMRs do have reasons to feel proud, in particular their ability to care for one another, the value they place on friendship and community, their exuberance and ability to enjoy one another and the world, their ability to survive in the face of traumatic life experiences, and their ability to name injustices and articulate how the world should be. Based on this observation, it is the conclusion of this study that PLMRs have unique and positive personal attributes that should be recognized and celebrated, and that they should be proud because of, not in spite of, who they are.

Criticisms of *Special*

Over the course of producing and performing the play, several people observed that this model of working with PLMRs had problems. Descriptions of these critiques follow.

A question of standards

A year after developing *Special*, we were asked to perform it on a professional stage to help an advocacy organization celebrate its 40th anniversary. Janet, who had helped develop the show, could not participate in this showing, but came to view it, for the first time as a spectator. Her response was that the show had worked well in the context of the community from which it emerged, where cast members had performed before their friends, family and community with such delight. On the professional stage, they appeared nervous, the seems seemed a bit juvenile, and that it was unclear how people in the audience, not being friends or family, were responding. Janet's fear was that as a tool of advocacy, *Special* could do much better outside the community in workshop format, but that the full show was not and never really had been up to "professional" standards. Hence, it might send the exact opposite message that we were intending - that in fact, PLMRs cannot perform such a show as competently as normals.

Two other people associated with me and the cast voiced similar feelings. On opening night of the first set of performances, one person commented that it felt like "an amateur picture inside a pretty frame," evidently referring to the fact that in spite of the professional lighting, sound system and artistic stage design, the group was trying to achieve something they could not achieve. Another person stated that the show illustrated the difficulties PLMRs have with such types of activities, especially in terms of memory, ability to sing well, stay in character, etc., and that perhaps they should do a film instead.

In response to these types of concerns, a friend and I developed an evaluation form that specifically addressed the problem of perpetuating stereotypes as a result of this play, and administered it at a showing at which more than 100 people were in attendance. Of the evaluations returned, many noted what worked and what didn't, as the evaluation form requested, but from a theatrical point of view. Only one challenged the issue of reinforcing stereotypes. It was filled out by Bill, Kim's friend who had discouraged her from taking the Special bus in the beginning (see <u>The bus incident</u>, Chapter 7). In his evaluation, he commented that he feared certain ideas or portrayals could lead to stereotyping. My friend who had helped me develop the evaluation form noted that comments like these always seemed to imply that the danger lay not with the commentator having stereotypes reinforced, but that the commentator feared that stereotypes would be reinforced for others. Yet others did not seem to emerge. From the evaluations taken on the first two nights as well as the following year, audience members indicated that what impressed them most was the way in which *Special* had demystified disability for them. Some commented that they were amazed at what these people could do. Others commented that at the beginning of the show they had felt some reluctance in their ability to identify with cast members, but by the end of the show, they felt like the cast members were real people, able to be approached like anyone else.

So even though the criticisms of *Special* do not reflect the majority of audience members' opinions, at least as represented in evaluation forms and face-to-face contact, they do raise two important questions. First, when someone claims that an event risks hurting others (e.g., reinforcing stereotypes), how are we to know that this in fact is the case? The criticisms made by Janet and others are empirical (i.e., a leads to b in the general population), yet were supported theoretically. For example, one person implied that asking PLMRs to perform in a way that highlights their handicaps runs against normalization theory and therefore should be avoided. It seems to me that if this claim is to be taken seriously, being an empirical claim, it should be empirically tested. Our evaluation was an attempt to do this, but of course one could argue that self-reporting is not a reliable way to find out if stereotypes were reinforced. Short of conducting more ethnographic and phenomenological research, I am not sure how else to find this out.

The second question raised by these criticisms has to do with the question of standards. Of course, not all theater can be judged by the same criteria; community theater was never intended to meet Broadway specifications, nor should it try. But the problem here is different. If theater as we know it requires skills that PLMRs generally do not have, and never will have, then how can they ever hope to do it well? Put this way, of course they will never be able to. The problems of memory, psycho-motor coordination, ability to concentrate, reading, and understanding abstract concepts will not go away and, as a consequence, theater by PLMRs will always be affected by this. However, the ability some have to improvise, to sing, to harmonize, to dance, to candidly talk about their lives, and to come up with zany, entertaining ideas cannot be discounted.

What must be considered, it seems to me, is the question of format. *Special* raises the possibility of considering theater as a different kind of experience, one in which actors' portrayal of characters is not dependent on pre-memorized lines, and one in which the kinds of quality one ordinarily looks for in singing, dancing and acting might be absent. *Special* raises the possibility that perhaps there are other standards of quality that audience members can look for. I would propose two: One, that any production created by a group of disenfranchised people is an act of power on their part and therefore worthy of attention. Two, that the messages that are likely to come out of this kind of production might not be readily discernible, but are nevertheless there and worth working to try to understand. This second point has been reinforced for me by the fact that *Special* has been well attended and loved by other PLMRs. Some kind of important meaning is passing from the cast to these audience members - a meaning which many normals (including myself) no doubt miss, but might do well to try to understand.

The need for integration: A normalization advocate critiques *Special*

The woman noted above who advocated normalization theory also criticized *Special* for the process we had followed. She argued that having so many disabled people congregated for long periods of time, working on issues that were obviously so painful to them, was why we had some of the interpersonal problems within the group that we did. In fact, after seeing the play, she went so far as to write a letter to the group (see Appendix B) stating her objections to the play, claiming that the process would have been richer for everybody had there been more of a mix of disabled and nondisabled people from the beginning - richer meaning that group members would have had more opportunities to befriend nondisabled people, thereby becoming more integrated into the community, more "normalized." This suggestion is also consistent with the normalization tenet that whenever possible, PLMRs should be mixed with normals to provide them with opportunities for modelling - that is, to learn how to interact more like normals.

It is difficult to respond to these criticisms without also taking to task the basic tenets of normalization theory upon which they are founded. For the purposes of this dissertation, however, what is relevant here are the issues raised by these criticisms vis-a-vis internalized oppression, visibility, and social identity. By starting from a premise of normalization, this woman believes that the most direct route to eliminating prejudice against PLMRs is to expand their opportunities for being with normals and living like normals as much as possible, and to raise the awareness of normals that PLMRs are capable of living normal lives like everyone else. The argument made by this dissertation is that internalized oppression is a serious cause of pain and negative behavior for this group, and that the cultivation of a positive social identity would go a long way toward reversing this oppression. Though details of how to do this are unclear, what is intriguing is that, in some ways, the play performed both functions of normalization and providing opportunities for visibility through increased contact with normals (stage hands, musicians, lighting and video people, artists, publicity people, assistants) and through increased access to "normalizing" experiences (conducting interviews, doing the play). Nevertheless, theories such as normalization do advocate that the social identity of being a PLMR should be ignored. This study shows that denying this identity and access to opportunities that might construct or reinforce it is likely to have damaging consequences for PLMRs struggling with the right to be visible.

In response to the infantilization argument, while I agree that stereotyping should be avoided, I also know that PLMRs simply do come off sometimes like children and, moreover, they are often having fun while doing it. When I have seen this phenomenon, I have asked myself: Should I discourage this behavior? (A friend of mine who works in the human services industry once commented that walking arm-in-arm with PLMRs is discouraged by some agencies, and that seeing me do this with group members put her in a quandary as to how she should behave when she was with us.) Of course, if I knew it was confirming negative stereotypes in the minds of the general public, I would discourage it and, in fact, I have recommended against certain ideas - for example, singing "childish" songs - for that very reason. But I have come to believe that it is not my place to tell other people, especially oppressed people, how to behave, even if I think it is in their best interests. On the contrary, that the burden is on _me_ to learn to understand their behavior perhaps not as _childish_, but _childlike_ - joyful, fresh, innocent, things that many adults have tragically forgotten. For in fact, I see them as double people - children and adults - and one of the great challenges in this work for me has been to constantly struggle with the tension between the two, knowing that I will never finally "figure it out." But neither would it be fair or productive for me to try to squash that which is beautiful in them by attempting to reduce them either to children or adults.

Other issues

Other issues arose in the development of *Special*, some of which are described below.

What group members learned: Participatory research as a means of conducting research and education with PLMRs

Participatory research is an approach to social change that enables people to conduct research and education (i.e., generate knowledge) about the oppressive circumstances of their lives, and to take action to change those circumstances (Hall, 1978). This study raises the question as to the success of *Special* as a technique of participatory research, and in particular, its usefulness as a research and education tool with PLMRs.

In examining the kinds of research and education processes and outcomes of this project, I have found it useful to consider Habermas' notion of three kinds of knowledge. According to Habermas (1971), humankind has three interests: an interest in achieving technical control of the natural world, an interest in mutual understanding, and an interest in self-emancipation. Correspondingly, there are three forms of knowledge which help us develop those interests: empirical/analytical, historical/hermeneutical, and emancipatory, or what Park calls instrumental, relational, and critical (Park, 1993, 1989). Instrumental knowledge denotes a "means-end" kind of thought - which processes will lead to which outcomes, which products will produce which results. It is the knowledge of prediction and control, an essential type of knowledge if we are to have any degree of control over our lives. Relational knowledge denotes a communal kind of thought - what is important to whom, how people are doing, who is in love or at odds with whom, what elements are building up or tearing down the community. It is the knowledge of caring, an essential type of knowledge for building and maintaining community and human relationships. Critical knowledge denotes a values-based kind of thought - what is right and wrong, what is socially just, what should be done for the good of all people. It is the knowledge of moral judgment, an essential type of knowledge for guiding thoughts and actions so that society's efforts might be directed not only toward what is expedient (instrumental) or helpful for certain communities (relational) but what builds dignity, respect, and self-determination for all people.

When using Habermas' notion of three kinds of knowledge, several educational outcomes become apparent. For example, group members acquired a great deal of instrumental knowledge in the development of *Special* by learning how to develop a play, design and conduct interviews, deal with group process issues, and "name" certain realities (e.g., oppression). They had also learned more about how the world works, especially in the state school, group homes, and agencies. And they all had learned and shared with the community what they knew about the technical abilities of disabled people - that is, that they can create and perform musical theater, they can conduct research, and they can express themselves on these matters succinctly.

Group members also acquired relational knowledge. They had learned things about cast members that none of them had known before though many had been friends all of their lives. They learned about the importance of solidarity, both amongst group members and with people who are faced with similar difficulties, such as people in group homes. Group members had also learned about how to create, understand and articulate the knowledge and experiences of disabled to people to the broader community, and to educate the community about how to be in relationship with people with different types of disabilities and life situations.

Group members also acquired critical knowledge in the development of *Special*. From discussions about how oppression works to how the world should be, from how discrimination works in specific sites (e.g., group homes) to how to be an ally of the disabled, group members talked about systemic injustices, possible causes and solutions, and to include these observations in the play. For example, Kim expressed a continuing interest in educating others about things she and other group members had learned and come to believe:

> I think where if anybody needs another group home or people who are in group homes, we should go and educate them by saying let other people (i.e., residents) tell you what to do for them, don't do it for them. I mean, don't take over their life. Where other people try to do that and that's where it's wrong, and when because everything's run by the state. Granted uh, when they're in programs and stuff, it's mandated by the state to do what they need for a group home but I still don't think the staff should tell the people what to do, it should be the other way around. And that's one point where I would like to go around and educate the, educate the public about it.

Special had also produced evidence that audience members had learned on various levels as well. One audience member reported that having seen the play "they became integrated into my life in a way that was not possible before the play." Others commented on their surprise at the fact that disabled people could produce such a show, and that certain members were so skilled. Some commented on the fact that they hadn't known that conditions in group homes were so bad, and hoped some kind of action would follow.

What group members did: Participatory research as a means of moving to action with PLMRs

As a participatory research project, *Special* included a component of action: the actual performance of the play. Additionally, group members took several types of action the course of developing both *Get a Job!* and *Special*. While we were developing *Get a Job!*, several group members assisted Kim in confronting a Department of Mental Health official in order to secure job training money. With the money earned from *Get a Job!* the group opening a savings account to establish a revolving loan system for group members. Since our first performance of *Special*, the group members have continued to develop and perform the play, earn money from it, make decisions on how to spend it, even negotiate with sponsors. In one case, they confronted a sponsor in order to demand fair payment for a performance. Kim began asking agency staff to call her by name instead of saying "Dr. so and so, your client is her" whenever she had an appointment.

These actions have represented great strides and, in some cases, tangible benefits for group members. However, when one considers the fact that one of the goals of participatory research is to bring about both material and structural change, these actions begin to appear somewhat limited in scope. In attempting to understand how they were limited, I developed the following table:

Table 7
Four kinds of action in participatory research[2]
and examples from Special

	TYPES OF CHANGE	
TYPES OF HELP	CHANGING MATERIAL CONDITIONS AND/OR ATTITUDES (E.G., EDUCATION PROJECTS, ADVOCACY, GROUP PURCHASES, FORMATION OF COOPERATIVES, ETC.)	CHANGING STRUCTURES (E.G., POLICIES, PRACTICES, LAWS)
HELPING SELVES	1. Personal/group, immediate - participating in base community - confronting a DMH official to help Kim get money for job training - group opening a savings account - confronting sponsoring agency on fair payment	3. Personal/group, long-term - Kim getting agency personnel to call her by name
HELPING OTHERS	2. Public, immediate - conducting interviews on issues of deinstitutionalized people - performing play on ablism	4. Public, long-term - none

Going down on the continuum from helping selves to helping others, action becomes increasingly public. Thus,

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[2] At first glance this table might appear confusing because it conflates material and attitudinal change, and because it conflates personal and group types of help. In fact, these ideas could be broken down further, separating material, attitudinal and structural, for example, or help for individual, group, and others. While such a breakdown might be useful for other purposes, this table is designed to illustrate what kinds of action the Friends Support and Action Group have taken to date, what more long-term and public forms of action might look like, why we did not move in those directions, and what might make this kind of action possible in the future. My thanks to Francis Bailey for pointing this confusion out.

the Friends Support and Action Group, having started with formation of the base community and taken action to advocate for group members and the group as a whole, eventually became more public in its presentation of theatrical productions and implementation of its interview project.

Going across the continuum from material conditions and attitudes to structures, action becomes increasingly long-term. Thus, Kim's insistence that agency staff refer to her by name required a willingness on her part to fight this problem over time. The need to apply oneself "for the long haul," as Myles Horton put it, is even more important with quadrant 4 - long-term structural change type activities, such as those undertaken by people involved in the Appalachian Land Study (Gaventa & Horton, 1981) and others.

Proceeding from quadrants 1 to 4, action becomes increasingly long-term and public - a prerequisite for bringing about structural change. Immediate action (quadrants 1 and 2) is likely to be more "project-oriented" (e.g., clean-up campaigns, sewing cooperatives, theater projects) whereas long-term action (quadrants 3 and 4) is likely to be more confrontive or "protest-oriented" (e.g., letter writing, press conferences, civil disobedience). The move from immediate to long-term action, then, is not simply a matter of making a commitment for a longer period, but also making a commitment to the kind of "protest-oriented" work that is usually required to transform structures.

Moreover, there seem to be two types of motivation at work. In the movement toward more long-term action in this study, Kim was motivated by a sense of urgency or frustration on the part of the actor; Kim finally reached the point where she felt she could no longer stand being called client, so she acted to change the situation. In the movement toward more public action in this study, people seem to be motivated by a desire to have justice done. One night before we took the stage, Charles said "Let's not go out yet."

"Why not?" I asked. It was already 7:30.

"The place isn't full yet," Charles said. "How many does it hold?"

"400," I responded, "but we sold 200 tickets in advance. I think this is the best we're gonna do tonight."

"This place should be packed," he retorted.

In this case, Charles' interest in taking public action seemed to be rooted in his desire to get message out. Similarly, in the literature, when people talk of taking more public action, whether it be changing material conditions, attitudes, or structures affecting others, they seem to be moved by a desire to have justice done.

Finally, group members in this study only moved to more public and long-term types of action when they felt capable of doing so. That is, empowerment is a prerequisite for any kind of movement toward transformative change. Group members only felt they could confront the sponsoring agency on fees for the play once they felt capable of doing so - a feeling that had grown out of the work they had done as a group. Kim claimed that after waking up singing "Can you see the real me?" to herself. The use of the word client was not even talked about as a problem by group members until Dean, an interviewee in the project, urged Kim to stop using the word. After that interview, Kim and others brought up the word on a regular basis as a point of dissatisfaction. After doing the play, she decided to seek a change in the agency. This table, then, illustrates not only the types of action people take in moving toward transformative change, but the roles urgency, justice, and empowerment play in that movement.

Given the goal of participatory research to bring about long-term structural change, this table also raises an important question: Why did FSAG not take any form of long-term public action (quadrant 4)? Given the types of problems raised by the FSAG in this project, particularly the types of discrimination and invisibility faced by PLMRs, this seems odd.

I believe there are two reasons. The first was my own ignorance. I was unaware of the overwhelming influence of fear and internalized oppression on how group members behaved and understood events in this project. In response to this factor as I now understand it, and would approach this kind of project in the future differently. First, I would provide the group with more group dynamics experiences to get them to learn how to confront each other, take feedback, and deal with conflicts productively. Second, I would gear exercises toward dealing with fear of normals. For example, I would structure time with group members to examine why they got nervous when they interviewed people, how in their discourse style some interviewees dominated their interviews, how to deal with big words, confusing ideas, etc. Third, I would introduce more normals to the group, at least for general group time, thought actual creation of the play would still be the domain of group members. Finally, having secured the help of other normals, I would focus on problems group members share as PLMRs, teaching them how the system creates those problems, and proposing ideas for long-term public activities. These ideas could be proposed by visiting other self-advocacy groups, visiting state representatives to discuss the status of current legislation affecting PLMRs, inviting guest speakers to talk to group members about issues in deinstitutionalization and what they can do about it as a group, or even going to press conferences on other issues to see if group members had ideas about how to do a press conference ourselves.

In developing this analysis, I realize that much of my attention during this project was fixed on the development of the play, and that I didn't know myself what kind of action I was looking for, beyond actually performing the play. Simply developing this 4-quadrant framework helps me understand how far we got, and what might be needed to continue if long-term public action is a goal we all share.First, both the group and I lacked the impetus to move toward long-term public action. I am not sure why we lacked the impetus, though developing and performing the play posed a sufficiently huge challenge for us. Group members did come up with suggestions for long-term public action - for example, collectively doing evaluations in group homes and attempting to change group home policies based on our findings. But because group members rarely followed up on these ideas, I believed we would only act on them if I was willing to play the role of primary organizer. Give the demands of the play, I was unable to do this. I also know that in order to take on any long-term public action, we would have had to involve more normals in the project because of group members' extraordinary needs as PLMRs (transportation, communication, etc.). This I also did not have the time to do.

The second reason I believe our project did not include long-term public action was because both the group and I lacked the impetus to develop long-term public action. I am not sure why we lacked the impetus, though developing and performing the play posed a sufficiently huge challenge for us. Group members did come up with suggestions for quadrant 4: collectively doing evaluations in group homes and attempting to change group home policies based on our findings. But because group members rarely followed up on these ideas, I believe we would only have acted on them if I had pushed for them and been the primary organizer behind them. Give the demands of the play, I was unable to do this. I also know that in order to take on protest-type activities, we would have had to involve more normals in the project because of group members' extraordinary needs as PLMRs. This I also did not have the time to do. Of course, this entire explanation would be different if we had felt a sufficient level of urgency or frustration to move to more public action. If, for example, the state decided to reinstitutionalize former residents of Glenview State School (half of our group), this would have been a different conversation!

How group members changed: Participatory research as a tool of empowerment

Of course, taking action was possible at all because of the kinds of empowerment group members experienced, not only in the development of *Special,* but since the base community days. Comments by friends, audience and community members tell part of the story:

Friend: George has so much more confidence since he's been in your group.

An agency worker: Marcia and Susan have been so happy since they've been in the play. They have something to do, something to look forward to.

The hosting minister: After doing this play, you can just see them open up and flower, just like a flower in the spring, with all the beauty and love they have to offer.

Alex, the agency worker for six group members: Since doing the play, Sam has become more inquisitive about things. Like when there's a bus taking people places, he talks about the Special Bus, why people ride on it.

Audience member: You all support each other so well.

Special videographer: I see George at the mall and he asks me for dating advice. I know Kim is working now, and you know that has a lot to do with her self-confidence, her work in the play."

While these comments speak to the kinds of changes others have seen in the group, the following description speaks to the kinds of changes I have seen in one group member - Sam. When I met Sam, he was already a self-possessed, intelligent, and witty person, able to talk about current events, personal issues, or his latest passion, usually some composer (now I think it's Tchaikovsky). Yet as I got to know Sam, I realized he, like all of us, had issues. A year prior to doing *Special* Sam had run up a $5,000 telephone bill calling 900 sex-line numbers. When we began exploring this habit in role plays, Sam insisted on not actually doing this in the play. In time, we came up with words that fit his story using the melody from the song

"Under the Boardwalk." Over the ensuing months, he reported that he had voluntarily put a block on his line so he couldn't call the 900 numbers, and his desire to call them was decreasing. About half-way through the project, Sam became more at-ease with the prospect of poking fun at his 900 number calling days, and urged us to do the song, which eventually became his favorite in the play. After we performed the play, he reflected on the changes he had gone through over the course of developing the play, realizing that while he still sometimes had the urge, for the most part his phone calling days were behind him and he could "come out" and have some fun with it in front of an audience. In one interview, Sam claimed this "more assertive" self was "the real him," and that in the past he had been unable to be so assertive:

> I don't think that was the real me back then (when I was younger) because I think the real person kind of like uh would speak up and know what they would want for a job know that they would want different things and not the same old thing. And I think that if I had had the opportunity to be with people that taught me how to be more assertive, I think I certainly would do it. But I, you know, I wasn't, and so as a result of it uh, you know that's why I didn't start working until probably later on, you know a real job, like 37 . . ."

After working on *Get a Job!* and *Special,* Sam claimed he had become more aware of the importance of "having his life together," which for him included keeping his house cleaner, being able to invite people over for dinner, attempting to play a lead role in making peace in the group whenever possible (Sam has a poster of Gandhi hanging on his living room wall). He also claimed that

> I think we've come a long ways uh, you know when we talk about now how we like to be treated equal, I think we do it to each other, I think for the most part. I think there was a time where we used to, mind you and I say used to have trouble with that, and I think we've come a long ways where we support each other . . . . "

PLMRs and critical pedagogy: What role analysis?

One of the key tenets of critical pedagogy as proffered by Paulo Freire is the importance of reflection and critical analysis in bringing about transformative action:

> As long as the oppressed remain unaware of the causes of their condition, they fatalistically "accept" their exploitation. Further, they are apt to react in a passive and alienated manner when confronted with the necessity to struggle for their freedom and self-affirmation. . . . It is only when the oppressed find the oppressor out and become involved in the organized struggle for their liberation that they begin to believe in themselves. This discovery cannot be purely intellectual but must involve action; nor can it be limited to mere activism, but must include serious reflection: only then will it be a praxis (Freire 1971:52,51) .

Given group members' cognitive impairments, Freire's call to "serious reflection" and praxis appears to be problematic. Serious reflection usually involves certain basic skills: the ability to articulate oneself verbally, the ability to read, write, and remember things, and at the very least, the ability to think abstractly. Yet it is these very skills that PLMRs by definition lack and will probably never be able to develop. This not to say that group members were unable to reflect seriously, or that they were unable to analyze certain situations critically, only that the importance normally attached to "serious reflection" perhaps needs to be rethought. Is such cogitation necessary? I am not convinced that Kim understood the causes of her exploitation, yet her frustration with the system, born out of organized struggle of a sort, proved sufficient to move her to transformative action when she insisted that they stop calling her client. Moreover, even if her frustration had not been sufficient, what kind of failure are we dooming PLMRs to if we are requiring "serious reflection" and praxis as part of their liberation?

Perhaps the definition of serious reflection and praxis need to be rethought in light of this problem. For in spite of their cognitive limitations, group members were able to name injustices, reasons for them, and appropriate courses of action. Of course, their ability to comprehend the details were limited, but this limitation did not prevent them from grasping the core issue - injustice - or the appropriate response - the necessity of treating people with respect and care. Thus, this study calls into question the role of critical analysis in enabling people to understand the nature of the problem and determining how to take appropriate action - a consideration that applies not only to PLMRs, but the allegedly "preliterate," people from nonwestern traditions, and the like. This study also raises the question as to whether the types of intellectual difficulties PLMRs have are due to their experiences - biological or social - as PLMRs, or whether they are due to class considerations. The types of activities PLMRs typically engage in, the types of things they value, and the types of problems they have, are more similar than dissimilar to people of low socio-economic status.

Visibility and the problem of "false knowledge"

We can make every effort to "see" someone, yet they still might not believe they have in fact been seen. In order for visibility to occur, then, it must be both enacted and recognized; visibility means that the seer actually sees (i.e., treats as visible) the seen, while the seen actually realizes that he is seen, or recognized, understood and accepted.

This raises the problem of false knowledge: what if someone feels visible, thinking he is actually being recognized and accepted, when in fact he is being treated as a token? This actually occurred to a boy in California who became the mascot of his school football team. For a while, he liked the attention lavished on him, resulting in positive behavior during that phase of his life. But years later, when he asked a young woman out, she avoided him consistently. In talking to others about his grief, he came to realize that his role as mascot of the football team had been token, that all along he had been treated as special not because of some positive quality, but because he was retarded! But how to explain his positive behavior during those high school years? I would argue that it was not based on visibility, but on "false knowledge," or an understanding that he was being treated in a dignified way when in fact he was not. If visibility requires that an act be understood as visibility on the part of the seen, it also requires that that act be an authentic act of understanding and acceptance, not just a token one. The role of the practitioner working with PLMRs, then, is 1) to provide them with opportunities for visibility; 2) to help them feel visible; and 3) to ensure that these opportunities are authentic, not just token. When this is done, visibility is not only a means to positive behavior on the part of the seen, but a means to authentic understanding on the part of the seer.

Most importantly, genuine acceptance of PLMRs involves acceptance by normals of PLMR as different - not inferior, but equal; and acceptance by PLMRs of their own condition, and appreciation of who they are as different, but equal. Thus, it is impossible to talk about visibility without also talking about the issue of social identity.

Conclusion

Over the course of the eight months it took to create and perform *Special*, group members revealed an astonishing array of thoughts, feelings and ideas most people would probably presume impossible for a group of people who have been labeled mentally retarded. Though the focus of this study was on eight people for eight months, in fact the kinds of outcomes experienced in the production of *Special* were the result of dozens of people coming and going, being members and supporters of the original Manna Base Community five years ago. This also included group and production assistants for *Get a Job!*, and additional friends and helpers who have continued to be a part of this group's life and history since *Special*. Additionally, though *Special* was designed as a participatory research project, it was also an ongoing support group, a source of entertainment, a place to get personal or financial assistance, a place to pray.

It is therefore difficult to say definitively that *Special* as a discrete participatory research project was the sole, or even main, cause of any of the outcomes cited in this study. To be sure, the theater experience had a profound effect on all involved, including the facilitators. But even more sure is the fact that any gains made by this group are attributable to over five years of struggling with our day-to-day lives in prayer, in work, in recreation, and in theater. More than anything else, what has produced the greatest amount of joy, growth, dedication and effort on the part of all group members is the love we have shared with one another - when it was easy, when it was fun, and when it was difficult. For at the base, I believe that what visibility is about is love. Seeing the real me means loving the real me, something we all need if we are ever to route out this scourge called internalized oppression.

But visibility is also about hope and hard work - hope that we can rise to the task, and the hard work it will take to finally dismantle the stereotypes. Can we learn to accept PLMRs as adults even when they act as children? Can we learn to accept them as knowledgeable even though they constantly forget or misunderstand? Can we learn to accept them as capable even though they cannot and never will drive or read a book? Can we learn to accept them as loving even when they become violent? Can we learn to accept them as attractive even when they stink of urine?

It is hard work, but it becomes easier when we speak not of disability, but "this" ability, for every PLMR I've met has at least one gem inside just waiting to be seen, picked up and polished. Group members in this study were no different: Sam's uncanny improvising skill, George's indefatigable and sometimes excessively corny sense of humor, Marcia's enormous efforts to bring her self-abuse under control, Susan's loyalty to friends.

It is hard work, but it becomes easier when we realize that different does not mean less or separate or inferior, but it does, or at least can, mean equal.

It is hard work, but it becomes easier if we choose to take our cues from those who know - the disabled themselves - and ask them to instruct us. How should we act? What should we say? What can we do to help? Sometimes they know, and will happily tell us. Perhaps this is the greatest gift people labeled mentally retarded have to offer us - the gift of having our eyes opened and, for once, being able to see.

APPENDIX A
A NORMALIZATION ADVOCATE CRITIQUES SPECIAL

The Values Implementation Project
Jo Massarelli, Director
17 New South St., Northampton, MA USA 01060
(413) 585-0717

September 4, 1992

Dear Kim, Charles and George,

Thank you for inviting me to your meeting regarding Special. I feel privileged that you would consider my input. I do have impressions to offer, but since they refer to the basic concept of the play itself I feel it is best done in a format other than a brainstorming session. So I decided to put my thoughts in this letter.

Much of what I have to say I've presented informally to Janet and Mark individually and at their request. Some of it may be hard to hear. Please accept these comments as coming from a friend who offers them in good will for you to take or leave as you wish. And thanks again for asking.

I feel your play Special has many strong points. Your energy and enthusiasm really came through as well as your commitment to producing an evening of education and entertainment. Having had my office next door to CCEA I've been in the unique position to get a glimpse of how hard you worked and that certainly came through on the night I attended your performance. I also enjoyed the incorporation of video work into the play, so much so that I left with the impression that film or tape would be an especially enhancing medium for your group to use to get its points across.

I do think as well that there are some fundamental problems which lead me to the conclusion that I would like to see the performance change utterly. I offer them here for your consideration.

The point you seem to be emphasizing (even with your title) is the unfair and unnecessary stigma and isolation that people labeled with impairments experience in our society. The point that follows then is that so called handicapped people are indeed people like the rest of us. I believe, as you do, that this issue affects all of us. Yet the very concept of a handicapped persons production reinforces negative stereotypes such as " mentally retarded people are happier with their own kind". Just the opposite of your intention! One of the problems you deal with over and over again is that of being grouped in with people with impairments and not given a chance to participate fully with typical citizens. Typical citizens have experienced isolation from impaired people too, and not always out of their own willful and selfish desires. Sometimes what people need is an invitation. So, if the time was spent to seek out involvment from people without impairments at the very start to share in these issues I think you would have a completely different production and one with a better chance of clarifying the damage done to society as a whole through the isolation, separation, and grouping of handicapped people. Also, think of all the time you spent in rehearsal! This time could be spent with a variety of people who might turn out to be some new friends.

An associated project of the Institute for Leadership and Community Development

There is another reason to expand your cast to include more non-impaired people and that is the issue of imagery in general, or how the play and actors are perceived by the audience. As it stands my fear is that people might walk away with impressions that sound like "isn't that sweet?, a group of people labeled mentally retarded put on a play and did a good job". I'd rather have people leaving saying "What a powerful play-I never thought about things from quite the same perspective before".

You raise many issues that are important, but perhaps because of the sheer volume of what you have to say nothing gets said with sufficient attention. I'd recommend limiting your scope of what you want to say and go for an in-depth approach.

This is partly why I said that film might be the way to go. A play is generally quite verbal and often depends on words to get the point across, yet much of what you seem to want to say is in the realm of feeling. With cooperation from people who are talented in this area much can be expressed with images on film or tape where language may be lacking. Film also gives you more leeway since you don't have to depend on excellence at the moment. Although you will lose in spontaneity I feel you will gain in a competent rendering of the issues.

I appreciate that my suggestions, should you take them seriously, will not be an easy thing to do. I feel strongly though that given the proper invitation people will see something good here that they will want to be a part of. I feel privileged that you would ask my advice and in that small way I may contribute something.

Of course you know that if you would like to discuss any of these thoughts I will certainly make myself available to do so. Thanks again for your invitation.

Take care,

APPENDIX B
SCRIPT OF SPECIAL

"SPECIAL"

The cast: (stage names; cast members' real names remain anonymous)
Happy Belle
Wild Tony
Serious Jo Masarelli
Rock Star George
Nice Joe Good
Bossy Jim Scott
Helpful Roy Rogers
Hard Workin Elvis Presley
Tough Kenny Rogers
Anal Stacey
Bastardly Mr. Bill
1/2 Funny, 1/2 Serious Anthony Jones
Amy

Assistants:
Stage hand
Bass
Guitar

Note: Directions to play assistants are pulled out in the margins. Stage hands = "Set," Orchestra = "Song," Lighting = "Lights," Audio & Video = "Audio" & "video," Tech person = "tech." In addition to tech assignments, tech person will also be responsible for cuing audio and video person.

SCENE 1 - THE BUSTOP

Set: A large mask is suspended back stage right with bubble wrap concealing it, ready to be rolled up progressively throughout the play to reveal the mask. A stop sign is suspended back center stage with a switch backstage, and a video screen is positioned back stage left. Signs like "retarded" and "disabled" are pasted to the wall in random fashion. The bus stand is center stage behind two chairs. Jim is seated stage left. Have ready: Each person should have a bus flat in hand, George in lead, sunglasses in pocket. E. Presley has spring, George ready to get bubble wrap, K. Rogers ready to get "retarded" sign.
Jim sings (a capella) two lines..."Can you see the real me, can you? Can you see the real me, can you?"

Lights up. Joe G and Jo M are holding mirrors in front of their faces and moving them while they talk.

Audio 1: Dialogue (following):

Jo M: So I told him "I need some way to get around."

Joe G: What did he say?

Jo M: He said "If you ride on the bus that says Special Transportation then people will think you're disabled.

Joe G: Well you are.

Jo M: Yeah, but I don't want to be labelled that.

Joe G: I don't either.

Jo M: To be honest, I wouldn't mind just taking the frickin' bus, just get where I'm going.

Joe G: Is that what you're doing now? Waiting for the Special Bus?

Jo M: Yeah, I just don't want my agency worker to see me here.

Audio 1 off.

Mr. Bill and Stacey enter, arguing.

Mr. Bill: So I think for once, for once, we're gonna make it to a movie on time. But no, we're driving down Route 9 and my hopes are smashed as you turn into Bread and Circus. We've got to have our earthy crunchy granola and organically grown sprouts, don't we?

Stacey: I see you eating plenty of this "earthy crunchy" food.

Mr. Bill: Sure. You also see me eating Dunkin Donuts, Tater Tots, Wonder Bread. How about popcorn? Do you think we'll ever get to a movie early enough to stand in line for popcorn?

Stacey: Can we stop fighting?! It seems like that's all we do any more is fight. Why don't we just try to act normal for a change?

Mr. Bill: Normal! There's a novel concept. Let's see, I've almost forgotten since I met, no no, I mean, ok here we are in beautiful Northampton, there's the Academy of Music. The movie there starts at 8:00. What's "The Crying Game" about? Do you know?

Stacey: No, but maybe we can ask someone. (looks around) There's a couple people on that bench there. Why don't we ask them?

Mr. Bill (stepping up to Joe G and Joe M): Ok, I'll give it a try. (Looks at them and turns away) No, on the other hand, maybe not. They're ... different.

Joe G and Jo M take off mirrors simultaneously and lean forward,

Jo M (calmly) What do you mean different?

Mr. Bill: No, I don't mean different <u>bad</u>, I mean different, different...

Stacey: Uh, special, uh, like the bus.

Mr. Bill: Yeah, that's it. Special. You know, the Special Transportation bus?

Joe G: Do you think other people are better than we are?

Mr. Bill: No, I...

Jo M: (interrupts) Wait a minute. He thinks different means special. In other words, we're not normal.

Joe G: But what's normal and what's different?

Lights bright.

Song: Special Bus

Exit Stacey and Mr. Bill. Cast enters with Special Bus. Jim sings first verse, cast joins on chorus.

After "I want it, I need it, I need a ride, Gotta have a ride, if you do, you know what people will say," Stacey and Mr. Bill lead cast into audience doing dance - Stacey with Roy R behind and Mr. Bill with Jo M. At stops in song:

Tech: Set of lights is on green when cast is moving, flashes red when they stop and say the following lines:

1. Jim: Driver's license? Are you kidding?
2. Roy R: Nope, we can't give you a checking account.
3. Joe M: We're sorry, but you're not qualified for this job.

Song ends with cast behind bus, Joe G and Jo M back on bench.

Lights out, except one on John.

Video 1: SuperSteve - At end of Special Bus song and applause, start audio; start video (leave audio on) when cast says SUPERSTEVE.

Joe G: Look!

Cast: Up in the sky! It's a bird! It's a plane! It's Supersteve!

Video 1 continues to end of segment.

Lights up.

SuperSteve enters stage left, singing: Here I come to save the day. SuperSteve is on the way...! Hey - what seems to be the problem here?

Jo M: Who are you?

SuperSteve: I'm SuperSteve - and I solve special problems in a special way.

Mr. Bill and Stacey enter stage left, fighting silently.

Joe G: Jo M here needs to take this bus because of her leg, but she doesn't like being labeled 'special'.

SuperSteve: No problem. I got an idea.

Jo M: What do you mean?

SuperSteve: I mean, check this out!

SuperSteve goes stage right and brings Stacey and Mr. Bill (fighting) back.

Watch!

Light change. Stacey and Mr. Bill freeze. SuperSteve zaps Stacey and Mr. Bill, cripples legs and puts mirror heads on them.

Audio 2: Plunk extend - play while SuperSteve is zapping Stacey and Mr. Bill. (Note: Not all audio parts will be necessary since some are now on the video as well.)

Joe G: Hey, let's go see a movie. Do we have time?

Jo M: I don't know. Let's ask them. Hey, can you tell me what time it is?

Mr. Bill: Time? Uh, yeah, let's see, I thought it was on my watch here...I can't see it!

Stacey: Well there's a clock tower just around the corner there. Let me see if I can see it (ambles stage left)...

Mr. Bill: What happened to my legs?

Stacey: I don't know. What happened to my legs?

SuperSteve exits giggling. Stacey and Mr. Bill exit grumbling.

Jo M: That was fun. But it still doesn't solve the problem.

Joe G: What problem?

Jo M: People still don't see who I really am!"

Song: Can You See the Real Me?

Audio 3: Rhythm for song. Start after Jim sings "Can you see the real me, can ya? Can ya?"

Cast enters from stage left, poking their heads through the bus windows, in a line in front of the bus by the first chorus "Can you see the real me?" On second verse, cast puts on sunglasses, exchanges them with other people a couple times, then crowds in on Roy R., who, frightened, breaks away stage right only to be reined back in by Kenny R. and George wraps her with bubble wrap. Cast circles around, then leaves on Me me me. Elvis comes out with "retarded" sign" and she and Kenny R drag Roy R off stage left.

Lights bright on song, darker when we are wrapping Roy R, strobe on Me me me me, then out.

Tech: Roll up bubble wrap in front of mask.

END SCENE 1

Video 2: Les, John talking about seeing the real me.

SCENE 2: INTERVIEW SCENE

Set change: 2 chairs on stage with small table between them, phone and file folder on top. Turn bus into phone booth and have ready to bring out on stage. Get people ready to enter scene, with Roy R in front.

Lights up on Mr. Bill and Jim.

Mr. Bill: Yes I'm glad to say we're all done with our interviewing and... we're not! We do! He's blind! Oh don't tell me this is one of those affirmative action hoops we have to jump through...this is one of those affirmative action...ok, send him in! Send him in!

(knocking sound)

Jim: Hello Mr. Bates.

Mr. Bill: Yes, hello Mr. uh, yes Scott. So good to see you, er, I mean, to have you hear for an interview. As you know, we are affirmative action employers and like to think of ourselves as friends of the disabled. Incidentally, just how long have you been blind?

Jim: Oh, since birth, but that don't mean nothin.

Mr. Bill: Oh, I'm so sorry! No, I mean, well I suppose that's no tragedy. Lots of people are blind. In fact, I have a couple blind friends myself. I think everyone should have a few handicapped friends, don't you?

Jim: Yeah, sure...

Mr. Bill: Would you oblige me in a role play?

(They role play, and Mr. Bill says to Jim): Don't call us, we'll call you.

Jim leaves walking stage left and runs into Elvis and Stacey. They ask him what's going on and he tells them about not getting the job. They ask him what he's doing today. He says he'll just go home and call his 900 numbers, and starts singing.

Audio 4: Start while they are talking.

Song: 900

Set: Phone booth is set up stage left during dialogue. SuperSteve is talking, then Roy R steps in, others waiting their turn, tapping each other on shoulders, etc. Elvis listens to each conversation; Jim "talks" to Roy Rogers on the break and she responds.

Song ends.

Lights dimmed.

Audio 4: continues with phone gag, Batman them, oops! Cut after oops.

Video 1: (return to SuperSteve piece) Start projecting SuperSteve over Batman audio, then at oops, start video audio track. After "more powerful than a locomotive," cut audio track, but leave video running.

Joe G: "Look!:

Cast: "Up in the sky. It's a bird. It's a plane. It's SuperSteve!!"

Video 1 off.

Lights up.

SuperSteve comes out from behind the phone booth - tearing off his shirt to expose super costume.

SuperSteve: "OK. I got an idea. From now on the Disabled people interview the normals."

SuperSteve exits.

Mr. Bill returns (as a laid back hippy-dimmwit) to be interviewed by Jim for a music job. Mr. Bill gives a sample performance, to which cast groans; Mr. Bill doesn't get the job:

Jim: "Sorry I don't think you normals can hear as well as I can.."

Mr. Bill: NORMAL!!!??? etc. exits

Jim: "Well, that was fun but I still don't have a job!...."

Cast exits.

Lights out.

Tech: Roll up bubble wrap in front of mask.

END SCENE 2

Video 3: Roger & Steve working.

SCENE 3 - HOMELESS SCENE

Set change: Bench or 3 chairs for bustop scene center stage again. Have cast ready to bring on cardboard buildings. Might want to have masking tape where people should stop.

Joe G and Jo M at bustop again. Jo is reading a newspaper.

Joe G: What'cha reading there?

Jo M: The Gazette. Look here. They just celebrated the closing of Belchertown State School. Where do you think all those people went?

Joe G: Well, I don't know. I think they're gonna have a lot of problems.

Jo M: Who? The state?

Joe G: No! The people who are leaving! Most of them are living in group homes. You know what that means, don't you?

Enter (stage left) Mr. Bill, sitting down on bus bench next to Jo M.

Mr Bill: What a great day! How are you guys doing?

Jo M: Great. Isn't it nice today?

Mr. Bill: Yep, sure is. I love this town on a day like today. Warm, sunny, quiet...

Audio 5: Venus

Mr. Bill: Oh there's that damn blind beggar. Don't give him any money. He just ruins the atmosphere here with the racket he makes with that stupid keyboard.

Jim: Hey man can you give me some money?

Mr. Bill: No I won't. Get out of my sunlight, would you please?

Jim keeps begging, Mr. Bill leaves in frustration, and Jim turns to the audience singing "Nobody cares if you survive."

Audio 5: Venus - cut when Jim sings staccato part.

SuperSteve: Oh shut that thing off (touching keyboard).

Video 4: SuperSteve - after cutting Venus audio, immediately put on SuperSteve audio and video.

SuperSteve turns to screen and waves: And shut that off too! We've seen it before. (walking over to Jim) Don't worry Jim. I'm gonna solve your problem.

Video 4 off.

SuperSteve whistles and yells out toward stage left: Come on out gang!

Cast comes out (hidden) behind cardboard "condos".

Song: Little boxes

SuperSteve: "See. Condos for everybody.."

SuperSteve leads Jim to condos where he one by one knocks at doors and tries to get in but no one will let him/her in....

Roy R in First Condo: "Do you have any money?"

Jim: "Well, no. No one will give me a job."

"Then forget it."

Belle in Second Condo: "We don't have any room."

Elvis Presley in Third Condo: "We don't like your kind."

Kenny Rogers in Fourth Condo: "You're just a street bum."

Joe G: "Wait a minute. This is stupid. These buildings are cardboard."

SuperSteve: "So what. Plenty of people are living on the streets in cardboard..."

Joe G: "What kind of help is that? We need real-life solutions. We're real people with real problems..."

All: Yeah!

Cast knock buildings forward and stand, looking at the audience firmly.

Lights out.

Tech: Roll up bubble wrap in front of mask.

END SCENE 3

Video 5: John, Colleen, Ken talking about experiences living in group homes

SCENE 4: GROUP HOME SCENE

Set: Belle, Tony, Joe Good and Jo M. are sitting around a table center stage, talking about that latest happening in town. George is in the background stage right watching TV, Jim is in his chair stage right listening to his walkman and looking at the log. Roy Rogers is sitting next to him reading a magazine.

Lights up after video.

Joe Good: He did?
Tony: Yeah, then he stepped on my fingers and called me Lenny.
Jim: George, did you do your jobs? Remember, you signed the Log!
George: Oh no! I forgot!
Roy: (striding over to George): You heard what he said! Do your job!
Tony: Hey! Can we be friends?
George: I'll do it now! (grabs a mop and starts mopping)
Jim: Come here! I want to show you the log!
George: No, I've seen the stupid log. I have to sign it every week.
Jim: It's not stupid. How else are we supposed to make sure everything gets done around here? This log is to <u>protect</u> you. It's to protect all of us.
Joe Good: No, I'm not real happy here either.
Joe M: You think this is bad... You should see the place I was living in before.
Joe Good: Was it a group home too?
Joe M: Yeah, except there, if you didn't do what they said, they gave you two-hour eye contact.
Belle: What's that?
Joe M: They go like this (stares at Belle).

(Anthony knocks on the door)

Jim: Would someone please get that? That should be Anthony. He called today, applying for a job as temporary staff here.
Joe Good: Another one?

Joe M answers the door, Anthony comes in, looking at people indifferently (not meanly, not kindly).

Jim: Yes, Mr. Jones, I'm glad to see you here. You're right on time. Yes, here, sit down. Sit down.
Anthony: Hi, I'm Anthony Jones, sometimes funny, sometimes serious, you know.
Jim: No, I don't.
Anthony: (looking at him) Well, anyway, I saw your ad in the paper and...
Jim: Yes, I know, I remember your voice. I talked to you on the phone.
Anthony: Yes, that's me. So this is the place? (looks around, looking a little confused)

Jim: Yes, this is the Rainbow House group home. Of course we don't like to call it that. This is their home. They're the residents. They call it home.
Anthony: Do you live here?
Jim: Me? No of course not, I... I mean, no, I live in Amherst! I wouldn't..., well never mind. Here, let me give you a tour of the house.

(Which he does without introducing Anthony to residents. As he walks by them they make like they're going to introduce themselves, then he turns the other way).

Jim: So what do you think?
Anthony: Well, I must say, it's not what I expected. I ...
Jim: Oh, that's exactly what so many people say. Yes, we take pride in the fact that we are client-centered here - I mean, resident-centered. The residents run the show. It's their home, you know.

(pause)

Anthony: (looking over at George): What's he doing over there?
Jim: Oh he's doing his chores. Mopping. This is Monday. George is mopping. See here in this log? Yep. We've got everything organized. You see, that's the way the residents like it. They say it's for their own protection, so we...
Roy (screaming): George, you missed this part!
Tony: Hey, can we be friends?
George: Ok!
Anthony: Let me see that (studies the log). Yes, I can see how this would be a help. If I'm hired as staff, would I be expected to enforce it?
Jim: Yep! Well, enforce isn't a very pretty word is it? Let's just say you'd assist the residents meet their own behavioral objectives.
Anthony: Come again?
Joe M: Our own behavioral objectives. You ever hear of an ISP?
Anthony: What's that?
Joe M: It's an Individual Service Plan. Well this house is run like we've all got ISPs just for this house.
Anthony: Oh. For your protection, I'll bet.
Joe M: Protection! I hate those damn things!

Lights out.

Tech: Roll up bubble wrap in front of mask.

END SCENE 4

Video 6: Ken, Tim, Colleen, then Ken again talking about problems with group homes

SCENE 5 - FSAG MEETING

Set: 12 chairs in a horseshoe center stage facing audience.

Song: Great change (Mr. Bill plays with cast)

Mr. Bill: Great changes in our lives. Any great changes happening these days? What's going on with you?

Each cast member talks about what is happening in their lives that day. After sharing, Jo M: (in her own words) We meet regularly to support each other, and to try to change how things work in the world. One way to do this is to continue to work on changing things in group homes, which we want to do.

Joe G: Another way is to make people feel welcome in the community.

Song: Where have all the people gone? (Mr. Bill leads on words)

Lights out.

Tech: Roll up bubble wrap in front of mask.

END SCENE 5

Video 7: Joe G showing someone around town

SCENE 6 - RESTAURANT SCENE

Set: Have cast ready to enter stage right with table, cake etc., Ken and Pauline with aprons, Serafino's sign to be posted somewhere.
Amy wheels out from stage right, pauses just before center stage, fumbles through her purse and drops a quarter. After trying to pick it up, Kenny R enters stage left.

Amy: Excuse me, could you...?

Kenny R walks right by. Elvis enters stage right:

Amy: Excuse me, could you help me. I dropped a quarter.

Elvis: Sure. (picks it up and gives to Amy) There you go.

Amy: Thank you so much. You're the third person who's walked by, but no one else would stop.

Elvis: Oh, that's too bad.

Amy: Do you live around here?

Elvis: Yes (and leaves stage left).

Song: By my side.

Joe G walks by, asks where she's going, and invites her to a party with some friends of hers. Joe gives Amy a push stage left, cast enters stage right with tables, cake, Serafino's sign, etc, chattering about anniversaries, and sing to Elvis and Kenny:

Song: Happy anniversary

Tawnya turns with Amy and says "Here we are. Hey look everybody. This is Amy."

Everyone greets Amy, asking "what do you do?" etc.

Audio 6: Louisiana Man; Elvis and Roy R dance.

Roy R (to Elvis): Hey Elvis, wanna dance?

Elvis: Sure!

Everyone claps along.

Amy (after song is over): Wow! You guys really know how to party!
Lights out.

Tech: Roll up bubble wrap in front of mask.

Song: Orchestra continues playing Eatin Good Food during set change.

END SCENE 6

Audio 6: Repeat Louisiana man during set change.

SCENE 7 - BUS STOP

Set: Two chairs center stage, with bus stand behind them. Cast members ready with bus flats.

Lights up.

Joe G: It's starting to get cold again.

Jo M: Yeah, I guess the good weather couldn't last forever.

Joe G: Are you still waiting for that frickin' bus?

Jo M: You must mean the Special Bus? I go back and forth. Sometimes I want to ride it and sometimes I don't.

Stacey: Are you guys talking about the Special Bus? Aren't you afraid of being labelled?

Jo M & Joe G look at each other, then turn to the audience: DON'T ASK!

Audio 7: Rhythm for FSAG song - cut on last "Friends Support and Action Group"

Song: FSAG song

Cast come out singing, and do curtain call.

APPENDIX C
ANNOUNCEMENT OF SPECIAL IN LOCAL PAPER

GAZETTE

Disabled cast tells it like it is in 'Special'

NORTHAMPTON — Friends Support and Action Group, 10 disabled adults from Northampton and Easthampton, have been writing and rehearsing since last October for this weekend's opening of the musical theater production "Special."

"Special" is a dramatization of the feelings and experiences of individual group members concerning the "special" label often assigned to developmentally disabled adults, said group leader Mark Lynn.

One scene revolves around member Colleen Barber. "Colleen has braces on her legs," explained Lynn. "She felt torn because the 'special bus' was the only way for her to get around town, but she had been told that if she used it she would be negatively labeled."

Cast member Pauline McGrath described another scene featuring Les, a blind man who encounters discrimination at a job interview.

"Special" promises music, dance and humor. All the group members joined forces to write the theme song "Eatin' Good Food."

The Friends Support and Action Group have been meeting on a weekly basis for the past three years to sing, pray and discuss their lives.

Some members have physical handicaps like severe arthritis or blindness. Others are adjusting to independence after having lived at Belchertown State School and Northampton State Hospital.

Creating and performing "Special" is a way for members to make a statement that could help bring about social change, said Lynn.

Friends Support and Action Group is run through the Center for Community Education & Action, which works with disadvantaged groups through community projects, workshops, staff trainings, theater and video programs.

The Campaign for New Development funded the organization of this project, and the Haymarket People's Fund will sponsor its videotaping.

The group will add the money earned from ticket sales to its personal fund, which finances activities.

"Special" will be performed Friday and Sunday at 7:30 p.m. at Northampton's First Churches. Tickets are $5. For tickets or information call 586-7173. The building is wheelchair accessible.

APPENDIX D
FOLLOW-UP PERFORMANCES FLYER

What's most noticeable about Special, aside from its eclectic mix of music, film and knock about skits is the kick the cast has in performing it.
—*The Valley Optimist*

SPECIAL NEWS

THE FRIENDS SUPPORT AND ACTION GROUP is composed of 15 disabled and nondisabled adults from Northampton and Easthampton, Massachusetts. The Friends have been meeting for 4 years and have written and performed two plays, *Get a Job* and *Special*. The creation and performance of these plays empowers a group that is frequently denied a voice, denied a presence—the developmentally disabled.

Our message is one of diversity and respect; our company encourages everyone to examine their pre-conceptions in accessible ways—through song and dance and comedy. Our *Special* performances and workshops enable people to discuss difference, labels and prejudice within an entertaining and educational atmosphere. Dramatizatized scenes and participatory activities heighten your awareness, which leads to less prejudice towards the developmentally disabled—towards anyone labeled *different*. The cast members re-create real-life events that draw you in, may make you laugh, and certainly make you think.

Performances of *Special* consist of scenes that dramatize certain issues that the cast members face as disabled people—fear of being labeled for riding on the "Special Transportation" bus, difficulties finding jobs and poverty, to name several. The play also presents activities that the group has undertaken in order to solve problems they and other disabled people face. Most notably they have conducted a research project in which they interviewed themselves and other people concerning conditions in group homes and what might be done to improve them.

Workshops consist of presentations or panel discussions on disability issues, presentations to elementary through high schools, various scenes from *Special*, and experiential activities and games. All are conducted by cast members and experienced trainers.

It was a very moving, very powerful, very wonderful play... We saw people dancing; we saw people with a terrific sense of humor; we saw people sensitive to the social barriers and limitations that are put in people's ways. We saw people analyzing what their problems are and how to deal with them, and how to change barriers and limitations and stereotypes. It all came through during the play Special in a very special way.
—*Reverend Peter Ives, First Churches of Northampton*

We have conducted workshops or performed at:

- The Celebrate Holyoke Festival
- StageWest
- Springfield Central High School
- First Churches of Northampton
- The Ethnography Conference, UMass.

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