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The University of British Columbia
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Date Oct 14/1988
ABSTRACT

This study was concerned with the behaviours, actions, and patterns of interaction of profoundly mentally retarded non-verbal deinstitutionalized adults (PMRs). The methodology utilized field research techniques which are observations of participants in their natural setting. The observations were of five profoundly retarded deinstitutionalized adults and took place over a three month period in the participants' group home and day program.

The observations were recorded daily in a field note book and were later transcribed into a protocol format. The protocols were then coded. The coding categories were developed by the researcher through abstractions which emerged from the data.

The coding categories revealed insights into the PMRs. The participants exhibited a hierarchical social order, displayed consistent seating patterns, and understood property ownership. The participants were noted to anticipate daily routines such as meals, outings, and bedtimes.

The researcher observed preferences by the individual participants for specific staff members. One participant appeared to display a heterosexual erotic preference for one staff member. Autoerotic sexuality was observed in three participants. Individual preferences for food, music, activities, and people were also displayed by the participants.

Stereotypic behaviours were prevalent behavioural patterns exhibited by participants who had individual and unique stereotypic motions. The coding of the stereotypic behaviour revealed that emotional responses were present during stereotitic movement. The researcher hypothesized that stereotypic movement was an observable response to the inner thoughts or ideations of the participants. The
literature on sensory deprivation suggests that individuals when exposed to a montonous environment develop their own sensory data (hallucinations) in the reticular area of the brain. Stereotypic behaviour appears to be an adaptation by the individual to monotony through self generated stimuli. The data from this study suggests that the degree of environmental stimulation influences the prevalence and incidence of stereotypic behaviour. There were data to support the hypothesis that the participants' stereotypic movement was interactive with the degree of environmental stimulation and the specific like or dislike of the participant to the stimulation.
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CHAPTER I. INTRODUCTION

A. BACKGROUND TO THE PROBLEM

Institutions for the mentally retarded are being closed in North America (Schreenberger, 1981). The mentally retarded are being deinstitutionalized and placed in group homes and private care homes in residential neighbourhoods. The rate of deinstitutionalization in Canada for mentally retarded persons, after 1987, is projected at ten percent per year (Canadian Association for Community Living, 1986). Current projections are that over the next thirteen years or by the year 2000 there will not be an institution for the retarded left open (Canadian Association for Community Living, 1986).

Deinstitutionalization has been occurring for the mildly retarded for the past twenty years (Lakin et al., 1981). More and more the institutions are places for severely, profoundly, and multiply handicapped persons, and now it is their turn to come to the community. It is predicted that homes on residential city streets will become the group homes for severely and profoundly retarded adults (Schreenberger, 1981).

The movement of the mentally retarded from the institutions to the community has been occurring in British Columbia. The institutionalized population in British Columbia has been reduced by approximately 35 during the period 1980-1986. Table 1, shows the decline in institutional placements and the increase in community placements for the same period. Community residential placements in the same time period grew in numbers from a low of 1,398 in 1981 to a high of 1,868 in 1986 or an increase of 470 community placements (British Columbia, Annual Reports, Ministry of Human Resources, 1980-1986).
Table 1: Placement of the Mentally Retarded in British Columbia

<table>
<thead>
<tr>
<th>Year</th>
<th>Institutional Placements</th>
<th>Community Placements</th>
</tr>
</thead>
<tbody>
<tr>
<td>1985-86</td>
<td>987</td>
<td>1868</td>
</tr>
<tr>
<td>1984-85</td>
<td>1016</td>
<td>1590</td>
</tr>
<tr>
<td>1983-84</td>
<td>1308</td>
<td>1555</td>
</tr>
<tr>
<td>1982-83</td>
<td>1339</td>
<td>1492</td>
</tr>
<tr>
<td>1981-82</td>
<td>1481</td>
<td>1398</td>
</tr>
<tr>
<td>1980-81</td>
<td>1526</td>
<td>1409</td>
</tr>
</tbody>
</table>

Source: (British Columbia, Annual Reports, Ministry of Human Resources, 1980-1986)

This study is concerned with profoundly retarded deinstitutionalized adults. The profoundly retarded comprise a small percentage of the total population of the mentally retarded. They represent a majority of the institutionalized population (Cleland, 1979; Snell, 1982; Westling, 1986). Predictably they present the most serious difficulties for community placement and integration (McCarver & Craig, 1984).

B. BACK WARDS

The profoundly retarded are institutionalized at an early age and placed on “back wards” often with the severely retarded (Cleland, 1979). The institutional experience of the back wards has been anecdotally documented and photographed (Blatt & Kaplan, 1966; Bogdan & Taylor, 1982; Braginsky &
Braginsky, 1971; Cleland, 1979; Thompson & Grabowski, 1977). The description of life on the back wards does not bode well for the assimilation of this group into the community. Examples of anecdotal narratives from visitors to back wards read:

The combined smells of antiseptic and excrement were overpowering. Haunting screams filled the air. An overwhelming desire to flee accompanied the turning of the key to the locked ward door. And there they were, an anonymous mass of unwanted humanity. The images were unforgettable: some nude, but most in baggy institutional garb; several in straightjackets or tied to long wooden benches; all with close cropped hair; many with scars; some hunched over; some drooling (Bogdan & Taylor, 1981, p. xi).

Along the seventy-foot wall of the ward were seated approximately fifteen men huddled in the fetal position, with their heads between their knees. Most of them sat totally still, a few rocked from side to side, a few rocked forward and backward. Beneath half of the chairs were puddles of urine. The room reeked of urine and feces, and feces were smeared over the floor, over the arms and legs, and on the trousers and shirts of numerous residents. Approximately half of the men were partially or totally unclad (Thompson & Grabowski, 1977, p. ix).

In sum, Ward Y and its inhabitants constitute a staggering visual, auditory, and olfactory assault on the presupposedly invariant character of the natural normal world of everyday life. Here, to a monumental degree, things are different (McAndrew & Edgerton, 1964, p. 313).

There is a Hell. It is on earth. In America we have our own special inferno. (Blatt & Kaplan, 1966, p. ii).

This, anonymous mass of unwanted humanity, is coming to the community from the back wards. Questions as to who the profoundly mentally retarded are, what they will do, and how they will assimilate into residential communities, all need to be answered. Little is known about the profoundly retarded in the community;

The bulk of our limited knowledge about the profounds derives from research on institutionalized samples. It is evident that research on the noninstitutionalized population is needed (Cleland, 1979, p. 16).
The goal to close the institutions seems laudable given the reports of the inhumane conditions of back ward life (Blatt & Kaplan, 1966; Bogdan & Taylor, 1982; Cleland, 1979; McAndrew & Edgerton, 1964; Thompson & Grabowski, 1977). The institutions might well have been redesigned to provide fair and dignified services for the profoundly mentally retarded. Especially, given the reports of their behavior and need for service (Cleland, 1979). This has not been the case. The mentally retarded will be deinstitutionalized on moral, political, and philosophical grounds rather than on empirical evidence (McCarver & Craig 1984).

The move to the community has meant smaller residential units of four to six bed group homes in British Columbia. The number of community placements in British Columbia is traced from 1981 to 1986 in Table 2.

Table 2: Number of Community Homes in British Columbia

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Homes</th>
<th>Number of Residents</th>
<th>Average Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>1985-86</td>
<td>449</td>
<td>1868</td>
<td>4.16</td>
</tr>
<tr>
<td>1984-85</td>
<td>387</td>
<td>1590</td>
<td>4.11</td>
</tr>
<tr>
<td>1983-84</td>
<td>374</td>
<td>1555</td>
<td>4.15</td>
</tr>
<tr>
<td>1982-83</td>
<td>323</td>
<td>1492</td>
<td>4.62</td>
</tr>
<tr>
<td>1981-82</td>
<td>283</td>
<td>1398</td>
<td>4.94</td>
</tr>
</tbody>
</table>

1Homes include all forms of proprietary residences, private hospitals, licensed and unlicensed boarding homes, unlicensed family homes, long term care facilities, nonprofit operated group homes, training centres and semi-independent living homes (British Columbia, Annual Report, Ministry of Human Resources, 1981-86).

The average community home size range in British Columbia is between four and five residents. Size can be a major factor when coupled with
resident/staff ratios;

On these so-called "back wards" where the PMR were crowded together, aggression levels were often very high and those who bit others were often, not infrequently rendered harmless by the removal of all teeth! So thin were the ranks of houseparents and so harried and desperate were the professionals that radical procedures were often required (Cleland, 1979, p. 70).

The size and staff ratio may well be important variables in the treatment of the profoundly mentally retarded. However, perhaps more important are the variables that include programs, individualization of care practices, and meeting of personal needs. Size and staff ratio will not guarantee adequate care and personalization of services. The group home on a residential street may still become a prison or an institution. Whether or not community living in group homes for the long term institutionalized profoundly mentally retarded is a viable and obtainable goal is a matter to be researched and not assumed.

Deinstitutionalization can be seen as major, or very minor, changes in the circumstances of life. All too often the goals plans are stated in terms of the places from which people are moving rather than the quality and nature of the places to which they move (McWhorter & Kappel, 1984, p. 9).

C. THE PROFOUNDLY MENTALLY RETARDED

Little is known of the lives of the profoundly mentally retarded. Often the severely and profoundly retarded are for the purposes of research, education, and habilitation, grouped together as one unit. This practice has been discouraged by some authors (Cleland, 1979; O'Grady & Talkington, 1976).

Among certain research and professional workers in the field of mental retardation, there is a tendency to lump the profound and severe levels of retardation together for the purposes of research and placement (O'Grady & Talkington, 1976). This is an indefensible practice and most who are experienced with both categories adhere to Grossman's (1977) distinction of profound and severe (Cleland, 1979,
This research is concerned solely with the profoundly mentally retarded and throughout the text PMR is used to denote the longer term deinstitutionalized non-verbal profoundly mentally retarded adults that are the participants in this research project.

The distinction between the severe and profound level of retardation is important. The reason is that the severely retarded do differ in their adaptive behavior, verbal language acquisition, and performance on intelligence tests (Cleland, 1979; Snell, 1982; Westling, 1986). Who are the PMR? The following descriptions of the PMR are quoted from previous researchers:

They have eyes but they see not; ears but they hear not; they have no intelligence and no consciousness of pleasure or pain; in fact, their mental state is one of entire negation. (Tregold, 1937)

They would be equally helpless and ill-adapted in a society of savants and in a society of savages. (Kanner, 1942)

Left to his own resources, even in a grocery store, the profoundly retarded person dies within a matter of days of starvation if he does not meet with accidental death before that. (Bowman, 1968) (Cited in Cleland, 1979, p. 2).

They are not toilet trained; aggress towards others; do not attend to even the most pronounced social stimuli; self mutilate; ruminate; do not walk, speak, hear, or see; manifest durable and intense temper tantrums; are not even under rudimentary forms of verbal control; do not imitate; manifest minimally controlled seizures; and or have extremely brittle medical existences (Sontag, Burke, & Yorke, 1973, p. 21).

These descriptions of the PMR are not optimistic. The content of the above reports strongly suggest that institutionalization is perhaps the best care medium available this group. The research on the PMR is mostly in institution settings (Cleland, 1979, Snell, 1982). Little is known about the PMR who reside in the
community. What is known is listed below.

1. In institutional settings the PMR do perform a great deal of stereotypic behavior (Baumeister, 1978; Baumeister & Foreman, 1976; Cleland, 1979).

2. The PMR do not develop language (Cleland, 1979; Westling, 1986).

3. It is unlikely that any other classification of the mentally retarded have as varied an etiological representation as the PMR (Cleland, 1979; Snell, 1982; Westling, 1986).


5. The PMR are the most commonly institutionalized and at the earliest age (Cleland, 1979; McCarver & Craig, 1984).

6. The PMR are the most medically fragile and the average life expectancy is 38 years of age for an institutionalized PMR (Cleland, 1979; Miller, 1975).

7. Two habits, pica (eating of objects such as dirt, paint, cigarette butts, or other seemingly inedible objects) and coprophagy (eating of feces) is not uncommon in the PMR (Cleland, 1978).

8. Little is known about the PMR outside of institutions and research laboratories (Baumeister, 1978; Cleland, 1979; Meyers, 1978; Taylor & Bogdan, 1981).

The prevalence of the PMR is estimated at .5 per 1000 by Mercer (1973) and Eyman and Miller (1979). Cleland (1977) estimates there were between 130,000 to 150,000 PMR persons in the United States in 1977. Miller (1975) found in a study in the western United States that 92% of the PMR population were in institutions and convalescent hospitals.

In summary the PMR are a small proportion of the population of
mentally retarded and are a heterogenous group of people with little known of their daily lives outside of institutional settings.

D. THE STUDY

This study is a first step along the road to understanding the deinstitutionalized PMR in their natural environment outside of an institution as residents of a group home. It is a study of the patterns, activities, and habits that form their daily lives. The purpose of the study is to develop analytic abstractions for description and the generation of theory about the life of a group of deinstitutionalized PMR adults in a group home. The intent is to observe their new life and develop descriptions of their lives, in contrast with the reports in the literature, of descriptions of back wards. Cleland (1979), Baumeister (1978), and Taylor & Bogdan (1981) call for studies of the PMR in their natural ecology and in the contexts of their activities.

The PMR have possibly been misunderstood and not been included as research subjects due to the nature of their unusual behaviors such as; self-injurious behavior (SIB), aggression, pica, coprophagy, and stereotopic movement:

Another reason that could be advanced is that the grossly deviant behavior observed in the profoundly retarded of any life age so overwhelm our social and cultural overlearnings that we are blinded to whatever their strange behaviors are trying to tell us (Cleland, 1979, p. 18).

Whatever the reason, the PMR have not been the subject of research to the same extent that the mild and moderate levels of retardation have participated as research subjects:
The mentally handicapped of severe and profound degree, who till recently received little more than custodial care, now claim our attention for an improved quality of life. Surely it is more than rhetoric to list the right to be research subjects as an essential right of severely and profoundly retarded people, for the basis of improving their lot resides in theory and data (Meyers, 1978 p. iii).

The PMR have for too long been thought of as objects of pity, dread, fear, or ridicule (Wolfensberger, 1972). Ignorance creates these emotions and prejudices. Yet, even researchers, who through qualitative methodologies, have developed an empathic perspective and advocacy role for the mildly mentally retarded have not extended their empathy and understanding to the PMR population.

There are few sights more pitiful than the children who live in institutions for the mentally retarded. The feeling is inescapable when one sees the profoundly retarded inmates, incapacitated, needing almost total care. Yet it is, perhaps more acute at the sight of the mildly retarded child. One's pity for the profoundly retarded is somehow tempered by the obvious nature of the deficits and one is relieved that institutions exist which assume this human burden (Braginsky & Braginsky, 1971, p. 11).

The intention of this study is to move past pity, fear, dread, and ridicule to understanding. The researcher began with uncertainty about whether the world of the PMR was understandable or whether it was a chaotic existence on the fringe of life that was incomprehensible to an observer. The discussion in the literature of the behavior of the PMR on the back wards did not alleviate the researcher's concerns regarding this matter. The research goal seemed to be to understand the nonunderstandable;

Profound retardation, by definition, means "unfathomable" and, in large measure, we are ignorant of their wants, hopes, and fears (Cleland, 1979, p. xi).
E. SOCIOLOGICAL AND ANTHROPOLOGICAL INVESTIGATIONS OF MENTAL RETARDATION

The degree of ignorance and lack of knowledge on the PMR in noninstitutional settings was a challenge for the researcher. The research project was based on seven classic studies of sociological analysis of mental retardation which explored the labeling and meaning of mild mental retardation:

1. Christmas in Purgatory, Blatt & Kaplan, 1966
2. The Cloak of Competence, Edgerton, 1967
3. The Cloak of Competence: Years Later, Edgerton & Bercovici, 1976
4. The Cloak of Competence After Two Decades, Edgerton, Bolinger, & Herr, 1984
5. Hansels and Gretels, Braginsky and Braginsky, 1971

All of the above works are primarily studies of mildly retarded persons. The nonverbal profoundly retarded population were not included in these studies. These seven studies were break through works in that each study revealed an understanding of mental retardation that awoke the reader to the world of the person labelled mentally retarded. Blatt and Kaplan's (1966) photographic account of the institutional treatment of the mentally retarded sensitized the reader to the deplorable conditions of institutions. This series of photographs were of five institutions in four different states. Blatt and Kaplan photographs stated the institutions were a purgatory for any human being.

Edgerton's longitudinal study of mildly handicapped deinstitutionalized adults sensitized the reader to the feelings, emotions, hopes, and desires of those
labelled retarded. The reader became aware of a person behind the label. The mildly mentally retarded person became someone that could be identified with and understood by the reader. Edgerton created an awareness of the coping mechanisms and the inner feelings of the hitherto unbiographed lives of the mentally retarded. Edgerton’s research methodology was participant observation in the daily lives of the mentally retarded people he studied:

Since this research was dedicated to learning about the problems of mental retardates in the community by observing and participating in the lives of such persons and by permitting them to present their own lives in their own words, the interview schedule, though focused upon certain information areas, was very loosely structured (Edgerton, 1967, p. 21).

Edgerton’s approach introduced the anthropological tradition to the field of mental retardation. His study, insofar as it was possible, attempted to see the mildly mentally retarded through their own eyes and to document their experience in their own words. Edgerton’s work was a first in the field of mental retardation and presented new insights into and about people labelled mildly mentally retarded. The utilization of participant observation proved to be a useful methodology and contributed to the understanding of the mildly mentally retarded.

The Braginsky’s (1971) work studied the capabilities of the mildly mentally retarded to exhibit psychological impression management and ingratiation strategies. They used an experimental design to explore and provide evidence for the similarity of psychological strategies between those labelled mildly mentally retarded and their extramural peers. The Braginsky’s work develops a concept of mild mental retardation as a ‘surplus population.’ Society controls unwanted children through labelling them retarded and institutionalizing them. The
Braginskys' call this method of controlling unwanted children "social sanitiation."
The poignancy of the Braginskys' interviews with mildly mentally retarded adolescents moves the reader to question the concept of mild mental retardation. The reader becomes attuned to the reality of the inner feelings and thoughts of the mildly mentally retarded.

Mercer (1973) through analysis of the population labelled mentally retarded in a typical American city throws further doubt on the validity of the concept of mild mental retardation as her results show a disproportionate number of minority groups represented in the mildly mentally retarded school aged population than one would expect from the prevalence rates. The meaning of mild mental retardation becomes questionable as Mercer analyses the labelled people and discovers that white middle class children are not labelled to the same extent as the poor, the black, and the Mexicans.

Bogdan and Taylor (1981) use interviews with two people labelled mildly mentally handicapped to gain an understanding of mild mental retardation from the labelled people. The lives of the two people that are interviewed are full of emotion and meaning. It is not a drab world for the two subjects but a world rich in feelings and symbolic meanings. The reader develops an awareness and understanding of these two peoples' lives and is richer and more informed from understanding how these two people cope, adjust, and attach meaning to their world. Bogdan and Taylor use participant observation as the methodology to research the world of the two participants. The interviewers developed rapport with the participants to obtain information from an "insiders" perspective on their lives, and the effects of being labelled mildly mentally retarded. The profound effects of stigma and how the identities of the participants are spoiled from the
effects of being labelled retarded is developed by Bogdan and Taylor. The participant’s point of view is presented in his own words and from his perspective.

Prior to these studies experimental quantitative research had dominated the field of mental retardation. Social scientists had not employed ethnographic methodologies for the study of mental retardation.

Anthropological and sociological methodologies have provided new insights into the care, treatment, and labelling of the mildly mentally retarded. These insights provided new knowledge on the topic of mental retardation and provided a look at the social world of the mentally retarded. The effects of labelling, the inner feelings of the mildly retarded, and the diagnosis and induction of marginal societal members into the ranks of the mentally retarded. Overall these methodologies presented evidence that:

The “retardates,” not unlike their extramural peers, display power strategies, adaptive styles, and ability to take into account the roles of others in their own behavioral choices. In short, they are not psychologically different from other specimens of humanity (Braginsky & Braginsky, 1971, p. iv).

The mildly retarded have received the benefit from sociological and anthropological research. The PMR have yet to benefit from this form of research methodology. Many reasons are given for the lack of research into profound mental retardation. Taylor and Bogdan (1981) state that difficulty in communicating with the PMR is one reason. The varied etiological composition of the PMR is another reason that is cited (Snell, 1982). Another stated reason is the PMR have unusual habits, that of pica and coprophagy. These habits serve as an effective barrier to research due to the abhorence of these practices by researchers (Cleland, 1979).
F. THE PURPOSE OF THE STUDY

This study is designed to provide descriptions for the purpose of developing analytic abstractions for understanding the behaviors of five PMR adults living in a group home. The study does not detail a comparison of their behaviors in the group home to their behaviors in an institution. The purpose of the study is to observe their new life using field research techniques. The concern is to develop theory, based on the data collected during the study, for the benefit of the PMR.

Presently there is a dearth of information concerning the subjective state, inner feelings, and activities of deinstitutionalized PMR. The research design is to observe the participants in their daily activities to develop an awareness of their everyday conduct and what they actually do in the course of living their lives. The participants' emotional responses will be observed as method of understanding their subjective world. To my knowledge, the literature contains no such systematic description. If decisions are to be made concerning the quality of life, living conditions, and treatment of the PMR, then something of their wants, needs, and desires must be expressed on their behalf.

The entire field of mental retardation, and especially at the level of the PMR, has been handicapped by our failure to recognize retardates as humans, not dieties, and possessed of both good and bad qualities. They are not "Angels Unaware" but people. Our emotional blinders have slowed knowledge production (Cleland, 1979, p. 22).

The observations will be utilized to develop a phenomenological understanding of the role and world of PMR persons. The need to develop theory for understanding the actions and behaviors of the PMR in group homes is much needed to contribute to the body of knowledge on profound retardation (Cleland, 1979; Craig & McCarver, 1984; Edgerton, 1983; McAndrew & Edgerton, 1964;
G. MAJOR CONCEPTS AND DEFINITION OF TERMS

This study examines a group of profoundly retarded deinstitutionalized adults in a community setting. The central concepts and terms used in the study are;

1. Mental Retardation
2. Sensory Deprivation
3. Institutionalization/Deinstitutionalization
4. Stereotyped Behaviour
5. Emotions
6. Inside/Outside
7. Adaptive Behaviour/Maladaptive behaviour
8. Symbolic Interactionism
9. The Paradox of Deprivation

The above concepts, one of which is an analytic abstraction were emergent throughout the research process. Some were developed prior to data collection, others during the data collection and yet, others while the data was being analyzed. The concepts of mental retardation, institutionalization and deinstitutionalization, adaptive behavior, stereotyped behavior, and symbolic interactionism were familiar to the researcher before the data collection started. During the data collection phase the concepts of emotions and deprivation, and inside/outside emerged as the data collection progressed. Finally, during the analysis of the data the paradox of deprivation and the search for evidence in the 'normal' population of the effects of deprivation emerged as a central concern.
to the researcher.

The profoundly mentally retarded are often compared to non-human primates (Berkson, 1967; Hollis, 1978; Lewis & Baumeister, 1982 McAndrew & Edgerton, 1964).

In at least certain respects, then, they are less human than some infra-human species. In short, the relationship between language, social interaction, and rule-oriented behavior is available here in vivo in a manner different from that found either among normal humans or normal non-humans (McAndrew & Edgerton, 1964, p. 328).

The researcher, in the course of the study and during the data analysis, became interested in comparing the development of stereotypic behavior in normal humans rather than the non-human primate studies. The importance of recognizing the PMR as humans, has importance, in terms of theoretical and practice issues.

The emergence of the major concepts during all phases of the research process is not uncommon in field research, where theory arises from the data. During the data analysis, while developing analytic categories for coding the data, an emergent concept developed for the explication of stereotyped behavior in the PMR. The emergence of this concept required linking theory and research in normal humans on their adaptation to monotonous, depriving, and boring environments and the behavior of the PMR.

In the following section the above terms are operationally defined as they are used in the context of this study.
1. Mental Retardation

Mental retardation refers to significantly subaverage general intellectual functioning, resulting in, or associated with, deficits or impairments in adaptive behaviour, with onset before the age of 18 years (D.S.M. III, 1980, p. 36). There are four classifications or subtypes of mental retardation reflecting the degree of intellectual impairment the individual displays. The subtypes are based on standardized intelligence test scores as shown in Table 3 (D.S.M. III, 1980, p. 39).

<table>
<thead>
<tr>
<th>Subtypes of Mental Retardation</th>
<th>IQ Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>50-70</td>
</tr>
<tr>
<td>Moderate</td>
<td>35-49</td>
</tr>
<tr>
<td>Severe</td>
<td>20-34</td>
</tr>
<tr>
<td>Profound</td>
<td>Below 20</td>
</tr>
</tbody>
</table>

The vast majority of the mentally retarded are in the mild range, approximately 80%. The moderate range accounts for approximately 12%, the severe range about 7% and the profound range around 1% (D.S.M. III, 1983; Fink & Cegelka, 1982).

This study is concerned with the profoundly retarded and does distinguish between the two categories of severe and profound retardation. This distinction is important as the severely retarded do develop some verbal communication skills
and manifest higher adaptive behavior (Cleland, 1979; Snell, 1982; Westling, 1986). All of the participants in the study were untetable, did not have even a single word for their vocabulary and thus were incapable of responding to test questions. Furthermore, all of the participants in the study were in need of total care and did not manifest any semi-independent living skills.

In contrast to the profoundly retarded, the severely retarded by adolescence will manifest some useful speech in most instances. Most severely retarded will attain adult mental ages of around years 3.5 - 4 whereas profoundly retarded mental age attainment will cluster at about 2 - 2.5 years. (Cleland, 1979, p. 3)

Other differences noted between the severe and profound levels include, the increased incidence of motor, sensory, physical handicaps, and earlier age of death for the PMR (Westling, 1986)

2. Sensory Deprivation

Sensory deprivation (SD) or as Suedfeld (1980) prefers to call restricted environmental stimulation (RES) refers to experiences which reduce the stimulation, the patterning, and expose the individual to a monotonous environment. RES refers to many experiences, which include reduction of absolute levels of stimulation, of meaningful patterned sensory input, of separation of family, especially the mother, and monotony. The severely and profoundly retarded are deprived by their institutionalization from their parents, from early childhood stimulation, and instead are exposed to a routinized, depersonalized, and physically restricted environment. Possibly boredom is a close correlate to deprivation. The concept of deprivation is one of understimulation for the individual.

Most authors and researchers in SD agree that profound changes occur
during SD or RES. There is a consensus that the individual experiences hallucinations, or retinal visual phenomena, disturbances of cognitive processing, and childish emotional responses (Heron, 1957; Schultz, 1965; Suedfeld, 1980; Zubek, 1969). There is accord that these effects are determined by the reticular formation in the brain stem. The reticular area if it is not aroused by environmental stimuli develops patterns on its own when understimulated. SD or RES is believed to have profound effects on children, even when exposed to SD. The results of studies while inconclusive is suggestive that the deleterious effects are life long for these children (Friedman et al., 1968; Fiske & Maddi, 1961).

3. Institutionalization/Deinstitutionalization

Institutions have been characterized by Goffman (1961) as places where a “person’s self is mortified” (p. 14). Goffman defines an institution as a setting where there is:

(a) a barrier between the person and the world,
(b) admission and processing procedures that deny self,
(c) social distance between the inmates and the staff,
(d) denial of information about yourself,
(e) rigidity of routine,
(f) block treatment of people, and
(g) depersonalization

Institutions for the retarded have been documented as fulfilling the above criteria (Blatt, 1970; Blatt and Kaplan, 1966; Biklen, 1971).

Deinstitutionalization refers to the removal of a person from an institution to a community home. However, it is a moot point whether a community home
is or is not an institution;

As is described in these chapters, the circumstances on community placement for many retarded persons are institutional in nature. One prominent fact of this situation is that these retarded individuals have no more control of most facts of their existence than they did in the state hospital (Bercovici, 1983, p. 189).

4. Stereotyped Behaviour

Stereotyped behaviour refers to:

highly consistent and repetitious motor or posturing responses which are excessive with respect to rate, frequency, and/or amplitude and which do not appear to possess any adaptive significance (Baumeister, 1978, p. 354).

Stereotyped behavior is a common phenomena in institutionalized PMR;

Anyone who has worked with severely and profoundly retarded individuals, particularly in institutional settings, cannot but be impressed by the frequency with which these individuals exhibit highly repetitive and rhythmical behaviors that are often very bizarre in character and which seem, on the surface, to be devoid of any adaptive significance (Baumeister, 1978, p. 353).

Common stereotypic behaviour includes finger staring, hand waving, head banging, and circle walking (Baumeister, 1978; Cleland, 1979; Hollis, 1978). These behaviours are not understood with respect to why they occur or why individuals maintain these behaviours in their repertoires (Baumeister, 1978; Berkson, 1967; Lewis & Baumeister, 1982; Hollis, 1978).

Stereotypic behaviour is often referred to as "self-stimulatory behavior" (Arkell, 1982). Baumeister (1978) discourages the use of this term as it implies that the function and adaptive significance of stereotypic behaviour is in fact for self-stimulation and this relationship has not been clearly established.

One study which used a field research methodology to study sixteen
retarded children in their residential and school settings recorded observations to support the self-stimulatory hypothesis for stereotypic behaviour.

Self-stimulation was observed frequently among the residents in the current study. It was often a response to boredom or frustration. It was a way of providing activity for oneself. In addition self-stimulation was also observed to serve two other functions. One, self-stimulatory behavior served as an attention gaining device. Two, it was also used as a mechanism for gaining privacy - a way of retreat (Arkell, 1982, p. 229).

Stereotypic behaviour is not clearly understood as to its function or adaptive significance. A review of the literature in Chapter II will include the theories related to stereotypic behaviour.

5. Emotions

Emotions are defined in this study as a person's evaluation of the environment with an accompanying physiological response. Thus, cognitive appraisals are a prerequisite to an emotional response (Arnold, 1960; Lazarus, 1968; Schachter, 1970). Emotional reactions are determined by an individual's interpretation of a situation or event.

Emotions, therefore constitute a communication between people. One person can understand the inner state of another person if that person is emoting. In a situation where people do not have a symbolic language system the emotional response of the other person can become a primary system for understanding that person's reaction to the specific incident.
6. Inside/Outside

Inside refers to the state of mind, thoughts and mental activities of a person. Inner being includes the day dreams, visual scenes, thought patterns, and inner mental life of the person. Inside is how the person appraises the environment and the emotional responses that are elicited. The inner life of a person is the essence of who they are to themselves (Solomon, 1976). When we are alone and without stimulation it is our thoughts, the patterns we see inside our minds, the voice we speak to ourselves with, and the voice which answers.

Outside is other people, it is interaction with the environment. Outer life is the sensory flow of stimuli that is other people. Our interaction with the environment constitutes our outer self. It is who we are socially. Outside is external and the antithesis of inside.

The concept of antithesis is entered into the discussion in relation to the ascribing of meaning to the world. When a person is inside he or she can day dream and not necessarily react to the outside. The outside events and people dimish and become faraway as we day dream or fantasize in our minds. Often we are rudely awakened to the “reality” of the outside world from a reverie to discover that we have missed a significant cue and are out of touch with the outside. Such an example is the familiar scene of a student engaged in a day dream and is suddenly brought back to the reality of the classroom discussion when he discovers that the teacher or professor has asked him a question and is waiting for an answer and the student is unaware of the question let alone the answer.

The degree to which a person develops internal fantasies, patterns, reveries, and inner life is significant. The notion of a dreamer out of touch with
"reality" or a person whose "feet are not on the ground" are not uncommon statements to hear in our society. The interpretation of these statements is usually that the person is living in a world of their own creation and does not correspond to the external world.

In the middle or the synthesis between inside and outside is the cultural learning of the individual. The midway point between inside and outside is how we interpret the environment, interact with it, and define and are defined by the environment and people in our social network.

7. Adaptive/Maladaptive Behavior

Adaptive behaviour is the effectiveness or degree with which an individual meets the standards of personal independence and social responsibility expected of their age and cultural group (Grossman, 1977). Adaptive behaviour is the measure of the degree to which an individual experiences success in adapting to the demands of his/her environment. The norms of the individual's immediate social group as well as those of the larger environment must therefore be taken into account when evaluating adaptive behaviour (Stack, 1984).

Maladaptive behaviour is the degree to which a person experiences significant difficulties in meeting the the demands of the environment. The concept of maladaptive behaviour is key in this study (Grossman, 1977; Snell, 1982; Stack 1984). Whether a behaviour is adaptive or maladaptive must be assessed in the context of the person's environment, history, and social group (Seltzer, Sherwood, Seltzer, Sherwood, 1981). Adaptive behaviour cannot be based solely on the imposition of one culture's ethnocentric interpretation of adaption as necessarily correct.
8. Symbolic Interactionism

The symbolic interactionist perspective is central to this study. The concept that the individual is not driven solely by inner needs but is also defined by other people is paramount to the understanding of human behavior. The notion that there is a "self" that is distinct from an ego and is a result of social interaction by other people was developed by Mead (1934) and Blumer (1969).

The construct of the "self" from this perspective is unique for:

The self is not seen as lying inside the individual like the ego or an organized body of needs, motives, and internalized norms or values. The self is the definition people create (through interacting with others) of who they are. In constructing or defining self, people attempt to see themselves as others see them by interpreting gestures and actions directed towards them and by placing themselves in the role of the other person. In short, we come to see ourselves in part as others see us. The self is thus also a social construction, the results of the persons perceiving themselves and then developing a definition through the process of interaction (Bogdan & Biklen, 1982).

This development of the socially constructed self allows for a perspective on the individual and society that the psychological construct of the ego does not permit. The construct of the "self" along with another important symbolic interactionistic construct, the "generalized other," provides a theoretical framework for increased understanding of the individual, social behaviour and society.

The "generalized other" construct was also proposed by Mead (1934). The developmental sequence of the "generalized other" starts at birth with the gradual awareness of the infant of "I-ness." That is the infant's ability to distinguish himself in terms of his own body, actions, and thought as distinct from the world and to be able to identify which is which (Schwartz & Jacobs, 1979). The next development that occurs is the child's awareness
and experience of other people as "you's." This is the child's recognition that other people have thoughts, feelings, motives, and emotions. At this stage it becomes possible for the child to mentally picture and imaginatively experience "you's" as having an inner life like their own without actually being able to hear their thoughts or experience their feelings and moods which is inferred from their outward observable behaviors.

The final stage is the development of "me-ness." People look at themselves introspectively, their actions, appearance, and inner dialogue. How do people look at themselves? Mead's theory was that it was from the perspective of the "generalized other" or as the person believes other people see him. That is, in essence, to see ourselves from another person's viewpoint. The perspective of symbolic interactionism allows a distinctively sociological conception of the self.

The person develops a subjective interpretation of the outward actions of others and ascribes inner feelings, thoughts and motives to these actions. The person then anticipates the responses of other people to their own actions and can modify their actions before they are performed on the basis of their anticipation of other people's responses. People thus become "self-conscious" of the reactions of others whether real or imagined. Thus the generalized other is internalized. "With the general ability to see oneself and one's acts from the standpoint of another human observer, it becomes possible to construct more specific generalized others" (Schwartz & Jacobs, 1979, p. 23).

The symbolic interactionist perspective has profound implications for social action for the individual self and social actions are united and
mutually influenced. Objective reality is obscured and subjective meanings become important. Blumer saw meaning not as objective fact;

It does not regard meaning as emanating from the intrinsic makeup of the thing, nor does it see meaning as arising through the psychological elements between people. The meaning of a thing for a person grows out of the ways in which other persons act toward the person with regard to the thing. Their actions operate to define the thing for the person; thus, symbolic interactionism sees meanings as social products formed through activities of people interacting (Blumer, 1969, p. 4-5).

This way of conceptualizing the self, the generalized other, and subjective meaning through the interactive process led to the development of research into the self-fulfilling prophecy and the study of the effect of "labelling" people (Bogdan & Biklen, 1982). This perspective has profound implication for the study of the PMR participants in this study.

9. The Paradox of Deprivation

A central concept of this research is the paradox of deprivation. The paradox is that the individual's reaction to deprivation is to create an inner world. The individual in coping with nothingness finds everything. The person when confronted with "nothing" from the outside creates an inner life that is complete, involving, and no longer seeks or needs interaction with the outside (Burney, 1961).

This paradox of deprivation has been explored by various authors (Berne, 1961; Burney, 1961; Heron, 1957). The concept that a depriving, monotonous, boring condition leading to profound changes in the individuals is not new. The changes include hallucinations, emotionality, and unusual behaviour.

Prolonged exposure to a monotonous environment, then, has definitely deleterious effects. The individual's thinking is impaired; he shows
childish emotional responses; his visual perception becomes disturbed; he suffers from hallucinations; his brain-wave pattern changes, (Heron, 1957, p 56).

Paradoxically, continued exposure to a monotonous and nonstimulating environment results in the individual developing an inner life that becomes a compensation, is preferable to interruptions from the outside. The inside life triumphs over the outside life. The individual does not go through, as Goffman (1961) claims, a mortification of the self but actually becomes a complete social unit unto him/herself not wanting the 'outside.' The paradox is that in the deinstitutionalization of long term institutionalized PMR adults the change of environments should serve to create new needs and should help to dismantle the barrier of self-isolation, however the autonomy of the individual appears to maintain itself through the change and to manifest itself in stereotyped behavior.

As previously mentioned the neurophysiological theory is that the reticular area of the brain manufactures patterns in response to lack of sensory input. The individual in essence creates his own stimulation. This stimulation is not observable by anyone else (Robertson, 1961).

H. SUMMARY

These terms and major concepts are used in the study which explores the subjective states and daily lives of a group of five profoundly retarded nonverbal deinstitutionalized adults in a group home. The following chapters will present; a literature review, the research methodology, the data collection, the results, implications for a theoretical understanding of the profoundly retarded, limitations of the study, and areas of further research.

The following chapter will review the literature on the profoundly mentally
retarded, stereotyped movement, institutionalization, sensory deprivation, and emotions.
CHAPTER II. REVIEW OF THE LITERATURE

This chapter will present a review of the literature on profound mental retardation. The review will include the following areas; (a) studies of the profoundly retarded, (b) stereotypic movement, (c) institutionalization, (d) sensory deprivation and (e) emotions. A review of each of these areas follows.

A. THE PROFOUNDLY RETARDED

Field research and ethnographic studies have not been utilized to advance the knowledge or understanding of the PMR (Taylor & Bogdan, 1982). The literature contains no ethnographic studies on the deinstitutionalized PMR. MacAndrew and Edgerton's (1964) ethnographic study of an institutional ward for the PMR concludes;

In summary, the whole area of mental retardation is, for the social scientist, a research backwater; and profound mental retardation is totally ignored (MacAndrew & Edgerton, 1964; p. 319).

The PMR, still have not been the topic of research for ethnography eighteen years later (Taylor & Bogdan, 1982). There are a number of reasons why they have not been the subjects for social science research. Field research or ethnography usually includes interviews with the subjects or participants in the study. The PMR do not develop oral language. The unusual, aggressive, and bizarre behavior of the PMR is another research barrier. The PMR are a small minority of the population. Finally, the PMR have largely been institutionalized and not been part of community life.

The majority of the studies of the PMR are on the institutionalized population (Cleland, 1979). The research that has been performed has been applied behavior analysis research (Snell, 1982). Unfortunately, many of the
studies use severely and profoundly retarded as their population and do not
distinguish between the two groups. Cleland (1979) discusses the difficulties of
this methodological error as it confuses the results of the severely retarded with
the profoundly retarded.

Prior to the 1970s the emphasis was on the classification and diagnosis of
the PMR. The PMR were labeled 'crib cases, low grades, vegetables, idiots, and
untrainable' (Bogdan & Biklen, 1977; Campbell & Bricker, 1984; MacAndrew &
Edgerton, 1964). The PMR are more likely to exhibit motoric, structural,
chromosomal, or sensory abnormalities than the less retarded (Berkson &
Landesman-Dwyer, 1974; Cleland, 1979; Snell, 1982).

The presence of a high degree of maladaptive stereotypic, self injurious,
and antisocial behavior in the profoundly retarded have been reported and
described by many researchers (Baumeister, 1978, Baumeister & Foreman, 1973;
Baumeister & Rollings, 1976; Berkson & Landesman-Dwyer, 1974; Cleland, 1979;
Hollis, 1978; Foreman & Baumeister, 1973). Stereotypic movement is so prevalent
in the PMR that it is used as a measure of the degree of retardation (Snell, 1982).

The PMR are the most commonly institutionalized group of those classified
as retarded (Eyman & Miller, 1978). The highest degree of stereotypic movement
and self-injurious acts is found among the institutionalized PMR:

Anyone who has worked with severely and profoundly retarded
individuals, particularly in institutional settings, cannot but be
impressed by the frequency with which these individuals exhibit highly
repetitive and rhythmic behaviors that are often very bizarre in
character and which seem on the surface, to be devoid of any

There was a shift in the 1970s in the scientific literature to a focus on
behavioral research and an experimental orientation with the severely and profoundly retarded (Berkson & Landesman-Dwyer, 1977 Edgerton & Langess, 1980). Berkson & Landesman-Dwyer (1977) use a methodology called applied behavior analysis and demonstrate that the severely and profoundly retarded can learn through operant conditioning and behavior ‘shaping’ in laboratory and restricted settings.

The results of applied behavior analysis on the severely and profoundly retarded were favourable to the extent that results demonstrated the PMR do acquire new skills. The problems of the behavior modification approach include:

- individual variability in acquisition rates,
- finding suitable reinforcers,
- programming of task sequences,
- failure to generalize beyond the training situation,
- lack of follow-up after training,
- and the dilemma involved in using aversive techniques (Berkson & Landesman-Dwyer, 1977, p. 432).

The above problems with applied behavior analysis have continued to be as valid in 1987 as they were in 1974. A further problem of the applied behavior analysis methodology is its total disregard of theory which could ultimately be detrimental to the PMR (Berkson & Landesman-Dwyer, 1977). These difficulties should not cloud the important contributions of this research over the past 30 years which has demonstrated that the PMR do learn and change and are not just ‘vegetables.’

Ethological research has been utilized as a methodology for the severely and profoundly retarded. The ethological approach emphasizes direct observation of discrete units of behavior in restricted settings (Sackett, 1978). Ethological studies have been few in number (Sackett, 1978, Vol. 1 & 2). The limitations of ethology are the arbitrary nature of dividing continuous human behavior into discrete units, the difficulty in measurement of movements, and ecological validity.
(Langess & Edgerton, 1978).

The PMR have been omitted as research subjects for many reasons, which are stated below;

(1) difficulty in measuring IQ and therefore in matching, describing, and grouping the subjects; (2) a prevalence of behavior problems; (3) an absence of language; (4) heterogeneity of etiology; and (5) the frequency of physical and emotional handicaps (Snell, 1982, p. 296).

Cleland (1979) states that the repugnant social habits of the PMR also contributes to their exclusion as research subjects;

Abhorence of coprophagy in humans has served as an effective barrier to research (Cleland, 1979, p. 52).

The literature on the PMR does not describe the behavior, social patterns, or daily activities in community settings in a holistic manner. The research is limited to applied behavior analysis, ethology, and institutional settings. The need for studies of the PMR in natural settings is a goal;

It is the consensus of the literature, if we are to improve our understanding of mentally retarded persons, we must study their lives holistically, where they occur, rather than in laboratories, we must listen to these people as they express their own views of their lives (Edgerton, 1984, p. 2).

The above sentiment is expressed by many researchers (Bercovici, 1983; Landesman-Dwyer, 1982; Edgerton, 1982, & 1984; Bogdan, 1983). A research methodology that will answer the need for ecological validity, absence of verbal language, and abherant behavior, is expensive and time consuming. Ethnography, field work, or participant-observation is a research methodology that meets these requirements. There are no ethnographic studies currently of the PMR in community homes.

The difficult task of a research study to describe the daily living and
subjective state of the PMR has been stated in the literature (Bercovici, 1981, 1984; Bogdan & Taylor, 1981; Edgerton, 1984, Edgerton & Langess, 1980; Gollay, 1981; Okolo & Guskin, 1984). There is no literature available on the subjective states of the PMR (Taylor & Bogdan, 1981), their emotional responses (Snell, 1982) and their lives;

Because of the rarity of the profoundly mentally retarded little is known about them outside of the institutions, (Cleland, 1979, p. 5).

The literature on the PMR has through applied behavior analysis demonstrated the PMR do learn 'new behaviors. The reports of stereotypic behavior, self-injurious acts, and antisocial behavior has resulted in requests for increased research with the PMR. There is present in the literature a group of authors who have called for qualitative studies on the PMR. There is a consensus in the literature that the development of theory for the PMR is weak and in need of attention. The PMR have not received a great deal of research attention, and the literature contains a significant amount of articles and reports that request more research to correct this omission.

It has been questioned whether the PMR even have emotions (Cleland, 1979). The emotions of the PMR, or their subjective states, has been raised as an important research concern;

Just because people's subjective states may not be directly accessible to us - as in the case of nonverbal retarded persons' - this does not mean that they do not have subjective states. If we have not understood the severely disabled person, it is because we have not attempted to do so (Taylor & Bogdan, 1981, p. 78).

The literature, overall, calls for increased research, holistic studies, descriptive works, and the development of theory concerning the PMR.
B. STEREOTYPIC BEHAVIOR

Despite the stereotyped behavior present in the severely and profoundly retarded very little is known about this phenomenon (Baumeister, 1978; Foreman & Baumeister, 1976, Hollis, 1978 Lewis & Baumeister, 1982). Baumeister & Foreman (1973) and Baumeister & Rollings (1976) have done inclusive reviews of the major theoretical perspectives concerning stereotyped movements. Each perspective seems to have some empirical evidence in it’s support (Baumeister, 1978).

The theoretical perspectives on stereotyped movement can be divided into school, those which place an emphasis on: 1) environmental deprivation, 2) organic and central nervous system impairment, 3) developmental aspects of maturation, and 4) learning.

1. The Deprivation Theory

The deprivation theory of stereotypic behavior, relates the development of stereotyped movement to deprivation in the development period (Baumeister, 1978; Berkson, 1973). The psychoanalytic belief is that it is due to a disruption in the mother-infant interaction (Baumeister & Foreman, 1976). The concept that sundering the mother-infant relationship causes stereotypic behavior has experimental support in primates who are removed from their mothers. Rhesus monkies separated from their mothers exhibited stereotyped movement whereas the control subjects left with their mothers did not exhibit this behavior (Berkson, 1973; Harlow & Harlow 1962).

The deprivation theory of stereotyped movement does not just focus on the mother-infant relationship but includes the amount of sensory stimulus present in
an environment. Experiments with adults in sensory-deprived environments have resulted in unusual experiences (Heron, 1957, Suedfeld, 1980; Zubek, 1969). The results of sensory deprivation experiments lead Berne (1961) to state that an adequately stimulating environment is paramount in the development of the person.

The ability of the human psyche to maintain coherent ego states seems to depend upon a changing flow of sensory stimulus. (Berne, 1961, p. 77).

Deprivation theory does not solely use the mentally retarded as their population to explain stereotypic behavior. Abuse, early hospitalization of children, confinement, and isolation especially in childhood are known to elicit bizarre behaviors (Baumeister, 1978, Friedman et al, 1968; Fiske & Maddi, 1961; Suedfeld, 1980). Research on sensory deprivation on ‘normal’ adults has shown that deprivation creates retinal visual phenomena (hallucinations), childish emotional reactions, and perceptual difficulties in a short time (Heron, 1957, Schultz, 1965; Suedfeld, 1980).

This has caused many authors in the field of mental retardation to hypothesize that institutions are depriving and unsuitable environments for the mentally handicapped (Bogdan & Taylor, 1982; Nirje, 1976; Wolfensberger, 1976). The institutionalized severely and profoundly retarded person exhibits more stereotyped behavior than non-institutionalized people (Baumeister, 1978; Bogdan & Taylor, 1982; Snell, 1982).

When institutional neglect and deprivation result in ‘maladaptive behavior’—for example, rocking and head banging—it is attributed to the condition of the inmates. Do labels help? Are labels useful? For the persons to whom they are applied—the judged—no. (Bogdan & Taylor, 1982, p. 16).

There are a number of descriptive features of stereotyped movements
that warrant some attention. For one, these behaviors seem to be related to institutionalization (Berkson & Davenport, 1962; Kauffman, 1967; Maisto, Baumeister, & Maisto, 1978). The common assumption is that there are debilitating factors in the institutional environment that initiate and maintain stereotypy (Baumeister, 1978, p. 355).

Among those residing in institutions, the incidence of abnormal stereotypies may be even greater. Berkson and Davenport (1962) and Kaufman and Levitt (1965) have observed about two-thirds of their samples engaged in some form of rhythmical movements, although a great deal of variability was evident with respect to the frequency, intensity, and topography of the behavior (Lewis & Baumeister, 1982, p. 124).

One difficulty is that the interpretation of deprivation causing stereotypic behavior rests on the assumption that institutional environments are depriving ones and not all authors agree with this assumption (Baumeister, 1978). There is evidence that indicates that environments that are depriving result in stereotypic movement.

The conclusion that stereotyped pacing and other mannerisms are caused by restraint or confinement seems warranted by both animal and human data (Lewis & Baumeister, 1982, p. 138).

Arkell (1982) refers to stereotypic behaviour as self-stimulatory behaviour throughout her study. The results of her research on sixteen severely and profoundly retarded children add a new dimension to the perception and interpretation of stereotypic behaviour.

It seems clear that for some children self-stimulation represents a way to escape from or avoid interaction. These children seem to engage in self-stimulation for the purpose of creating an intrapersonal space around them (Arkell, 1982, p. 491).

Arkell’s view of stereotypic behaviour as self-stimulatory and self serving presents a different and unique perspective for these behaviours. Arkell includes not only avoidance but also attention seeking through stereotypic behaviour.
Several incidents in the field notes suggest that three children engaged in self-stimulatory behaviour for the purpose of gaining staff attention (Arkell, 1982, p. 236).

Arkell summarizes her viewpoint on stereotypic behaviour:

It is postulated that retarded individuals self-stimulate because they are bored, frustrated, upset, or even hungry. Although the present study did not focus on self-stimulatory per se, observations indicate the validity of these findings as reported in the literature. In addition, the present study indicated that self-stimulation may serve two additional functions among profoundly retarded institutionalized children (Arkell, 1982, p. 491).

The hypothesis that an understimulating environment results in the individual compensating by performing self-stimulating behaviors through a homeostatic mechanism within the individual is the theoretical basis which underlies this school of thought on stereotypic behavior. Baumeister questions this theory:

At this point, as intuitively appealing as the theory seems, the self-stimulation interpretation seems too vague and general, lacking the precision necessary to differentiate critical variables that, on the one hand, initiate the behavior, and on the other maintain it. Indeed, a persuasive argument may be made that stereotyped movements actually induce a state of stimulus deprivation. (Baumeister, 1978, p. 362).

2. The Central Nervous System Damage Theory

The central nervous system damage and organic damage school correlates the degree of stereotyping with low IQ. This, Baumeister (1978) agrees, is a possibility since stereotyping behavior and severe and profound retardation are positively correlated. What is not taken into account is people who are not severely and profoundly retarded who exhibit stereotyped movements.

There are descriptions of the blind, the autistic, and prisoners in solitary
confinement that exhibit stereotyped behavior (Baumeister, 1978; Burney, 1961). Further studies reveal that not all severely and profoundly retarded people exhibit stereotyped behavior (Lewis & Baumeister, 1982; Snell, 1982). It does not appear consistent that if central nervous system or organic damage is the causal factor that such a heterogenous group under different circumstances would exhibit stereotyped movement.

There is evidence from neurophysiological research that deprivation effects the brainstem, particularly the reticular formation. A brief summary of this research and theory states;

Here is a neurophysiological explanation for stimulus hunger, as well as for the vivid memories, explorations of the self, and other phenomena reported by REST subjects. The formulation is also centrally relevant to theories that relate REST effects to changes in central arousal or activation of the organism (Suedfeld, 1980, p. 385).

The development of stereotypic movement could be a function of the reticular area.

3. The Developmental Theory

The developmental school is represented by Berkenson (1973) who states that stereotyping is an exaggeration and extension of behaviors that are normal at some point in the development of the higher primates including man.

Longitudinal studies reveal that a variety rhythmic motor patterns characterize normal human development during the period of infancy. A reasonable conclusion is that some forms of rhythmical and repetitious behaviors, such as body rocking, are, in fact essential to normal development of motor, social, and learning skills. (Baumeister, 1978, p. 360).
4. Learning Theory

The most recent contribution to theories on stereotyping are those from learning theory, which state that the social consequence of the behavior is why it is inserted into the person's behavioral repertoire (Spradlin & Girandeau, 1966). This seems a spurious argument, as often stereotyping occurs in situations on institutional back wards, where no social consequence or antecedent occur. Further, in cases of deprivation through isolation there is no social consequence for the actions that the individual exhibits (Burney, 1961).

5. Summary

Stereotyped behavior is a major phenomena observable in a majority of institutionalized profoundly retarded persons. It is an area in need of theoretical understanding and of ecological analysis and research (Baumeister, 1978). Regardless of theoretical school, it appears that stereotypies are a manifestation of a response to deprivation, whether it is an under stimulating environment, a sensory deficit (blind, deaf), separation of the mother and child, a confined environment, with or without a damaged central nervous system. The effects of metabolic disorder is a difficult area. One study concludes that the effects of deprivation for a group of children with a metabolic disorder negatively affected their development. A second group of children with the same metabolic disorder who had not experienced the deprivation were significantly higher in the areas of social and interpersonal behavior, language and comprehension, intelligence and personality adjustment.

It can be stated that PKU, with its biochemical substrate, is a most complex disorder. The evidence at this juncture suggests that the variations in outcome are in part related to the influence of early stress of physical immobilization, sensory restriction, and isolation
experiences (Friedman, et al., 1968, p. 302).

C. INSTITUTIONS

The focal point of this study is the care and treatment of the profoundly mentally retarded. The stereotypic behavior of the profoundly retarded population has already been noted. The profoundly retarded are the most frequently institutionalized. One issue is, whether institutional care, is in the best interest of this group, or whether community living is a better alternative. There are a number of opinions on this matter and, at best, the research findings are contradictory (Heller, 1984).

1. Arguments For Deinstitutionalization

Institutions have been criticized as depersonalizing, rigid, depriving, and self mortifying (Goffman, 1961). Biklen (1977) describes institutions for the mentally retarded as a form of “colonization” of the defined and labeled class of the population known as mentally retarded. The concept of colonization refers to a two class system where the ruling class exploit the colonial class, and control them (Biklen, 1977). In fact, many institutions did employ names like ‘Colony Farm’ where inmates worked for substandard wages, if any were paid at all, and were segregated from society (Biklen 1977; Wolfensberger, 1972, 1975).

Blatt & Kaplan (1966) presented photographic essays which testify to the atrocious conditions of institutions for the mentally retarded. The photographic essays depict the institutions as deprived inhuman environments that should be closed.

Braginsky and Braginsky (1971) provide evidence that institutions for the
retarded are 'surplus population control' centres. Their thesis is that society controls it's deviant and unwanted population through institutionalizing them. They give examples of parents who do not want their children, children who misbehave, and orphans being labelled as mentally retarded and subsequently institutionalized.

Bogdan and Taylor (1981) regard institutions as stigmatizing, demeaning, and not preparing the mentally retarded for community life. They, in a similar vein to Mercer (1973), view mild mental retardation as a social construction.

First, we regard 'mental retardation' as a crude metaphor, and we reject completely its reification to the status as an 'illness of the mind.' We do not believe (nor has it been demonstrated) that retardation is a real physical or intrapsychic state located somewhere in the heads of those who have been labeled 'mentally retarded.' Retardation exists, from our perspective, only to the extent that certain persist in calling certain other people retarded (Braginsky & Braginsky, 1971, p. 30).

These authors see the institutional population as mistreated, misdiagnosed, and scarred for life from the experience. It is often believed, that possibly the midly retarded can benefit from deinstitutionalization, however the need still exists for the more severely retarded. This has been rebutted;

Contrary to the usual stereotype that holds that severely disabled persons (i.e. those presently institutionaled) are proper candidates for institutions, the studies show that small-scale community facilities are especially important to severely handicapped persons, for with them there is a greater premium on individualization treatment attention and greater risk of the depersonalization characteristic of total institutions (Laski, 1980, p. 173).

Institutions have been regarded as detrimental for the care and treatment of the mildly and moderately retarded (Bogdan & Taylor, 1982; Braginsky & Braginsky, 1971; Mercer, 1973, Nirje, 1972; Wolfensberger, 1972, 1975, 1980). Institutions are now being used more and more as repositories for the severely
and profoundly retarded population. The mildly and moderately retarded have been deinstitutionalized and the severe and profound have been left in the institutions.

It has been commonly observed that institutions are gradually becoming populated almost entirely with behavior problems, the multihandicapped, and the severely retarded, all of which are difficult to serve in the community (McCarver & Craig, 1984 p. 115).

The care and treatment in institutions for the severely and profoundly handicapped has been documented as unfit for anybody (Bogdan & Taylor, 1982, Conroy & Bradley, 1985). The deprivation and inhumane conditions on one institution’s back ward was detailed by a mildly handicapped person, who was sent there as punishment, and gave an insider’s account of what took place on that ward:

When I first arrived there and saw all the people I thought, ‘Oh, no. What am I getting into now? What’s going to happen?’ There are all of these people just sitting around and rocking back and forth and back and forth. Some of them were pulling their hair and eating it. One was in a straitjacket. They had to keep her in it because she hurt other people. They were just sitting there looking at their hands and twirling them around. (Bogdan & Taylor, 1982, p. 133).

The photographic essays, the studies, and the reports on the condition of the institutions for the retarded became central to the debate concerning the treatment of this population. Wolfensberger (1972, 1975, 1980) opposes the institutionalization of the retarded on the grounds it is deviant, perverse, and devaluing for the mentally retarded. Wolfensberger supports the closure of the institutions for the retarded. This position is supported by many authors and researchers who ask for the development of community residential programs as alternatives to the stigmatizing experience of institutionalization (Blatt, 1970; Edgerton, 1967; Goffman, 1961, 1963; Nirje, 1972). This group’s main arguments
are:

1. institutions for the retarded are dehumanizing and depersonalizing,
2. institutionalization has adverse effects on child development and behavior,
3. large institutions are an obsolete concept in service provision and need to be replaced with small community based models of service delivery,
4. an institution is not the least restrictive environment for the retarded
5. all retarded persons regardless of functioning level can make progress if given the appropriate intervention strategies and programs (Sontag, Certo, & Button, 1979; Snell, 1982).

2. Pro-Institutionalization Arguments

One group which is in favor of institutionalization was summarized by Ellis (1979) as believing:

1. institutions for some retarded persons are the least restrictive environment,
2. there is little empirical support for the benefits of community placement for the severely and profoundly retarded,
3. existing research on community placement of the severely and profoundly retarded is a 'methodologist's nightmare' and has extrapolated results beyond what has been proven,
4. behavior modification programs with the profoundly retarded have not been proven through research in the literature to be effective,
5. community based programs that do not result in significant improvement should be closed (Ellis, 1979).
3. Neutral Position On Institutionalization

Finally, there is a third group, that takes a neutral position on the institutionalization issue. Their position has been stated by Zigler (1971) and Zigler & Balla (1976, 1977) who note that:

1. a majority of community placements have been for higher functioning individuals,
2. institutions and community placements are difficult to study and are not static predictable facilities but are diverse in their nature,
3. age, preinstitutional history, IQ, severity of physical, mental, and emotional handicaps are difficult to operationalize especially across studies,

4. Research Results On Deinstitutionalization

The debate over the institutionalization/deinstitutionalization of the mentally retarded is ongoing in the literature (Kleinberg & Galligan, 1983; Tsovoldt & Tsovoldt, 1983; Snell, 1982; Zigler, 1971).

Despite the lack of definitive research on the effects of institutionalization and the benefits of deinstitutionalization, the institutions are closing. The reasons appear to be more on moralistic, philosophical, humanitarian arguments than as a result of factual empirical evidence.

The results of deinstitutionalization research are mixed and often contradictory as to the benefits to the individuals (Edgerton, 1984; Heal &
The belief that deinstitutionalization would greatly improve the quality of life and functioning level of the retarded is a matter to be researched and not taken for granted (Bercovici, 1983; Brooke & Baumeister, 1977; Edgerton, 1984). Thus, while there was an initial optimism that deinstitutionalization would have a tremendous impact on the adaptive behavior of the mentally retarded, research at this point is bogged down (Heal & Fujiura, 1984). It has been stated that even the variables studied may not be relevant;

The emphasis on verification of hypothesis rather than the generation of theory, with the attendant constraints of operationalism, has led many researchers into ever more objective and precise exercises in the measurement of variables that are nowhere demonstrated to be the most relevant for prediction or understanding. (Edgerton, 1984, p. 3).

5. Summary

In summary, the institutions are characterized as unsuitable due to inhumane conditions, deprivation, and social stigma. Deinstitutionalization will occur because of the social perception of the institutional environment as depersonalizing, restrictive, and stigmatizing. It has been summarized that:

Abuse, drugging, isolation cells, straitjackets, unsanitary conditions, medical neglect, and an utter lack of programming characterize the worst of these institutions, but more subtle forms of neglect may be found at all of them (Bogdan & Taylor, 1982, p. XIII).

The theory that underlies the deinstitutional movement is; that the deprived environment and stigmatizing treatment the person receives results in deleterious effects on that person. Blumer (1969) states that who we are, is a result of how we are treated and perceived by others.

The symbolic interactionistic perspective states that the environment and
the social group which compose our social world determine how we perceive ourselves. Thus, the institutional experience of back wards, depersonalization, and devaluation could result in the person believing he is less than human. One person labeled mildly mentally retarded gave this account of the effect of placement on a ward in an institution:

I almost didn't make it. Then the big day came that I went from H to my first ward. I don't like the word 'vegetable' but in my own case I could see that if I had been placed on the low grade ward I might have slipped to that. I began feeling myself slipping. They could have made me a vegetable. (Bogdan & Taylor, 1982, p. 43).

Much of the deinstitutional movement is based on the premise that the social environment is important in the development of the person as stated in the symbolic interactionistic perspective. The social treatment of the person and the social structure of the situation determines the actions and behaviors of the person. The Principle of Normalization developed in Scandinavia may be viewed as an application of the symbolic interaction perspective to the mentally retarded (Bank-Mikelson, 1972; Gruneswald, 1972; Nirje, 1972).

The theory of 'normalization' (Nirje, 1972; Wolfensberger, 1972, 1975) states that the social and cultural context of a person is paramount to the perception society has of them as well as how they perceive themselves. Deviancy say the adherents to normalization is one of perception rather than objective fact. Deviancy may be changed as social perception changes.

The first institutions in the 1870's were not erected because the retarded were seen as a social menace, but in order to give them asylum from the public. In only twenty or thirty years after that, the approach reversed, and the retarded became reinterpreted as a menace, and society as needing protection from them. Finally there is the reversal of deviancy by restoration, rehabilitation, and reintegration, (Wolfensberger, 1980, p. 13).
Wolfensberger (1972) states that the mentally retarded will be viewed as deviant as long as they are institutionalized. The institutions will, by their segregated nature, actually make those institutionalized deviant because of the abnormal cultural context. The theory of normalization states that the mentally retarded population should be exposed to culturally normal living situations not abnormal institutional environments (Nirje, 1972).

The effect of the social and cultural environment on the development of the person underlies the severely and profoundly retarded population being deinstitutionalized. Today, in spite of the fact that research findings are contradictory, the institutions are being closed. The profoundly retarded are being sent to group homes in the community (Bruninks, 1981).

D. DEPRIVATION

The literature on the effects of sensory deprivation (SD) or restricted environmental stimulus technique (REST) has been reviewed by Suedfeld (1980) and Zubek (1969). The studies and empirical evidence of the effects of SD or as Suedfeld recommends more accurately naming this experimental procedure REST on humans is universally recognized as deleterious if the exposure is prolonged:

A changing sensory environment seems essential for human beings. Without it, the brain ceases to function in an adequate way, and abnormalities of behavior develop (Heron, 1957, p. 56).

As will be demonstrated throughout the following chapters, an absence of variety, i.e., an environment offering little or no stimulus change, is an aversive state which most men seek to avoid. Too long an exposure to unchanging sensory input produces, as will be seen, physiological, cognitive, perceptual, and affective impairments (Schultz, 1965, p. 1).

When a subject is put in an environment without patterned and unchanging stimulation, he may relax and fall into a state of lowered arousal and sleep, he may focus attention on his thoughts, or he may
keep scanning his introceptive and exteroceptive fields, for stimuli. Either an experimental set, or his own sensitizations to peripheral sensory changes, may initially lead to reports based on idio-retinal phenomena, inner ear noise, or illusions. Eventually the subject may become sensitized to more organized images whose site of origin lies higher in the nervous system (Zuckerman, 1969, p. 125).

Actually, stimulus reduction is a powerful way to elicit changes in a variety of psychological and behavioral processes (Suedfeld, 1980 p. ix).

Sensory deprivation is central to understanding stereotypic behavior and the care and treatment of the mentally retarded. It is believed that institutions are environments which deprive people of culturally normative experiences, of dignity, and of normal emotional experiences (Blatt, 1970; Blatt & Kaplan, 1966; Bercovici, 1983; Bogdan & Taylor, 1981; Edgerton, 1967; Braginsky & Braginsky, 1971; Biklen, 1977; Wolfensberger, 1975; Goffman, 1961).

The central tenet to all of the theories on stereotyped movement are also based on deprivation: deprivation of mother child experiences, deprivation of environmental stimulation, deprivation of social rewards, deprivation of organic completeness or central nervous system completeness. All of the theories in someway show a lack or deprivation of something. Profoundly mentally retarded people experience early institutionalization and often have central nervous system damage so it is difficult to isolate the particular depriving condition which creates and maintains the stereotyped movement.

Skeels and Dye (1939), in a classic study, report significant results on the effects of early environmental intervention. They took two children from an orphanage and placed them on a ward in a state institution for mentally retarded women, who stimulate the infants. The two children exhibited significant increases in intellectual development. Skeels and Dye in a later study, confirmed their earlier finding, by transferring thirteen children from an orphanage to
similar wards and comparing them, in terms of intellectual development, to
twelve children who remained in the orphanage. A year and a half later, the
children placed on the institutional ward, had increased an average of 27.5 IQ
points. The children who remained in the orphanage dropped an average of 26.2
IQ points in the same time period.

Skeels followed the children longitudinally, with a follow-up study after
three years and twenty-five years. Skeels (1942) reported that the experimental
group children retained their intellectual development in foster homes and that
the children in the orphanage decreased in intellectual ability.

In a follow-up study Skeels (1966) found that the thirteen children in the
experimental group enlarged the differences between the two groups in intellectual
performance. Indeed, all thirteen children were self-supporting, they had an
average of twelve years of school completion (one had a Ph.D.). In contrast, the
twelve children in the control group, half were in institutions and the median
grade completion was less than third grade, and one died in an institution in
adolescence. This study is one of the few longitudinal studies of children and
demonstrates striking differences due to differential stimulation in early childhood.
Kirk (1958; 1965) found similar trends in a series of studies on young mentally
retarded children.

Friedman, Sibinga, Steisel, and Sinnamon (1968) studied the effects of
sensory restriction due to separation from their families of children with
phenylketonuria (PKU a metabolic disturbance which results in severe/profound
retardation). They identified a group of PKU children whose parents had
identified hospitalization of their children before age 3 for an average of fifteen
days, and compared them to a group of PKU children who had not suffered
parental separation. The two groups of children, while approximately equivalent in severity of retardation initially, the authors concluded that the group of sensory restricted children displayed a greater degree of impairment in intellectual performance, communication skills, and interpersonal relations.

The results of this study while inconclusive are interesting and;

The possibility that such problems as PKU make the child more vulnerable to adverse effects of stimulus restriction, or that stimulus restriction is an exacerbating or catalytic factor in the development of some psychological sequelae of physical syndromes, is certainly worth investigating (Suedfeld, 1980, p. 127).

The above studies support the hypothesis that monotonous environments are detrimental to the mentally retarded and have significant effects on the intellectual and social development of the person. Baumeister (1978) wonders what the effects of a monotonous environment would produce on highly intelligent people as he considers causal factors for the profoundly retarded;

One need only imagine what might happen if people of superior intelligence were placed for long periods in situations in which stimulation is grossly lacking in such quality and/or quantity that the normal cuing properties of the physical and social environment are severely disrupted (Baumeister, 1978, p. 354).

The research of Heron, Hebb, Doane, Scott, and Bexton (1951) studied the effects of a rigidly monotonous environment on just such a population as Baumeister imagined. Their results, based on male college students, found the effects of deprivation of sensory stimuli deleterious to the subjects. In some of the subjects own words;

Eventually some subjects reached a state in which it took too much effort to concentrate, and they became, “content to let the mind drift” as one subject put it. Others said: “My mind just became full of sounds and colours, and I could not control it”;
"I just ran out of things to think of"; "I couldn't think of anything to think about." Several subjects experienced "blank periods" when they did not seem to be thinking at all (Heron, 1957, p. 54).

This is the effect of short term monotony on intelligent culturally normal people. Think of the effects of monotony on back wards for babies left in cribs without stimulation during the early developmental years. Heron (1957) sums up his research by stating that prolonged exposure to a monotonous environment has negative effects on the individual. The characteristics of these effects are, thinking impairments, childish emotions, visual hallucinations, and alteration in the brain wave pattern.

The recent studies indicate that normal functioning of the brain depends on a continuing arousal reaction generated in the reticular formation, which in turn depends on constant sensory bombardment. It appears that, aside from their specific functions, sensory stimuli have the general function of maintaining this arousal, and they rapidly lose their power to do so if they are restricted to the monotonously repeated stimulation of an unchanging environment. Under these circumstances the activity of the cortex may be impaired so that the brain behaves abnormally (Heron, 1957, p. 5).

In essence, Heron is saying that the brain creates its own data (hallucinations, sounds, and colours). When the outside environment is monotonous and unchanging the individual develops an inner life of his or her own.

Suedfeld (1980) has described early reports of the effects of SD as over stated. However, he also concludes;

There is certainly no doubt that subjects in restrictive stimulation conditions experience perceptual phenomena. Among these are extremely vivid dreams, daydreams, fantasies, hypnagogic and hypnopompic imagery (that is, experiences that occur in the borderline state from wakefulness to sleep and vice versa), spontaneous firing in the retina, and perception of endogenous,
residual, or low intensity stimuli of which the experimenter is unaware (Suedfeld, 1980, p. 30).

The effect of SD on a person includes; impaired cognitive functioning, hallucinations or retinal visual phenomena, and awareness of experiences inside the mind that the 'outsider' cannot experience. The clinical evidence is important in developing a theoretical understanding of the PMR who have been institutionalized from early childhood. This concept of inside/outside has profound ramifications in terms of profoundly retarded persons who were institutionalized early in life. The back wards had little activity other than feeding times and diaper changing. With little or no hugging, interaction, games, or being taken for walks. It is difficult to imagine what inner life must have developed for those left alone through infancy and the developmental period.

Christopher Burney (1961) spent 586 days in solitary confinement. In his book, Solitary Confinement, he depicts a ritualistic life that compensates for the lack of stimulation. Burney, at points, does not want to talk or interact with even other prisoners, but only wants to be left alone to his solitary musings:

In two places in this book I refer to my reluctance to correspond with my neighbour in the cell next door. On the first occasion my reason was a good one, since he might easily have been an informer. But on the second it was pure self-sufficiency. I simply could not be bothered to interrupt my own train of thought. Thinking - musing would be a better word - was by this time my whole life outside my appetite, and I can remember to this day how petulant I became about it. Once I had embarked on a train of thought I only wanted to stay on it, and it never occurred to me that my neighbour's desire to talk was no less legitimate than mine to be silent. (Burney, 1961 p. xi).
Burney is able to discuss his coping with monotony, because unlike the severely and profoundly retarded, he has language to tell the tale;

As soon as I had fallen into a steady rhythm of pacing I would drift into day-dreams, mixtures of memory and desire, the past retouched to show it as the ideal life for any future (Burney, 1961,p. 21).

Burney experiences life on the bedrock and finds it to be an “affair of the mind and reality merely the eternally mysterious beloved.” The subjective state of the person needs understanding in order to create knowledge of the experience. Burney told his tale of the life and mind of a man in solitary confinement. The tale of the severely and profoundly retarded person needs telling in order to promote awareness and understanding of their subjective world and their adaptation to deprivation.

The use of autobiographical and anecdotal written material has been criticized;

It is impossible to gain from the published anecdotal literature a view of the effects of isolation and monotony uncontaminated by danger, physical privation, and uncertainty of rescue (Suedfeld, 1980, p. 4).

This criticism of autobiographic records is pertinent to the clinical study of stimulus deprivation, but not to the understanding of the phenomena for the institutionalization of the PMR. Institutionalization is, unfortunately an experience which encompasses physical privation, danger, and uncertainty of danger. The previous sections cited passages concerning the back wards noted; aggression (which could be construed as danger), physical deprivation (in terms of food, toileting, and confinement), and uncertainty of rescue (release).
The theoretical development and explication of sensory deprivation has been discussed by Robertson (1961). This author theorizes that;

With a marked reduction of external stimuli, it is reasonable to assume that the interaction of external and internal stimuli is weighted considerably on the side of the latter. In extreme sensory deprivation, there is little or no interaction between internal and external stimuli and an individual response is probably determined entirely by various internal stimuli but the selective suppressing effect of external stimuli is lost, resulting in a sudden crowding of consciousness with material that is ordinarily unconscious. In such a case, a person may seem to compensate for the absence of external stimuli by projecting thoughts, feelings, images, which may then be reacted to as though they originated outside the person (Robertson, 1961, p. 34).

The theoretical point Robertson raises is that the internal life appears, to the person who has experienced SD, as if it originated and existed outside of the person. There is, for the person who has experienced long term SD, a confusion between inside and outside stimuli. The observer who watched such a person would be unaware of the inner stimuli that elicited the emotional reactions and behaviors of that person. Robertson states that the person's behavior would be detached from any background or context. The importance of the effects of SD in developing this phenomena in people is critical to the awareness of the PMR who has been exposed to long term SD through institutionalization.

E. EMOTIONS

In 100 B.C., the Stoic Greek philosopher Epictetus, stated that it was not the events that upset people but their perceptions of the events that upset them. Epictetus was saying that emotions are a result of the person's appraisal of the environment. The role of cognition or intellect as opposed to the affect or
emotions of humankind has fascinated philosophers, psychologists, and people in
general.

Cognitive theorists have concluded that all emotions presuppose cognitive
evaluations of situations as good or bad (Arnold, 1960; Ellis, 1967; Lazarus,
1968; Mandler, 1975; Schachter & Singer, 1962). In other words, cognitive
appraisals lead to emotion reactions;

What is an emotion? An emotion is a judgement or set of
judgements, something we do. An emotion is a judgement which
constitute our world, our surreality, and it’s ‘intentional objects.’ An
emotion is a basic judgement about our Selves and our place in the
world, the projection of the value and ideals, structures and
mythologies, according to which we live and through which we
experience our lives (Solomon, 1976, p. 185)

Emotion, then does not exist in its own right, as a special and
almost mystical sort of entity, it is, rather an essential part of an
entire sensing-moving-thinking-emoting complex. What we usually label
as thinking is a relatively calm and dispassionate objective appraisal
of a given situation... And what we usually label as emoting is a
relatively uncalm, passionate, and strong evaluating of some person or
object (Ellis, 1967, p. 47).

Emotions, according to these authors, depend on people evaluating their
environment; once the evaluation or appraisal has been made, then there is may
emotional response;

Different appraisals in people lead to different responses (Lazarus,
1968).

It is possible that the same circumstance leads to different appraisals and
responses at different times depending on how we interpret the situation
(Solomon, 1976; Lazarus, 1968; Schachter, 1970). For example, when I am tired
and irritable I am more likely to respond to criticism with anger than when I
am rested and calm. It is also proposed by these theorists that different
appraisals result in different emotional responses;
They point out that all organisms evaluate their environments and that emotions depend on such prior cognitive evaluations. They also emphasize their belief that each emotional reaction is different because of the particular appraisal that led to it. Different appraisals lead to different emotions (Plutchik, 1980, p. 287).

The concept of the emotional response resulting from a prior appraisal is critical to this study. Once an appraisal is made, the emotion is the response and there is accompanying physiological arousal (Arnold, 1960; Lazarus, 1968; Schachter & Singer, 1962). The response which is manifested allows access to the subjective state of the person. A person without language, for instance, could communicate his/her anger at a specific situation through "showing" the anger response.

Emotional reactions may be viewed as a communication system for whether the person is appraising the environment as good or bad. Emotional responses are a way to understand that person and his/her view of the situation. The phenomenology of a person is available, to some degree, through their emotional reactions to an observer. Further, according to the cognitive theory of emotions, the understanding of how the person perceives the world may be accessed through their emotional responses.

Emotions as cognitive appraisals of the environment by a person and emotions as a communication system are central to access the subjective states, thoughts and feelings of the severely and profoundly retarded non verbal adult. Emotions represent one of their few communication systems.

The reading and inferring of the subjective state of the person through emotional responses is difficult. It is, however, a major step in the development of an empathic perspective of the PMR. The awareness of the emotional responses to external events and objects and separating these stimuli from
internal phenomena has the potential to increase understanding of the likes and dislikes of the person as well as to develop programs that are appealing, and hence motivating to the person.
CHAPTER III. METHODOLOGY

SECTION I: THE FIELD RESEARCH TRADITION

This chapter will be divided into three sections for the purposes of describing, defining, and applying the field research tradition as a research methodology. Section one will give a general account of the field research tradition. Section two will discuss the research design of this study. Section three will describe the application of the field research tradition and present an example of the techniques of data collection, the researchers' role, analysis, and results of this methodology.

A. THE FIELD RESEARCH TRADITION

Social science research has been described "as a choice between two conflicting research paradigms" (Hammersley & Atkinson, 1983). These two conceptions of social research are often called quantitative and qualitative (Schwartz & Jacobs, 1979) and naturalism and positivism (Hammersley & Atkinson, 1983). At issue, in this debate, between these two paradigms is the nature of the social world and how it should be studied.

The historical development and research methodologies of the qualitative tradition will be reviewed in this section. Terminology in this tradition "and the exact use and definition of these terms, as words like field research and qualitative tradition varies from user to user and from time to time" (Bogdan & Biklen, 1982, p. 3). This tradition has many names; "and is known as field work, ethnography, case study, qualitative research, interpretive procedures, and field research" (Burgess, 1984, p. 2). In this study the term field research will be used for this tradition.
Field research has been associated with the collection of "soft" data (Bogdan & Biklen, 1982), collected in natural settings (Hammersley & Atkinson, 1983), and studied from the participant's point of view (Burgess, 1984). This traditions includes particular schools or methods known as "symbolic interactionism, inner perspective, the Chicago School, phenomenological, case study, interpretive, ethnomethodological, ecological, and descriptive" (Bogdan & Biklen, 1982, p. 3). Regardless of the terminology, field research attempts to capture the insiders perspective and understanding of their world (Schwartz & Jacobs, 1979).

Field research has its roots in more than one academic discipline. Understanding this tradition means transcending disciplinary boundaries (Bogdan & Biklen, 1982). The disciplines of anthropology, sociology, and social psychology are all part of the development of field research.

The historical roots of field research are very old. The last fifty years has been cited as the significant developmental period for this tradition (Hammersley & Atkinson, 1983, p. 4)

B. THE HISTORICAL DEVELOPMENT

Field research has important theoretical and epistemological foundations. The historical context is important as it contributed to the formation of this tradition. This section will define field research and describe the historical context and the genesis of field research.

Social researchers using field research methodologies share common characteristics and "focus upon the ways in which participants interpret their experience and construct reality" (Burgess, 1984, p. 3). This statement is significant in order to understand field research. The field researcher, in order to
understand the social world realizes that, "the actor acts towards his world on the basis of how he sees it and not on the basis of how the world appears to the outside observer" (Blumer, 1969, p. 17). The researcher, in field research, must understand the world as the participant experiences it and not as an objective fact that exists outside of that person. This is an important distinction between field research and positive science. It is a fundamental foundation of field research that the social world is defined by the participants and is not an objective reality.

The historical emergence of field research occurred in the latter part of the nineteenth century. This historical era was the time of urbanization and the impact of mass migration from rural areas to the cities created vast social problems (Bogdan & Biklen, 1982). The social suffering of this period was documented in descriptive, in-depth, and moving accounts which laid the foundation for field research. For example, photographic essays by Jacob Riis (1870) exposed the dreadful life of the working poor in America. Le Play (1879), used a method called "participant observation" to study working class families by living with these families becoming a natural part of the "setting."

This period also had journalists, social workers, social surveyors, photographers, and statisticians attempt to expose the suffering and conditions of the poor in order to promote a social remedy to end the wretched conditions. This trend continued into the 1900s with rich descriptive accounts of the conditions of the poor being employed by different groups to promote social change. Survey's became an important tool for social research. Booth (1886) used surveys in London over a seventeen year period. Booth employed surveys and statistical analysis that were interwoven with rich descriptive accounts of human
stories. At this time field research and the quantitative approach were used together to provide an account of the lives of Londoners.

C. ANTHROPOLOGICAL MODELS OF FIELD RESEARCH

Anthropology applied the concept of field researchers studying people in their natural setting as a methodology for understanding foreign culture. Franz Boas was perhaps the earliest significant contributor to this fledgling tradition (Bogdan & Biklen, 1982, p. 8). Boas believed in the use of ethnographic accounts from people who had spent time in the "natural setting." The time spent in the natural setting, at this point, was very brief but the idea of studying foreign cultures by living in them had taken root.

Radcliffe-Brown in 1910 went to Australia to study Aboriginal culture. His research took him to a hospital setting where he met with the Aboriginals. Though, in retrospect, his work did not take him to the natural setting of the Aborigines, Radcliffe-Brown did not rely on accounts from for his insights and like Boas, met first hand with the people he sought to understand. Radcliffe-Brown's work has been criticized as "the veranda model" of ethnography because the Aboriginals were summoned to his veranda, often accompanied by interpreters where the researcher questioned the specific Aboriginal out of context with respect to the natural setting and with no real experience with the person.

Bronislav Malinoski (1922) was the first anthropologist to consciously want to capture the foreign culture by living and being a part of the natural setting within the culture he was studying. Malinoski attempted to live, speak the native tongue, and be a familiar part of the Trobriand Islanders' lives. In his own words he wanted to "grasp the natives point of view" (in Bogdan & Biklen, 1982).
Malinoski’s (1967) diary reveals his own frustration and sense of failure to truly grasp “the natives point of view” despite all of his efforts. The critics of Malinoski referred to this particular type of anthropological field work as the “noblese oblige” period. It was referred to by this name as this time period was equated with the Industrialized nations exploiting the third world.

Anthropology continued to study native culture through field research and participant observation under a developing school called the structural functionalists. Evans-Pritchard (1940) in his classic work the Nuer is an example of this school of anthropology. Margaret Mead and Ruth Benedict contributed to this research tradition and approach. Mead’s work on the South Sea Islanders and Benedict’s studies with the Indians of the South West United States are a continuation of anthropological research through participant observation.

D. SOCIOLOGICAL MODELS OF FIELD RESEARCH

Field research methods have also been an integral part of sociology (Hammersley & Atkinson, 1983). Sociologists have employed both field research methods and the quantitative methods. Max Weber, one of the major figures in sociology, developed a concept called “Verstehen” which emphasizes sociological inquiry that has as its goal an empathic appreciation of the person (Schwartz & Jacobs, 1979).

Weber’s influence assisted sociological methods in gaining the perspective of the participant being studied. A major step in field research which followed Weber was the founding of the “Chicago School.” This school in the 1920s and 1930s contributed enormously to field research by using participant observation in natural settings (Bogdan & Biklen, 1982). The Chicago School grew, flourished,
and was responsible for such works as the Polish Peasant in Europe and America (Thomas & Znamier, 1927) and the Gold Coast and the Slum (Zorbaugh, 1929) to mention but a few of the works from this school. The Chicago School crossed the boundary to anthropological methods under one it's founding members Park. It was Park's contention, "indicated in a paper that was to be the blueprint for the Chicago School studies that anthropological methods which had been useful to study North American Indians should be used in the study of inhabitants of the Chicago area" (Burgess, 1984, p. 16).

The Chicago School relied on the study of a single case, whether it was a person, group, or neighbourhood (Bogdan & Biklen, 1982). The approach used in the research was called interactionistic. This method emphasized the social and interactional nature of reality. Sociology had moved away from social work, social action, and reformist tendencies, and taken up the study and understanding of the social world for it's own sake. The Chicago School focussed primarily on minority groups and deviant individuals which set the tone for much of the sociological investigation of that period.

A similar and parallel approach arose in Britain. This approach was labeled 'community and locality studies' (Burgess, 1984). This approach involved research strategies of living in the field, using key informants, documentary techniques, observations, and the collection of statistical data. Sociology had become a scientific discipline through the evolution of the field research tradition and distinguished itself from social work and social reform movements.
E. THE EPISTEMOLOGY OF FIELD RESEARCH

Field research is interested in the meaning people ascribe to events and to their lives. This section will examine the theory of the social world as developed by G.M. Mead and Herbert Blumer. These men conceptualized a perspective of the “self” and the social world that form the basis of the field research approach to investigating the social world.

Mead (1863 - 1931) is often considered the founder of social psychology. Mead developed the discipline of social psychology on the premise that:

The self is no longer some structure of inner people which exist in all human psyches. It is the internalizations of the social processes by which groups of people mutually interact. Learning to participate in group action gives one a sense of self and vice versa. (Schwartz & Jacobs, 1979, p. 23).

Field research undertakes to not only observe the actions and reactions of the participant as an outsider but seeks to understand the actions from the participant’s point of view. Mead saw social research as not attempting to understand an objective world of empirical fact, but to uncover the understanding of the meaning that the participants ascribe to the world.

Herbert Blumer (1969) applied the term “symbolic interactionism” to this approach of understanding people and the nature of the social world. A concise summary of Blumer’s theory of symbolic interactionism is:

It (symbolic interactionism) doesn’t regard meaning as emanating from the intrinsic make up, nor does it see meaning arising through the psychological elements between people. The meaning of a thing for a person grows out of the ways in which other persons act towards the person with regard to the thing. Their actions define the thing for the person; thus symbolic interactionism sees meaning as social products formed through activities of people interacting (Blumer, 1969, p. 4).

The symbolic interactionist perspective is at the center of the issue of the
nature of the social world and how to study it. The methodologies, research
techniques, and strategies require the researcher taking the participant's role,
seeing the world from the participant perspective, and being aware of the
creation of new definitions of self and the social world.

In the view of interactionists, people interpret stimuli, and these
interpretations, continually under revision as events unfold, shape their
actions. The same physical stimulus can mean different things to
different people and, indeed, to the same person at different times

F. RESEARCH TECHNIQUES EMPLOYED IN FIELD WORK

This section will review the various methods and techniques employed in
field work. Most commonly, field researchers are found in "natural settings." The
first step the field researcher must accomplish is to "gain access" to the setting
that has been selected for the research. Gaining access means obtaining formal
permission to carry out the research (Bogdan & Biklen, 1982; Burgess, 1984;
Hammersley & Atkinson, 1983). Once formal access has been granted to the
researcher informal access needs to be achieved. Informal access refers to gaining
permission and acceptance from the actual participants who are to be studied.
Formal access often can mean that permission is sought from an authority who
will not be in the setting or a participant in the study. Thus informal access
from the participants is key if the research goal of achieving the participants'
perspective is to be achieved. This stage is synonymous with establishing rapport
with the participants. Once accessed has been granted and rapport developed the
research can begin.

The methods a field researcher utilizes to collect data in the setting
include the careful recording of field notes, in depth interviews, formal and
informal observations, documentary analysis, and the use of a field journal.

The field researcher develops a sampling frame for times that observations will be done in the setting. The sampling frame must be comprehensive and ensure that observations will cover all aspects of the lives, places, and events of the participants. Once the sampling frame is determined the researcher will observe in the setting in accordance with the schedule. There are two types of observations the researcher records; these are informal and formal observations. The purpose of informal observations is to build a data base about the setting and the participants in general. The formal observations are close and detailed observations of specifically chosen events, persons, or activities.

Two other techniques are important in carrying out field research. The first is the field journal. The researcher records impressions, makes analytic notes, records personal feelings, thoughts, ideas, and significant events in a field journal. This journal is a diary of the research process and the reflexivity of the researcher’s role in the setting.

The second important technique is the researcher’s development of sensitizing concepts to develop an awareness of the patterns and understanding of the participants in the setting. The beginning stages of field research have been characterized has being on the top of a funnel. The funnel appears to the researcher as large, but at this stage the researcher must remain open to all concepts, ideas, and experiences. As the research develops the funnel narrows and the researcher becomes increasingly focussed (Hammersley & Atkinson, 1983).

In summary, the first stage of research, is gaining access, developing rapport, developing sensitizing concepts, and remaining open to the participants and the setting. The funnel, at this time is very wide and the researcher
experiences a sense of bewilderment at the top of the funnel.

The second stage in the research process involves developing an extensive 'data base.' The researcher, by this time, should be an accepted an unobtrusive part of the setting. The informal and formal observations serve to build the data base. The hunches, insights, and analytic notes of the researcher are kept in the field journal. The sampling frame should be comprehensive to capture the full life of the participants and ensure an adequate data base. There is sometimes a danger of 'going native' (Burgess, 1984). This refers to a researcher who becomes so involved with the participants' perspective that there is an over identification with the participants. The researcher must be aware of the dynamic of over involvement and the field journal is an excellent place to monitor this 'going native' and avoid saturation in the setting.

The data base is constantly reviewed by the researcher. Sensitizing concepts, analytic notes, and 'hunches' have to be explored to determine their efficacy in analyzing the data base. The researcher, before becoming lost, should take a break from the setting to maintain his perspective and review the emerging sensitizing concepts. This allows the theory to emerge from the data. The review of the data base for key words, events, topics, patterns, inconsistencies and exceptionalities is important in preparing to code and analyse the data. The researcher now starts to focus more specifically in the setting. The researching is moving down the funnel. Once the data base is complete the researcher codes the data. The coding categories must allow for the inclusiveness of all participants, events, and settings.

The sensitizing concepts and theory must be constantly reviewed for inclusiveness of data. The analytic framework that is developed from this process
arises from the data. The researcher uses induction in developing a comprehensive analysis of the data. Data analysis requires coding the data. The researcher through sensitizing concepts develops categories and typologies which form a model for the analysis of the data base. The analytic framework is checked, to ensure frequency and distribution of categories is taken into account in the emerging model. The method of constant comparison is used to review the data for inclusiveness of typical cases, negative cases, and the researcher inductively develops theory from this process.

The researcher is now ready to triangulate the data and his model. Triangulation entails matching the coding categories the researcher has developed converging and correlating with each other. The coding categories triangulate if they occur in different contexts, at different times, and in different places in the data base. The degree of triangulation is dependent on the inclusiveness of the researcher's model.

The final stage of field research is linking the model to theory. The field research approach has been a major contributior to the creation of theory. The more general and abstract the categories developed by the researcher are, the more likely the model will link to formal theory (Glaser & Strauss, 1969).

G. REFLEXIVITY

A unique perspective of field research is the awareness of the impact of the researcher on social phenomenon being studied.

There is no way in which we can escape the social world in order to study it; nor, fortunatley, is that necessary (Hammersley & Atkinson, 1983, p. 15).

Field research's recognition of the importance of reflexivity demands that
the researcher understands the effects of himself on the setting by testing hypotheses against other information and data collected in the setting.

The focus of field research is in the participants' natural setting, gaining the insiders perspective, and recognizing that social reality is constantly shifting as people interact to construct the social world. Reflexivity means that the field researcher must take into account his effect on the social setting and constantly reflect upon the reciprocity between himself, the setting, and the participants. Reflexivity is at the heart of field research. It is a fundamental tenet to this tradition and means there is not a separate, distinct, objective social world of 'fact.' Theory, the process of social inquiry, and analysis in the field research tradition, together with the participants and the setting are viewed as part of the same reality and are all part of understanding the social world. There is, in this tradition, a simultaneousness to the social world, theory, research procedures, and analysis. The field researcher must be aware of this reality in understanding and gaining the participants' point of view.

H. GROUNDED THEORY

An important role of the field research tradition is the development of theory (Glaser & Strauss, 1967). The field research tradition intentionally has theory emerge from the data. The emergence of theory from data ensures a 'fit' between the theory and the social phenomenon being studied (Glaser & Strauss, 1967). Grounded theory requires that the field researcher inductively compares his theory and data with other theory, data, and phenomenon concerning the social world. Theoretical integration is extremely important if formal and substantive theory is to be generated.
Grounded theory begins with the study of a defined social unit. The interpretation of a social unit can be; 'a person, a status, a type of behavior, a relationship, a group, or a nation' (Strauss & Glaser, 1970, p. 4). Once the social unit is defined it is essential the field researcher develop an adequate sampling frame over a temporal span which will capture the setting and the lives of the participants.

The goal of this research tradition “is focused on analytic abstractions and constructions for the purpose of description, or verification, and/or generation of theory” (Strauss & Glaser, 1970, p. 4). The concept of grounded theory uses induction to develop even more inclusive theory, if the researcher’s data base is large enough to warrant this procedure.

The nature of the field research paradigm allows for the generation of new theory using the induction of substantive and formal theory through the method of constant comparison against the researcher’s model.

I. SUMMARY

The field research tradition has it’s roots in specific historical conditions and as a reaction to the rise of positivistic science (Hammersley & Atkinson, 1983). This was a reaction to the objectivication of the social world. Field research is concerned with the symbolic interaction of social awareness and the self consciousness of people. This offers a unique perspective for understanding the social world. The recognition that “the self is the definition people create (through interacting with others of who they are)” (Bogdan & Biklen, 1982, p. 34). Thus the self is perceived as a social construction. Field research examines the meanings people ascribe to their world from their perspective. The role of
the person in interpreting the social is embedded in this tradition "basic to the approach is the assumption that human experience is mediated by interpretation" (Blumer, 1969, p. 17).

The recognition of the social construction of the self and the social world through interaction is fundamental to field research;

The emphasis upon meanings that individuals construct and modify during the process of interaction holds implications for research (Burgess, 1984, p. 4).

The research process consists of defining a social unit, gaining access to a natural setting, developing rapport, and 'grasping' the insiders perspective. The principle of reflexivity monitors the impact of the researcher on the social phenomenon being studied. The goal of this research paradigm is to explicate the common sense ordinary perspective of the insider and his subjective experience of the social world. The field researcher has a view that human actions "are based upon, or infused by social meanings, intentions, motives, attitudes and beliefs" (Hammersley & Atkinson, 1983, p. 7).
CHAPTER III. METHODOLOGY

SECTION II: RESEARCH DESIGN

This section will review field research as a methodology with the PMR. The research design including, the role of the researcher, selecting the sample and case, gaining access to the setting, the observation schedule, entering the setting, developing rapport with the participants and staff, and analysing the data will be presented.

A. FIELD RESEARCH AND THE PROFOUNDLY MENTALLY RETARDED

The research methodology for this project employs a design similar to anthropological field work. Recognition in the literature of the need for small, wholistic, in depth case studies of the PMR in their natural setting has been identified (Bercovici, 1981, 1983; Edgerton, 1984; Gollay, 1981; McAndrew & Edgerton, 1964; Okolo & Guskin, 1984; Taylor & Bogdan, 1981).

It is the consensus of this literature that, if we are to improve our understanding of the community adaptation of retarded persons, we must study their lives wholistically rather than in laboratories, and we must listen to these people as they express their own views (Edgerton, 1984, p. 2).

One barrier with the PMR is the difficulty in listening to 'their own views' as they do not develop a verbal language system. Thus, the traditional field research method of including interviews with the participants is not available with the PMR. There have been no inclusive studies done in the natural settings; group homes, activity centers, and community outings of the PMR. Observation will be the major technique employed in this study. Observation is an important scientific procedure; 'Science begins with observation and the recording of empirical events' (Heal & Fujuria, 1984, p. 20). The observations
from this study will be a first step in describing and analysing the behavior and
daily living patterns of the PMR in the contexts of a community setting.

The observations will record the empirical aspects of the subjective states
of the participants. Awareness of the subjective states and phenomenological
aspects is important in developing a body of knowledge concerning the PMR.

Accessing the subjective states of the PMR has been proposed;

We must be rigorous in our attempts to develop techniques to
understand the subjective states of those we have not traditionally
considered as being possible to understand. If we have not understood
the severely disabled person, it is because we have not really
attempted to do so. The problem is ours and not theirs. (Taylor &

The research design will move past laboratory experiments and observe all
aspects of the lives of the PMR in an attempt to rigorously grasp their views
and subjective states. The researcher will become a part of the natural setting
and contexts of the lives of the participants as has been suggested;

To carry out such ethnographic naturalism, we must have prolonged
contact with people, and we must become, if only relatively so, a
'natural' part of the lives of mentally retarded persons. By virtue of
our prolonged and somewhat unpredictable presence in their world, we
hope to see more than the obvious (Edgerton, 1984, p. 6).

The PMR have been viewed as a fringe group of humanity (Cleland,
1979, McAndrew & Edgerton, 1964, Wolfensberger, 1972). This study will
attempt through observation to enter into the world of the PMR and observe
first-hand their daily emotional responses and interactions to develop description,
verification of existing theory, and new theory from the data base;

Just because peoples' subjective states may not be directly accessible
to us, as in the case of nonverbal retarded persons, this does not
mean that they do not have subjective states. If we have not
understood the severely disabled person, it is because we have not
attempted to do so (Taylor & Bogdan, 1981, p. 80).
The research design utilized a field research methodology known as participant observation. The researcher as participant observer becomes a natural part of the setting and observes with minimal disruption the daily life of the participants. The goals of participant observation have been summarized by Madge (1953).

The primary task of the participant observer is to enter into the life of the community being studied. If this task is achieved, there will be two consequences: his subjects will learn to take him for granted and thus to behave almost as though he were not there, and he will learn to think almost as they think (In Edgerton & Langess, 1984, p. 339).

In summary, the research design was a field research methodology utilizing participant observation. The researcher entered into the natural setting of the participants and become a natural part of their community. The design utilized observation of the participants through prolonged exposure to their normal daily activities. The participants point of view and subjective state was described through observations of their activities and emotional responses in their daily lives.
CHAPTER III. METHODOLOGY

SECTION III: THE RESEARCH METHODOLOGY

This section will apply the field research approach to a specific sample and case of the PMR. The details of selecting the sample and the case for study, the role of the researcher, gaining access, the observation schedule, entering the setting, developing rapport with the participants and staff, data collection techniques, and analysing the data will be reported.

A. THE SAMPLE AND THE CASE

The sample and case of study in field research has been defined as a social unit (Strauss & Glaser, 1970). The social unit for this study is a group home of deinstitutionalized PMR adults. Deinstitutionalization of the mentally retarded in British Columbia has entailed utilizing non-profit societies for the mentally retarded and private operators of homes as the alternative to institutional placement. The majority of the deinstitutionalized population have gone to community group homes. Community group homes are usually eight or fewer people unrelated by blood who live in a house. The staff in group homes usually work in shifts and do not live in the group home.

Table 4 details the number of institutional placements versus community placements in British Columbia for the period 1984-85 to 1985-86. The decline in the institutional population in 1985-86 is the result of the closure of one institution in British Columbia. Table 5 details the placement of the resident population of that institution. Table 5 lists the type of placement residents from Institution X. These tables were compiled using the 1984-85, 1985-86, Annual Reports of the British Columbia Ministry of Human Resources.
Table 4: The Decline of Institutional Placements Between 1984 and 1986

<table>
<thead>
<tr>
<th>Year</th>
<th>Community Placements</th>
<th>Institutional Placements</th>
</tr>
</thead>
<tbody>
<tr>
<td>1984-85</td>
<td>1590</td>
<td>1331</td>
</tr>
<tr>
<td>1985-86</td>
<td>1868</td>
<td>987</td>
</tr>
</tbody>
</table>

Table 5: The Admissions, Discharges, and Closure of Institution X 1983 to 1985

<table>
<thead>
<tr>
<th>Year</th>
<th>Admissions</th>
<th>Discharges</th>
<th>Resident Population on March 31</th>
</tr>
</thead>
<tbody>
<tr>
<td>1984-85</td>
<td>6¹</td>
<td>321</td>
<td>0</td>
</tr>
<tr>
<td>1985-86</td>
<td>17</td>
<td>33</td>
<td>315</td>
</tr>
</tbody>
</table>

¹ Admissions: Respite admissions for period March-August, 1984

Discharges:
- 257 Community Placements
- 7 Community placements after short-term admissions
- 54 Transfers
- 4 Deaths

Table 6: The Type of Residential Facility Residents from Institution X Were Placed

<table>
<thead>
<tr>
<th>To Family Home</th>
<th>To Independent Home</th>
<th>To Community Residential Facility</th>
<th>To Another Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>0</td>
<td>257</td>
<td>54</td>
</tr>
</tbody>
</table>
The sample was selected, with regard to Cleland's (1979) point of separating severely and profoundly retarded persons for the purposes of research. All of the participants were profoundly retarded nonverbal deinstitutionalized adults. The case, or social unit of the study was a group of five PMR persons who resided in a group home. The typicality of the social unit was integral to the study. The social unit chosen reflected common group home size in the area the studied was done. The non-profit Society which provided the service operated eleven group homes. The group homes had between three and seven people with a median and mode of four persons per group home and an average of 3.1 residents per home.

The sample and case met the typicality requirements for the research project, and formed the social unit for the study.

B. CONFIDENTIALITY AND RESEARCH CONSENT

The name of the non-profit organization, the participants, the staff, the municipality, and the group home site have been changed to protect the integrity and rights of the participants. The confidentiality of everyone in the study was guaranteed as part of the consent to participate in the research agreement.

The non-profit agency provided consent for the participants as they were unable due to mental incapacity to provide informed consent of their own. The agency had a twelve person Board of Directors. The Board of Directors were unanimous in their approval of the research proposal. The staff were also approached by the researcher for consent to participate in the study. The approval and permission of the staff was also unanimous. The letters of research consent and agreement to participate in the study are in Appendix A.
C. THE ROLE OF THE RESEARCHER

The role of the field researcher may be regarded as a point on a continuum that falls somewhere between the 'complete participant' and the 'complete observer' roles. The other roles that have been described as points along this continuum are the 'participant-as-observer' and the 'observer-as-participant' (Gold, 1958; Junker, 1960; Hammersley & Atkinson, 1983).

The complete participation role is characterized by the researcher being covert about his research and attempts to pretend that he is a natural part of the setting. The role of complete participation, while superficially very appealing, contains difficulties for the researcher. Some of these difficulties are; the inability to openly record information, tape interviews, and step back and observe openly as the researcher. The complete participant role also has ethical problems regarding the rights of the participants to privacy, no written consent to be research subjects, and the deceitfulness of the researcher in the setting.

The 'complete observer' role is again a covert role. The researcher as complete observer has no contact with the participants. Observation is usually through a one-way mirror or from a window. The researcher is removed from the participants, cannot use interviews, have direct interaction, or access to the full context of the participants' lives. There are ethical implications with this approach due to the covert nature, as stated for complete participation.

The disadvantages of these two researcher roles are;

Adopting either of these roles alone would make it very difficult to generate and test theory in a rigorous manner, though both may be useful strategies to adopt during particular phases of the fieldwork, and in some situations may be necessary (Hammersley & Atkinson, 1983, p. 96).
The participant as observer role allows the researcher to openly state his research intentions to the participants. The participant observer role allows the researcher to participate, yet, still be a full time researcher and not displace a role in the natural setting, or to be tied to that role to the detriment of the research role.

The observer as participant is a more formal role than the participant as observer role. The contact the researcher has with the participants is brief and formal (Burgess, 1984). The observer as participant role is essentially observation only.

The participant observer role was the goal of the researcher for this study. The researcher was an employee for the nonprofit society in the setting. The employment position was that of Executive Director for the Society. This employment status was a potential area for role conflict between the researcher and the staff of the group home and day program. In essence, the potential conflict was that the staff would significantly alter their usual patterns of behavior due to the presence of the 'boss.' There was a designated supervisor in each program who hired, appraised, and supervised the staff.

The researcher met with the staff and supervisors to review the research and explain the purpose of the study. The potential role conflict was discussed with everyone. The staff, called Adult Service Workers (ASWS) if they perceived the researcher as an Administrator and "boss" would alter their usual patterns in the presence of the researcher. The supervisors' roles were reinforced as well as the researcher's role as participant observer. The role of the researcher was to participate as an
Adult Service Worker (ASW) in the setting.

The ASWs served as the direct care staff for the participants in both the group home and the day program. The researcher did not consider a participant observer role as a profoundly mentally retarded participant. Thus, the researcher took a participant observer role as an ASW and this was acceptable to the supervisors and the staff.

The role as ASW required the researcher to assist the participants in, eating, bathing, dressing, toileting, and all aspects of the participants' day to day lives. The role of ASW also required food preparation, house cleaning, floor washing, dish washing, and other domestic activities. The researcher as a result of these duties dressed in the clothes of the ASWs, that is in blue jeans, casual shirts, and runners. The performance of these duties did much to reduce the role conflict. The researcher, on entering the setting, in many respects sought assistance from the ASWs in regards to routines and duties. The role conflict diminished and acceptance as a participant observer and not as “boss” by the supervisors and ASWs was achieved through the ongoing participation in the setting.

The acceptance and rapport that was established between the researcher and the staff was concretely shown through participation as an ASW. An example was that the researcher often drove the van on outings as he possessed a 'class 4' licence. The eight weeks in the setting was ample time to become familiar with the routines and duties of the staff. It seemed to the researcher that the staff accepted him as a staff member in the setting and this was commented on by the ASWs to the researcher.

Another safeguard, with respect to role conflict, was the prolonged
exposure of the researcher in the setting. The researcher was present in the setting for eight weeks and the observation times ranged from two to six hours. The ability of people to manage their impressions decreases over time and with familiarity of an observer in a setting.

The acceptance by the participants was a different matter. The participants did not appear to have a difficulty in accepting the researcher as an ASW participant observer. Through familiarity, the researcher, was able to become a natural part of the setting and able to observe the normal activities of the participants with minimal notice by the participants or the ASWs. The researcher through the ASW role became familiar with the participants in many situations. The rapport developed with the participants through familiarity and trust in daily interactions. The concept of trust between the researcher and the participants is difficult to explain. The concrete acts that led the researcher to believe that trust had developed were incidents such as; participants hugging the researcher after several visits to the setting, participants leading the researcher to the door and upon the researcher opening the door the participant taking the researcher's hand and taking him for a walk.

The one to one situations the researcher had with the participants includes outings, walks, bathing, and dressing. These situations allowed access to many situations for the researcher for observation that would have been missed had there not been rapport with the participants and staff.

There is a danger of 'going native' (Malinoski, 1922) and over identifying with participants in the setting. There were two classes, in some
respects of participants, the staff, and the PMR participants. The PMR participants did not seem to be aware of the role of the researcher as observer. There was not a danger in over-identifying with the PMR in the sense of 'going native.' The difference in ability, communication, and needs were so significant as to preclude the 'going native' dynamic.

The relationship between the researcher and the staff was a different matter. The staff manifested a similarity to the researcher in ability, communication, and social role. The balance the researcher sought to maintain was an outsider/insider equation. This equation allowed the researcher the insiders' view while maintaining a perspective that permitted analysis of the data which did not reflect a bias from 'over-rapport' with the staff (Hammersley & Atkinson, 1983). For example, the staff viewed much of the participants' behavior as 'self-stimming' and explained this to the researcher. The view of stereotypic behavior as self-stimulation would have biased the analysis of the data and provided a theoretical framework for explaining stereotypic movement. The researcher was aware of the dynamic and tried to guard against the tendency to accept the opinions and the ideas of the staff.

The researcher recorded all his observation openly in front of the staff and participants. The staff had been briefed on the nature of the study and the role of the researcher. The staff and researcher were able to, within the first week of the study, work together with facility and ease. The researcher had in the past worked in group homes and was familiar with the routines and duties of group home workers. The staff in both the group home and day program were not often visited due to the
behaviors of their clients. The staff of both programs welcomed the researcher and the interest shown in their programs.

The researcher had done a small pilot study fourteen months earlier on the participants. Due to the high turn over rate in the staff who work with the PMR none of the staff from the pilot project were employed in either program. The pilot project had served to acquaint and sensitize the researcher to the PMR and the role of the staff, but not to specific staff members.

D. DATA COLLECTION AND RESEARCH TECHNIQUES

The researcher maintained a field journal, a field notebook to record observations, and typed the observations into a computer in a protocol format for analysis. Each of these items used will be reviewed below as to their application in the study.

1. The Field Journal

A field journal was maintained on a daily basis by the researcher while doing the study. The field journal or diary was used to record, the researcher's impressions, analytic notes, and to record significant thoughts and ideas while in the setting. The diary was also used to record reflections on the study and the researcher's role in the setting. As time was spent in the setting the reflections on the study began to include speculation on emerging trends, patterns that were noticed, and possible coding categories for the analysis of the data.

The field journal became the forum for the researcher to reflect on ethical implications of the study and the participants he was observing. It was in the
field diary the researcher monitored his thoughts and feelings concerning his relationship with the participants and with the staff, that is the reflexive action of the observed changing because of the observer and the observer changing because of the observed. The researcher in the diary began to note inferences he had seen, ideas that arose for coding, analysis, and for clarification. It has been noted that:

In no other form of research is the process of doing the study, and the people who are doing it, so consciously considered and studied as part of the project. The reflective part of the field notes is one way of attempting to acknowledge and control the observer's effect. The reflective part of field notes insists that research, like all human behavior, is a subjective process. (Bogdan & Biklen, 1982, p. 32).

The researcher wrote in the field journal discussions with the staff, comments they made, and specific insights and feelings concerning the role of the researcher in relation to the staff. The field journal was also utilized by the researcher to note the actions and interactions between the researcher and the participants. For example, one entry concerned favouritism with one of the participants. A portion of the journal entry dated April 1st, 1987 reads;

I must watch favouritism with June. She has come to me immediately when I enter the house. She was so well behaved on the walk and the visit to Unity. June and April did, I guess, compete for my attention.

The field diary was used to develop inferences from the data. An example of developing inferences in the journal is the entry on April 19th, 1987 reads;

It's nerve racking, these formal observations, the participant/participant interaction was a good idea but there is so little of it that I wrote other observations as well. However, a coding idea might be INNER------OUTER
INNER-> the participants seem so inward, it would be important to read about others from deprived backgrounds (ie.) solitary confinement, long time prisoners, etc. My hunch is that the finger staring, circle walking, stereotypic behavior, noises (guuurring, eeeaaahhing), maybe
even the self-abuse is their inward 'island universe' response to years of institutionalization and the cultural abheration that is a response to deprivation.

OUTER-> this is the clients interaction with the environment. It is the overlap of their inward life on to the world. It is their point of entry for us to them and for them to our world. My hunch is the hugging, wanting to go for walks, pushing, even to an extent food, back rubs, maybe even the bathing is their outer actions, their contact with the social world.

In summary the field journal was used to monitor reflexivity, inferences, and impressions by the researcher throughout the study.

2. The Field Notebook

The researcher kept observation notes each time he was in the setting. The observation notes were made in a stenographers note pad, and the date, place, participants and staff were recorded at the start of each observation. The overt role of the researcher as participant observer allowed the researcher to openly record the observations in the setting. The open recording of events as they occurred did not bother the participants or the staff.

The field notes began with informal observations for a two week period where the researcher recorded the tone, mood, and general description of the settings, participants, and staff. The informal observations were a wide perspective at the informal stage and facilitated the researcher in achieving acceptance in the setting. The informal observation sensitized the researcher to the routine, participants, and staff. The researcher sought to write the fields notes as objectively as possible including the details of what occurred.

The formal observation notes were more specific. The researcher used seven focussed observations to note the interactions that occurred between the participants. The participant interactions were few in number and duration. The
researcher included in these focussed observations details of dress, colour, sound, and routine in the setting.

The formal observations included a detailed observation of each one of the participant for a seven day period. It was during these individual observations that a rapport between the researcher and participant seemed to heighten. For example, at the end of a week of formal observations the researcher had a sense of the likes and dislikes of that particular participant. The researcher made observations as to each participant’s favourite place to sit, activities the participant engaged in, favourite music, and visible emotional responses during the seven day observation period. The researcher spent many hours alone with that participant.

The researcher was involved in all aspects of the participant’s life including; bathing, toileting, dressing, eating, activities, and outings. The fieldnotes recorded all the events that transpired for each of the participants during the seven day formal observation period. (The observation schedule is listed in Appendix B).

3. The Protocols

The written observations from the field notebook were then typed into a protocol format. The format used allowed for ease of reading and coding of the details and descriptions of the activities. The researcher typed the field notes into a computer using a protocol format. The typed protocol format facilitated the coding of the data through the lay out and numbering of each line of the protocol. The use of the computer was only for word processing and retrieval of additional copies for analysis (see Appendix C for examples of an informal and
formal protocol).

The observations from the field notebook were typed into the computer at the end of the observation. This process of transcribing the observations daily served a useful function other than for ease of data analysis. This function was the researcher reread the fieldnotes as he typed and this often provided a familiarity with the data that might have been missed. For example after an observation and recording the observations in the field notebook the observations were then typed into the computer and the complete observation would be relived and the participants' behavior re-experienced. Often comments and insights were added to the field journal during the typing phase.

The protocols became the data base that the researcher analysed and coded. The protocols were reviewed during the time in the setting by the researcher to search for patterns, trends, and concepts. Notes were made on the protocols and reviewed again throughout the project.

4. Data Analysis

The assumptions underlying the field research approach posit the lack of separation between the collection of data and the analysis of data phase. Data analysis was continual throughout the research project. The process of analysis involved a constant and continuous review of the data. The field diary noted, hunches, patterns, analysis, themes, and categories. The researcher engaged in the development of sensitizing concepts daily to capture in these concepts the maximum amount of data. Field research requires researchers to treat the social unit they study as 'anthropologically strange' in order to make explicit the assumptions that he or she takes for granted as a culture member (Hammersley
& Atkinson, 1983). The researcher in developing sensitizing concepts sought to explicate the interactions, activities, and behavior of the participants.

The constant comparison of data, theory, and sensitizing concepts resulted in the development of coding categories. Glaser and Strauss (1967) suggest that segments or slices of the data are taken in turn and compared with other segments of data similarly categorized as well as its relevance to other categories. The researcher then re-examined the data for inconsistencies, contradictions, patterns, and themes. It is an important technique in field research that the theory must arise from and "fit" the data (Bogdan & Biklen, 1982; Burgess, 1984; Hammersley & Atkinson, 1983). The researcher reviewed the data and categories to develop an inclusive abstraction true to the data to arrive at a theory of the social construction of the setting and participants.

The process was one which required the researcher to inductively seek other situations which were similar to the setting and data. Glaser and Strauss (1967) suggest using literature and other studies to develop sensitivity and comparisons to other social situations. For example, many of the stereotypic behaviors the participants exhibited are common in situations where people are waiting or bored. One such behavior was exhibited in one of the participant’s who was a ‘circle walker’. This behavior if exhibited by people in an airport, while waiting for appointments, or in prison may be viewed as a strategy to cope with waiting or as a result of boredom. The question of whether stereotyped behavior (eg. circle walking) was a result of boredom became salient. Another participant was a ‘sweater picker’ and often picked pills of wool from her sweater. Clothes straightening and sweater picking is again not uncommon behavior in people who are nervous, bored, or waiting.
The researcher then went to the literature to develop an awareness of behavior of prisoners and others coping with monotony and boredom. The notion of stereotypic behavior as an adaptive response to boredom was inducted into the analysis. There was then a systematic comparison of the inductive situations and the researchers data and then a review of the total data of the research to check for inconsistencies and other themes. This process led to the development of typologies which fit into more general categories.

The model which was developed from the typologies was then reviewed against the data base. Again inclusiveness of data was checked, inconsistencies, patterns, and negative cases examined to determine the efficacy of the model. The model needed to account for data in different situations, times, activities, and participants. The model arose from the data and was not be imposed on it.

5. Data Analysis Techniques

This section will review the development and process of data analysis. The emergent nature of the analytic abstractions throughout the research project is important in field research. The analysis of data was continuous utilizing the field journal, the observation protocols, and comparison to existing formal or substantive theory. The resulting interpretation of the data is presented with a case example from one of the participants to illustrate the process of analysis.

The researcher reviewed the informal observation protocols during the first two weeks in the setting. The field journal entries for the informal observation period noted on the first observation date, March 31, 1987;

look for emotion- or indicators of emotions (ie) smiles, laughter, tears etc. Watch to see if there is a pecking order. Watch for the mortification practices which might deny self to the participants.
An analytic note in the field journal for April 2nd, 1987 read,

The social distance factor, you should watch for more intently. Participant initiated interactions between each other seem minimal.

At this stage in the data collection the focus of the journal entries was on, what to look for and categories of behavior or patterns in the participants. Other journal entries again mentioned the distance maintained between the participants, which furniture the participants sat in, and the overall pattern of movement, activity, and routine. A detailed diagram of the both the group home and the day program was made on April 4th, 1987 which the researcher used to chart movement, furniture usage, and activity patterns (see Appendix D).

The April 8th, 1987 field journal entry summarized the analytic hunches of the first nine days of observations;

- Emotion is noticeable in the participants. What’s the meaning?
- What about a personality inventory for each person?
- Explore the idea of participant/participant boundaries
- Explore the idea of staff/participant boundaries
- Is there an overlap of boundaries?
- What about patterns of movement in the participants?
- Dominance/pecking order in the participants.

The staff seem very objective, program oriented, lacking personal knowledge and interaction with ‘the guys’. There doesn’t seem to be a lot of ‘fun’- ‘games’- or development of rapport. It’s more a routine of meals, meds, toileting, grooming, in a technical routined way.

‘the guys’ was a short term used by the researcher to refer to the participants in the observations notes, the field journal, and in discussions with the staff, the term applies to both men and women participants.

The analytic hunches were consolidating into a perspective to view the participants, staff, and actions observed in the setting. The April 9th, 1987 field journal entry theorized at great length on a social distance theory and coding
category system. This theory and sensitizing concept did not mature due to further observations. Social distance in terms of physical space between the participants was not a significant category for analysis.

The emotional reactions and responses of the participants continued to be noted in the formal protocols and in the field journal. A type of behavior referred to as 'stereotypic behavior' (Baumeister, 1978; Berkson, 1967; Hollis, 1978; Lewis & Baumeister, 1982) was very prevalent in all the participants in all the protocols. The example of May, one of the participants, will be used to illustrate the development of the analytic abstraction process which form the results section and interpretation of the data into theory.

A section of a formal observation of May on April 22nd, 1987 reads in the protocol:

6:45 27. May is gurring louder than I have ever heard her before. She goes into hysterical giggles as she sits in her usual position on the green chair. She sits there and laughs hysterically and claps her hands.
7:03 37. She stays seated guurrring and face fingering and occasionally laughing.
7:45 17. Lidia & Marian (staff) both give May a tickle. May laughs and giggles.

The observation of May on April 23, 1987 notes in the protocol:

2:30 19. May touches the outside of the cup but takes her hand away I assume from the steam etc. it is too hot to drink. May puts hand on it from time to time. May laughs and rocks and checks the coffee with her hand.

The protocol of April 25, 1987 reads:

p.1 27. May hyperextends- pounds her hands- makes loud noises-
1:10 28. curls and uncurls-as if in pain. Then she strips.
2:00 38. She starts to laugh at apparently nothing, rocks more and more she becomes very loud to the level of shouting and claps her hands.
2:25 47. I go over and touch her ears, she smiles and giggles so I tickle
38. her ears and she laughs and giggles.................................
p.2  21. May is on the trampoline she won't stand but sits and smiles
3:25  22. and giggles and laughs as I bounce her on it. She is guurring
23. and giggling and seems to love the motion. She moves so her
24. movement makes the trampoline bounce her..............................

The above observations on May led the researcher to develop an analytic
abstraction concerning emotions in the PMR and their relation to stereotypic
behavior. After the data collection, during the data analysis stage, the researcher
read in the literature concerning emotions and the PMR;

One fact stands out--seldom, if ever, do professionals or direct-care
workers with the PMR even bother to look for expression of
underlying emotions in this retarded group. Since I first offered my
seminar entitled "Profound Mental Retardation" in 1965, I have
repeatedly inquired of graduate students, "Have you ever noticed a
PMR blush?" and "Have you ever noticed a PMR sitting alone, in
relative solitude, break into a broad grin or laugh?" For, if we had
unequivocal affirmatives on both questions, we would have evidence
that some among them have the capacity of self or other regard or
that a thought crossed their mind and caused them to smile (Cleland,
1979, pp. 80-81).

The observable emotional response, smile, laughter, giggles was noted in
the protocols in a variety of contexts and in all the participants. The field
journal had mentioned the importance of emotion. During the analysis the
researcher had read literature concerning a cognitive theory of emotions (Arnold,
1960; Lazarus, 1968; Solomon, 1976). The sensitizing concept of emotional
responses was beginning to evolve into a coding typology predicated on a
cognitive theory of emotion.

The theory that emotional responses were the result of cognitive appraisal
and was indicative of internal thinking or, as Cleland stated 'that a thought had
crossed their mind' was developing the sensitizing concept of emotional response
into an coding typology. The researcher noted that May laughed when alone,
when on the trampoline, and when tickled. Laughter, an emotional response was
present in a number of contexts. An analytic note on May in the field journal entry of April 27th, 1987 reads:

May will go for a walk, she will bounce on the trampoline, she will laugh when she is on the trampoline and I believe, because I'm laughing too, it's because the trampoline is fun and it's 'funny' when 'solid' ground bounces you into the air. For a moment, as we laugh together, we both understand each other.

The use of emotional responses as an inference to an 'inner life' in May and as 'evidence' that thought was occurring in May gave support to the analytic abstraction of a complex inner life in the participants. The analytic abstraction of inside outside that the researcher had developed was beginning to triangulate within the data. Emotional responses were present in all the participants, in all contexts, the literature supported the concept of emotions as evidence of thoughts, and if there were thoughts then the concept of an 'inner life' was theoretically very possible.

The field journal and the informal and formal protocols also noted a change in the intensity and degree of stereotypic behavior in the participants depending on the emotional response. May, when she was 'happy' (giggling, laughing, smiling) exhibited a different rate of stereotypic behavior than when she was 'sad' (crying, frowning, hyperextending her body). In the 'common sense' approach to observing behavior (Hammersley & Atkinson, 1983) May's emotional responses and stereotypic behaviors were congruent. The concept of congruence meant that the stereotypic behavior, for example, hyperextending her body to show displeasure, her vocalizations sounded displeasure, and her hand smacking, all expressed displeasure, unease, upsetness. The data supported that the stereotypic movement of the participant altered in degree and intensity and was "expressive" and congruent with the emotional response. May exhibited qualitative
differences in her vocal tone, body language, and facial expression which were congruent to an interpretation of happy, sad, pleasure, displeasure.

The researcher sought for theory to explicate the origins of the thoughts in the participants which became emotions, then emotional reactions. The deprivation studies of Hebb, Doane, Scott, Bexton, and Heron (1951) with male college students offered theory to explain a rich internal mental life for normal male college students when exposed to a monotonous, boring, unstimulating environment. The effects of a prolonged monotonous environment created emotional reactions in the subjects;

Not surprisingly, the subjects became markedly irritable as time went on and often expressed their irritation. Yet they also had spells when they were easily amused. In the interview afterward many of the subjects expressed surprise that their feelings could have oscillated so much, and that they could have behaved so childishy (Heron, 1957, p. 54).

The researcher, in the analysis inducted this childish oscillating emotional state to explain the behavior of the participants. Further, the experiments of Doane, Hebb et al noted that;

Many of them, after long isolation, began to see “images.” One man repeatedly saw a vision of a shaded rock by a tree; another kept on seeing pictures of babies and could not get rid them. Several subjects seemed to be having dreams while they were awake. Not until one of the experimenteres himself went through the isolation experience for a long period did we realize the power and strangeness of the phenomenon (Heron, 1957, p. 54).

The evidence offered by the deprivation experiments including the literature reviews on sensory deprivation by Suedfeld (1980), Schultz (1969) and Zubeck (1969) was viewed as relevant in the explication of the phenomenon the researcher had recorded. The participants’ stereotypic movement and emotional behaviors were explainable. There is evidence to support that the deprivation and
monotony of long term institutionalization resulted in an inner world of hallucinations and patterns that were not explainable through changes in the external environment. The participants lived in a world of their own. It was an inner world of isolation an adaptation to deprivation, understimulation, and monotony.

The 'unfathomable' behavior of the PMR could be understood. The induction of deprivation experiments in 'normal' humans offered an explanation for behavior in the PMR, who had been considered 'less human in some respects than some non-human primates' (McAndrew & Edgerton, 1964, p. 318). Cleland's (1979) desire to understand the strange behavior of the PMR could be grounded in the theory of the effects of deprivation on humans.

The analytic abstraction of inside/outside had a 'goodness of fit' to the data base the researcher had collected. The method of constant comparison required the researcher to review the data base for negative cases, contradictions, inconsistencies, and exceptional events. The researcher was aware that the level of abstraction of the inside/outside theory could result in data not being included in the analysis. A complete reread of the data developed middle category between inside and outside. This category was labeled overlapping boundaries. This category represented a middle position between inside and outside. The participants and the staff interacted, or experienced reciprocity and mutual interest in the overlapping boundary category.

The inside 'culture' was the inner life that was expressed through the emotional responses of the participants to the visions, patterns, or 'hallucinations' that were the inner subjective lives of the participants. The inner life was developed as a result of the institutional experience; early sundering of the
parent child bond, non-stimulating childhood spent on large wards in cribs, with few staff to interact, the participants had been exposed to long term monotony. The behavior of the participants was not 'unsual' given the sensory deprivation literature (Heron, 1957; Schultz, 1965; Suedfeld, 1980; Zubeck, 1969).

The outside 'culture' was based on experiences of interaction, remaining with parents, an interactive stimulating environment, and the development and use of symbols. The outside group were represented by the staff. The outside group inferred that the participants' stereotypic behavior was an aberration with little adaptive significance (see also Baumeister, 1978). The staff interpreted stereotypic behavior as 'self stimulation.' The outside group did not understand the meaning and communications of the inside group. Thus there was a boundary between the two groups. The behavior of both groups was in response to the perception of the boundary that separated inside and outside. The shift from inside life to outside interaction on the part of the participants was categorized as overlapping boundaries. These events, actions, and activities composed reciprocity between the two groups and the participants 'came out' and interacted with the staff and environment.

The example of May will illustrate the overlapping boundary category.

The field journal entry of April 28th, 1987 reads in part,

May sees and hears different things than I do. She is often happy or sad with concomitant laughing/crying, hyperextending or hand clapping. This is her world. 'We' the staff are peripheral to her inner world and her emotions. 'We' are outsiders. We can and do enter into her world but as marginal members. Her world is one where she is in her own world, the boundary of her's gently touches our world. She sits on a chair tangential to us, but not far away. She lies on the couch tangential to the other clients, but not far away.

The protocols were then examined for boundary overlaps examples. The
incident on the trampoline was one noted event. The following protocol excerpts relate boundary overlaps where May communicates her wants to the staff;

Protocol 5

p.2

13. Lidia has been rubbing May's back the whole time, when Lidia stops May takes her hand and Lidia says 'Oh you want more, let's take your sweater off, because it's hard on my hand' Lidia and May co-operatively get the sweater off. Lidia continues to rub May's back. April is picking at her sweater and occasionally puts her fingers in her mouth with I guess the fuzz balls on them. Lidia and Maria (both staff) discuss children they know. and tonight's dinner. Maria leaves the room. May stands up and takes Lidia's hand. Lidia says 'Where do you want to go?' They walk off together in the direction of the kitchen.

Protocol 24

p.2

10. May returns to the chair and sits down. May picks up the spoon from the counter again, and this time gives it to Katie (a staff) 11. Then May pulls on Katie's arm, Katie doesn't respond. May then hands her a plate, then a lid to a jar, May now tugs on Katie's arm again. Katie says to May 'Show me what you want' May takes her to the tea kettle and Katie plugs the kettle in and May sits down.

Protocol 26

p.1

41. Lynn (a staff) sits on the table right next to May. May takes Lynn's arm and moves it across her. Lynn says 'What do you want May?' May keeps tugging on her arm. Lynn gives her a back rub. May quietens down and appears to relax. May is so much quieter now.

Protocol 28

p.1

39. May gets up and takes a yellow cup from the cup board. Sal says 'Put the cup back May.' May puts the cup back on the shelf. May now goes to the kitchen counter and leans on it with her elbows. May then goes back and gets the cup again. Sal again asks her to put the cup back and May returns the cup. May then goes to her green chair and sits down.

These events and actions were coded and or examples of over lapping
boundaries between the inside and outside. The actions of the participant were
directed towards objects, people, and requested something. The participant had
entered the world of interaction and meaning through physical gesturing and the
use of concrete objects as a symbol for requesting coffee. The excerpts given are
not inclusive but illustrative of the actions used for May in coding boundary
overlaps.

6. Summary

This section has applied the field research approach to a study of the
PMR. The social unit for the study has been described and the research consent
and confidentiality reviewed. The example of May was presented to illustrate the
continuous process of analysis in field research and as a process in developing
analytic abstractions. The analytic abstractions of; inside, outside, and boundary
over laps was presented with examples from the observation protocols. The
following chapter will describe the setting, the participants, and the group's social
structure.
CHAPTER IV. DESCRIPTION

This chapter will describe the physical setting of the participants' group home, day program, and their daily activity schedule. A description of the participants, their physical as well as their personal characteristics, will be presented from the observation protocols and the field journal. A typical day in the life of each participant is given describing the behaviors and activities. Finally the participants will be discussed using the analytic abstractions of; inside, outside, and boundary overlaps.

A. DESCRIPTION OF THE PHYSICAL SETTING

The group home and day program for the participants was operated on a twenty five acre site owned by Society X. The site provides vocational and day programs for approximately 100 mentally retarded people and residences for twenty-four mentally retarded adults. The site contains a system of roads, lawns, street lights, and paths that connect four large homes, five green houses, a barn, wood work shop, three small homes, a recreation hall, chicken house, central administration building for the Society, and open ditches on three sides which form the property line. The Society opened this site in 1971. This site is characterized by it's rural seclusion. It is situated approximately half way down a dead end street. It is twelve kilometers from the town center and three kilometers to a main road and bus service. There are several other farms on this street.

There are four identical large wood framed tar and gravel roofed buildings that dominate the site. These four buildings were designed as group homes to house ten mildly mentally handicapped people per home with a set of house
parents. The house parents had a separate suite in each of the group homes. A change in the philosophy and administration of the Society had resulted in the mildly mentally handicapped residents being moved to smaller more community based group homes of four to six residents. Two of these homes were left vacant as a result of this change. These two homes remained empty for about a year. It was these vacant homes that were utilized for the deinstitutionalized PMR participants. One is their group home the other is their day program building. The buildings are approximately fifteen years old.

The one building used as the group home has had the interior renovated. The renovations included panelling the walls to prevent the participants from smashing holes through them. Glass windows were replaced with impact resistant glass to prevent the participants from breaking them. The kitchen was sealed off from the dining room and high a impact glass window installed. The staff can observe the participants in the living and dining room from the kitchen. The interior of each home has ten private bedrooms, one house parent suite and a large, cavernous, and austerely furnished living room/dining room area. Overall the interior atmosphere is spartan, drab, and unimaginative.

Locks have been installed on every door in both buildings. The staff have keys for the locks and control which rooms the participants may enter. What little furniture there is has been either built on to the wall or bolted to the floor. The small two seat couches bolted to the floor are made of high density indestructible polyeurethane. These couches accompanied the participants from the institution. The built in benches on the walls have cushions covered in a vinyl material that is waterproof. A large built in book case dominates one wall of the front room. There are no books in this book case and only a few toys and
puzzles. There are three artificial silk plants in the front room. The limited number of prints and posters that adorn the walls are protected by plexiglass that is affixed over the picture by screws which go directly into the wall. This large bleak cavernous approximately 6,000 square foot house is ‘home’ for the five participants.

The day program building, situated approximately thirty feet away is identical, only it has not been renovated. This building has tiles missing from the floor, holes in the walls, and is badly in need of repair. The roof leaks, the toilets were, often during the observation period, either plugged or not working. The furniture in this house is a delapitated collection of legless couches, broken chairs, and old school tables. The participants push this furniture around the front room. The kitchen in this house has been similarly sealed off from the dining room with the observation window installed. There are no pictures on the wall or plants in this building. The house, overall, appears to be an abandoned derelict building.

Janitors clean both homes daily but the unmistakable smell of feces, urine, and pinesol are prevalent in both homes despite this daily routine. The shared yard is maintained by a landscaping crew on a weekly basis. The homes are unmistakably drab, unstimulating, and utilitarian environments which lack character and personality.

A fence surrounds the two houses and a tree lined path connect the two programs. The participants move from the group home to the day program and back Monday to Friday each week. The common yard is used by the participants seven days a week. This isolated rural site, a place clearly for the mentally retarded, is the community placement for the deinstitutionalized PMR
participants.

B. THE DAILY ACTIVITY SCHEDULE

The daily schedule for the participants was structured and routinized. Each day there was a format of activities which was followed and co-ordinated between the group home and day program staff. An overview of this schedule is presented in Table 7. The schedule of activities will be described in the section titled "A Typical Day." In order to typify each day, one activity in the day program will be described for each participant which best exemplified the behaviour of that participant.

Table 7: Daily Schedule

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>6:30-7:30</td>
<td>Wake-up and grooming</td>
</tr>
<tr>
<td>7:30-8:30</td>
<td>Breakfast and medications</td>
</tr>
<tr>
<td>8:30-9:00</td>
<td>Toilettng and walk to day program</td>
</tr>
<tr>
<td>9:00-10:00</td>
<td>Circle activity</td>
</tr>
<tr>
<td>10:00-10:40</td>
<td>Arts and crafts</td>
</tr>
<tr>
<td>10:40-11:10</td>
<td>Coffee break</td>
</tr>
<tr>
<td>10:10-11:50</td>
<td>Communications</td>
</tr>
<tr>
<td>11:50-1:00</td>
<td>Lunch</td>
</tr>
<tr>
<td>1:00-1:40</td>
<td>Music</td>
</tr>
<tr>
<td>1:40-2:10</td>
<td>Coffee break</td>
</tr>
<tr>
<td>2:10-2:30</td>
<td>Vocational Training</td>
</tr>
<tr>
<td>2:30-3:00</td>
<td>Clean up and return to group home</td>
</tr>
<tr>
<td>3:00-4:00</td>
<td>Medications and tea time</td>
</tr>
<tr>
<td>4:00-5:30</td>
<td>Free time</td>
</tr>
<tr>
<td>5:30-6:30</td>
<td>Dinner time</td>
</tr>
<tr>
<td>6:30-8:00</td>
<td>Free time, walks, and bathing</td>
</tr>
<tr>
<td>8:00-9:00</td>
<td>Medications, snack, bed</td>
</tr>
</tbody>
</table>
C. FIRST IMPRESSIONS

The first impression on entering the setting is one of chaotic, patternless, pointless, and bizarre behavior. The researcher felt that he had left the normal everyday world and entered an island of insanity. One protocol records this observation of a scene on entering the participants' group home:

Protocol# 47
page 1
1. May is naked from the waist down lying on the bench couch.
2. There are two large B.M.s on the floor, one in the dining room
3. one in the front room. Dan is walking on his tip toes with one
4. hand holding his penis while the other is waving in the air.
5. He is dressed in red shorts, a blue top and bare feet. Dan sits
6. on the window seats waves his hands in the air then rubs his
7. eyes folds the cushion around himself and bites one hand while
8. picking his ear with the other hand. May starts to hyper-
9. extend her body, while smashing one hand into the other and
10. gurring louder and louder. May begins to cry and jumps up
11. and goes running into the kitchen on tip toes gurring and
12. smashing her hands together. Dan makes motions in the air
13. as if he were playing an imaginary guitar. Tim circle walks
14. around and around the front room making small ooh noises
15. occasionally extending one arm. April comes in on tip toes
16. holding two sweaters under her arm vocalizing eeaahheeaahh

The assault on the senses of the smell, the nudity and, the unusual behavior seemed beyond comprehension. A casual observer cannot but be moved by the difference in behavior to the ordinary everyday world outside of this setting. The initial observations of the researcher recorded the actions, sounds, and sights of the participants. The field journal recorded the researcher's struggle to develop sensitizing concepts to provide categories of behavior to develop an understanding of the participants.

The field journal entry of April 4, 1987 reads:

Prepare a file on each participant from the observations include: how they interact with staff and other participants, likes, dislikes, descriptions, things they do, stereotyped behaviors,
patterns, any personality characteristics they have.

These analytic notes, to observe the obvious, became the concepts for the researcher to code similarity of pattern, routine, and actions by the participants. A later entry in the field journal of April 17, 1987 recorded for each of the participants' activities, likes, patterns, and characteristics that were repeated in different observations for each participant. The 'sense' of there being a purpose and intentionality in the actions of the participants was gradually being observed by the researcher. The observation protocols recorded similar activities, actions, and behaviors. The researcher was becoming acquainted to the individuals and the setting.

The strangeness of the setting faded in the researcher. The observation of recurring actions in the participants was apparent and the pattern of actions was not chaotic and pointless. There was a nascent start to understanding the participants' behavior. As time progressed and the researcher became more familiar with the setting and the participants, the actions and behaviors became more familiar and predictable. The following section will describe each of the participants and develop a composite profile of their everyday actions and behaviors from the protocols and field journal.

D. INDIVIDUAL PARTICIPANT DESCRIPTIONS

Participant One: Dan

Age: 21 years

Height: 6' 2"

Weight: 153 lbs.
a) Physical Description

Dan is a tall, slight curly haired, native Indian male. He is attractive in appearance. He has large brown eyes and a pleasant smile. Dan walks on his tip toes. Both of his hands are calloused near the wrists where he bites himself. He has all of his teeth. Dan, unlike many descriptions of the PMR, does not have any physical deformity or grotesque malformation of his body. Overall Dan is a handsome, tall, dark haired, male in his early twenties. He is the youngest participant in the sample group.

b) A Typical Day in the Life of Dan

Dan was one of the last participants woken up in the morning. He received one to one attention from an ASW and was dressed and groomed by one of the staff. Dan was the last person to come into the dining room. It was approximately 8:00 am. Dan came into the front room and stood beside June. He twisted his fingers through her hair. June screamed and pushed him away. Dan smiled and sat on the window seat. He waved his arms in the air. Celia (staff) came over to him and put his runners on him. Once Celia left, Dan got up, put one hand down the back of his pants, and came to the observation window. He ‘hand waved’ at the window, then turned, smiling, with his hand still down his pants and returned to the window seat.

Breakfast was served and Dan was called to the table. He didn’t move or respond to the call. Dan was brought to the breakfast table by Celia. She tried to have him sit down but he went to the food cart. Celia used a piece of toast to lure him away from the cart and seated him at the table. Dan gulped down a full glass of juice. Celia had him pick up his spoon by using a hand
over hand technique. This method of training (hand over hand) required the staff to use their hands over the participant's hands and, in essence, make the person perform the motion that was desired by the staff. Dan ate all his cereal. Celia left to assist Tim. Dan tried to steal June's cereal but Katie (staff) came over and through hand over hand had him sign food. Katie gave another helping of cereal to Dan. She went into the kitchen. Dan tried to steal May's juice but Celia interceded and gave him another glass. Katie brought out waffles but Dan did not eat them nor did he look at them.

Dan stayed seated at the table drumming the table top with both hands. He was the last one at the table. Celia came to the table with a coat and asked Dan to stand up. Dan got up, Celia saw he had been incontinent, his pants were soaking wet. She took him to the bathroom, had him strip, wiped him, and dressed him in clean clothes. Dan joined the rest of the participants who were waiting at the door. The group was led by Katie to the day program. Katie worked at the day program and came on shift an hour before the day program starts to assist the participants to dress and have breakfast.

The next major event of the day was the day program. Dan arrived at the day program at 9:00 am. He entered with the other four participants and went into the front room. Dan was often left out of the activities in the day program. A typical time for Dan in the day program started with him in the morning 'circle exercise' beside Larry (staff). Dan did not appear interested in the day program activities. The 'circle exercise' started and Dan reached out and grabbed Larry's hair. Larry disengaged Dan's fingers from his hair. Dan tried to grab Larry but Larry held his hand and said 'No Dan.' Larry, hand over hand, had Dan roll a ball across the circle. Dan did not look at Larry or the ball.
Dan was rocking rhythmically. Larry, hand over hand, had Dan push balls. Dan continued rhythmically rocking.

The circle exercise ended and Dan stayed seated on the floor. Tim (PMR) came up behind Dan and sat down and pushed Dan. The pushing was ignored by Dan. Tim pushed harder and Dan turned and gently hugged Tim. But Tim kept on pushing Dan. Larry came over and had Tim follow him out of the room. Dan stayed seated and occasionally did a 'rock star' stereotypic movement. This stereotypic movement looked as if Dan were playing an imaginary guitar while he shook his head.

Tim returned ten minutes later and started to push Dan again. This time Dan vocalized a small ‘eee!’ sound and put his hand on Tim's shoulder. Tim stopped pushing and they sat side by side. Larry came over and had Tim follow him again. Tea was being served and Dan was the only person who was not invited for tea. Dan sat and performed stereotypic behavior, he rocked back and forth, waved his hands, and occasionally did a 'rock star' movement.

Tim returned after tea and again started to push Dan. This time Tim pushed Dan with his feet. Dan ignored Tim, but in order to remain seated Dan had to adjust himself to the force of Tim pushing on him. Dan, after five minutes, got up and moved to another seat. Dan sat and did his 'rock star' stereotype. Larry came and had Tim follow him to the bathroom. Dan put his hand into his pants and moved his hand up and down over his penis.

Five minutes later Dan got up, took his hand out of his pants and sat cross legged in front of the stereo set. Dan put his ear right on the speaker, a rock song was playing, Dan rocked in time to the music. He was the only person in the front room. He rocked and swayed to the music. He turned the
volume up and changed the station. Dan sat back down on the window seat, put his hand back into his pants, and layed in the sun that was coming through the window. The rest of the time spent at the day program was similar for Dan.

The next significant event for Dan was returning to the group home. The day program ended at 3:00 and the participants walked back to the group home. A typical afternoon for Dan is illustrated by the following record of Dan’s behavior and actions before dinner, at dinner, and going to bed.

Dan, on return from the day program, saw Maria (staff). He went up to her and hugged her. Dan was smiling as he pulled her close to him. Maria moved back but Dan took her hand and vocalized an ‘eeee.’ He then hugged her again. Maria managed to leave the embrace and Dan followed her. Glynda (a staff) said to Maria ‘You toilet Dan and May and I’ll take June and April.’ Maria agreed and took Dan to the toilet.

Maria undid Dan’s belt and zipper and had him pull his pants down. Dan sat on the toilet and urinated. Dan stood up with his pants down and hugged Maria. She told him to pull up his pants but he kept hugging her. Dan had a big smile on his face. Dan saw his face in the bathroom mirror and waved at himself. Maria got out of the embrace and again said to Dan ‘pull your pants up.’ This time Dan pulled up his pants. Maria buttoned and zippered them up.

Dan followed Maria to the front room. He went to the window seat and sat on it, cross legged. He did a ‘rock star.’ Later, he put one hand down the front of his pants and rubbed himself. He turned and lay on his stomach and rubbed his penis against the cushion, moving backwards and forwards.
Later, Dan got up and circle walked with a spinning motion. He waved his hand at his reflection in the observation window. Maria and Glynda came into the dining room and Dan immediately went to Maria and hugged her. Maria managed to leave the embrace and he followed her into the front room. Maria took April to the toilet and Dan returned to the window seat.

Dan’s next activity was dinner. Dan was a picky eater, his two food interests were juice and bread. He was led to the table by a staff member. Dan sat at the table and crossed his legs with his feet on the bench. Glynda (staff) removed Dan’s juice and said ‘Put your feet down.’ Dan put his feet on the floor and Glynda gave Dan the juice. He drank the full glass in one gulp. Dan reached for a piece of bread and ate it very quickly.

Dan looked at the dinner on his plate but did not eat anything. Glynda mixed his potatoes and meat together. She, hand over hand, had Dan use his fork to eat. Dan, after tasting the food, ate everything on his plate. Once his plate was empty Dan got up and went to the food cart. The juice container and bread were on the cart. Dan grabbed two pieces of bread and quickly got both pieces into his mouth. Glynda ran over to him and removed some bread from his mouth. She reseated him at the table. Glynda gave him another glass of juice.

Dan drank the juice in one gulp. He placed the glass on the table and reached over to June’s glass. Glynda took Dan’s wrist to stop him from stealing June’s juice. Dan stood up, took Glynda by the arm, and led her to the food cart. Dan placed her hand on the juice pitcher. Glynda took the juice container off the cart, reseated Dan, and poured him another glass of juice. Dan gulped the juice down, got up, and went into the front room.
After dinner was an unplanned activity time in the group home. Dan attempted to open the door to leave the house. A staff person opened the door and Dan stepped out onto the porch. Dan loved to go for walks around the site. He especially loved the greenhouses and would often led the staff there. Dan was allowed into the greenhouses by the staff member. Once inside the greenhouses Dan walked up and down the aisles, through all the greenhouses. Dan didn't touch the plants or flowers. He seemed content to just explore the houses and look at the plants. When the staff led Dan back to the group home he resisted going up the steps. Dan appeared as if the walk was not sufficient and tried to go away from the home. The staff managed to get him back inside the group home.

Once inside, Dan sat alone at the window seat and again rubbed his groin against the cushion. He waved his hand at the reflection of himself in the window, exhibited stereotypic movement through a repetitive circle walk. Dan was incontinent and Maria took him to the bathroom and helped him take his pants off. Maria removed his shirt, shoes, and socks. Dan smiled at her and grabbed her, rubbing his body against hers. Maria had him take a shower and she towel dried him as he smiled at her. They went down to his bed room, Maria leading and Dan, naked, followed her.

Once in his bedroom, Dan lay back on the bed, his arms behind his head, and stretched out smiling at her. It was a ‘seductive’ mood, position, and attitude in Dan. Maria had Dan stand up and get into his pajamas. Dan did very little to help her to clothe himself. He stared at her smiling and again stretched out on his bed. He reached for her but Maria said ‘No Dan.’ Maria left the room. Dan lay down with a wide grin on his face, at times he laughed
out loud. Dan did his ‘rock star’ stereotyped movement. He rolled over and rubbed his groin on the mattress. Later he rolled onto his back. He had a smile on his face. He put both his hands down the front of his pajamas and rubbed up and down. He stopped and took one hand out. He giggled and tapped the mattress with one hand. Then he lay on his stomach again and ‘humped’ the mattress. Then he rolled onto his back and put a hand down his pajamas and rubbed up and down very quickly. Then he was quiet and still. He pulled the covers up around him. Dan closed his eyes and slept. The time was nine thirty.

A weekend day often meant Dan would be taken to a park. Dan appeared to love visits to the park. Dan got out of the van and walked into the park unescorted. Dan went straight to the swings where he sat on the swing and pumped his legs and swung back and forth. He stopped the swing by placing his feet on the ground as brakes. He turned around and around on the swings until the chains were wrapped tightly. Dan removed his feet from the ground and the swing spun him around. Dan left the swings and wandered to a park building where he tried to open the doors. The doors were locked. Dan walked around the park not going near the staff or other participants. One of the staff noticed Dan wandering out of the park and led him back, by the hand, to the swing. Dan swung again. He got up to walk around but the staff led him to the van. Dan got into the van unassisted by the staff and sat with a smile. Back at the group home Dan would try to walk to the greenhouses but the staff led him by the hand up the steps and into the house. Finally, back in the front room Dan went straight to the window seat and laid on it. Soon, his hand was in his pants. The evening routine would be the same as the weeknight routine.
Participant Two: June

Age: 38 years
Height: 5’ 8”
Weight: 140 lbs.

a) Physical Description

June’s hair is almost white, her piercing ice blue eyes are striking, and her skin is almost the colour of paper. These characteristics are typical of a person with PKU (phenylketonuria), which is the cause of June’s mental retardation. June’s size is also striking, she is large for a female. The hair at the back of June’s head is sparse and matted from the continual rhythmic rolling of her head on the floor and on chair backs. June’s hands are blistered and scarred from her biting them. Her face is scarred from stitches where she has hit her head into walls, usually putting holes through them. Her body, while stocky and strong, has a protuding stomach, and her pants always appear ready to fall down. June stands out as unusual in physical appearance. Overall, her physical presence is unusual.

b) A Typical Day in the Life Of June

June was up early in the morning. The only other participant awake and dressed before June was May. One staff member assisted June with dressing. June then came into the front room. A usual morning for June is described by the following composite of her activities made from the observation protocols.

June was seated on the green couch in the front room. She was holding a runner in each hand while she rocked from side to side and rubbed her head against the back of the sofa. June heard the kitchen door open and quickly ran into the kitchen and sat in one of the chairs. She was still holding her runners.
She held them out to Celia (staff) who ignored her. June dropped the runners and brought her hands beside her head and rolled her head from side to side, 'finger staring' alternately at one hand then the other.

This stereotypic movement was specific to June. She held her hands with her fingers folded on the palms of either hand, her thumbs bent inward, and rhythmically stared at each hand, for a few seconds. June frequently performed this behavior for extended periods of time.

Celia started to prepare breakfast and June looked and stared at her. Celia started to load the breakfast onto a cart to wheel into the dining room. Suddenly, June jumped up and tried to push the cart out before it was fully loaded. Celia moved to stop June, but she screamed and resisted. Sal (staff) came into the kitchen, went to the cupboard, got the place mats, and handed them to June. June took the place mats, rushed into the dining room and dropped them on the dining table. June turned around and ran back into the kitchen. June returned to the cart, which was now fully loaded.

June pushed the cart and Celia did not stop her this time. The cart hit the kitchen door frame and wouldn't move. June screamed and screamed, she hit her head with her hand. The force of the blows was very powerful. Celia and Sal tried to console her and said it was 'o.k.' but June screamed and hit herself. Celia 'lured' her to the table with a piece of toast. June sat down at her place and ate the toast. June was given her cereal in a training bowl. She ate from the bowl with a spoon. June tried to steal May's cereal, but Celia gave June more in her own bowl. June had more toast given to her by Sal. June drank some of her juice, and started to rhythmically head rock and finger stare. Tea was given to June once her cereal and toast were finished. June
drank the tea down in gulps and got up and ran into the front room. She picked up her runners and came back to the dining room and shoved them at Celia, who said ‘Not now.’ June kept pushing the runners at Celia who told her no, as she was helping Tim. June dropped the runners and ran into the front room and sat on the green couch with her feet tucked up and began her rhythmical rocking and finger staring. Celia finished with Tim and went over to June. Celia put June’s runners on her. June left for the day program with the other participants.

A typical day for June at the day program was to ‘finger stare and rock’ most of the time. Any activity that was planned by the staff had to be done ‘hand over hand.’ There was an important and special time at the day program for June. This was any activity or event that Larry (staff) did with June. Larry appeared to be very special to June and her behavior for Larry was different than with the other staff members. An illustration is provided in the following excerpt from protocol #29;

47. Larry hand over hand has June roll a ball. She looks at him pleadingly but he does not give her a candy reward. Larry

48. says ‘roll the ball’ and June rolls a ball. Larry says ‘Good Girl’

49. June but still does not give her the candy reward.

Contrast Larry’s success in having June participate in an activity to a much more frequent response in the following illustration with June and Katie (staff) in the same program taken from protocol #30;

48. Katie places a domino in the middle of the table and asks June to go first and match it with one of hers. June finger

49. stares and does not respond to Katie. So Katie hand over hand
has June push a domino next to the first one and gives June a candy from the bowl. June makes ‘crying’ sounds. It is June’s ‘turn’ again, and this time she resists much more vehemently. She locks her arms so Katie can’t move them. When Katie offers her candy to unlock her arms June does not look up or respond to the candy. June makes little whimpering noises like she’s ready to cry. The next time Katie puts the candy on the domino but June does not even look up from her finger staring, June now pushes her chair away from the table and on her next turn will not even move her chair to the table. June never for the remainder of the exercise comes back to the table or participates. All of the staff comment on June’s special relationship with Larry and how Larry could have June participate in activities no other staff could achieve with her. June would stay at the program from nine o’clock until three o’clock. June’s next major day change occurred when she returned from the day program to the group home. June loved to be in the kitchen. She sat in a chair, stared at her fingers and nodded her head rhythmically from side to side. Most days June would act upset and ‘disconsolate.’ Often she threw a temper tantrum regardless of staff intervention, attempts to pacify her, or engage her in activities. A typical disconsolate period for June is illustrated by protocol #32:

1. June is in the dining room screaming. She runs out onto the patio and circles coming back in the house screaming. Now June sits on the dining room bench and lets out another scream. She gets up and runs to the TV couch, May is lying there, but gets up and goes to the other couch when she sees June at the couch. June lies on the TV couch and screams. Maria (staff) says ‘I’m going to the kitchen do you want to come?’ June gets up and follows Maria to the kitchen making little whimpering noises behind her. They are in the kitchen. There is a knock on the front door. Maria goes to answer it and June runs out of the kitchen making crying noises. June sees the office door is open and goes into the office and lies on a couch there. She finger stares and rhythmically nods her head. She stops head nodding and looks at one hand, stares at it. Then inexplicably she starts to laugh.
Later in this protocol June again became restless and disconsolate. The scene settled down as the staff started to prepare dinner and like most nights June sat on the dining table and stared in through the window watching the staff make dinner. June sat on the table night after night watching the dinner being prepared, rocking and finger staring. June had a healthy appetite and most nights ate two or three helpings of dinner. June ate on a training plate with a spoon and occasionally would use her left hand to grab the food in her hand and shove it in her mouth.

After dinner for June was much like before dinner. Often June wandered around the house disconsolate. The staff tried to find ways to settle and calm her. Certain techniques appeared to work on some occasions and not on others. There were three main techniques which will be illustrated below. The first was a puzzle, the second was clipping her nails, and the third was allowing June into restricted rooms (ie. the office or kitchen).

The puzzle was a child’s 8” by 6” frame puzzle of animals. June would look for the puzzle. If she couldn’t find the puzzle she took staff members by the hand to places the puzzle was commonly kept, made ‘oo, oo’ noises, and rung her hands. If the puzzle was found she took the puzzle, ran into the front room, and laid on the couch. June held the puzzle, rocked and moved her head from side to side in a rhythmic movement.

June loved to have a finger nail clipped by the staff with finger nail cutters. The nail clippers were kept in a cupboard in the kitchen. June led a staff member there and put their hand on the cupboard door. If the finger nail clippers were missing the staff would use another item, often a BIC lighter and pretend to cut one of her nails. After this June stared at the staff member and
grimaced. She returned to the couch or chair, tucked her feet up, and 'finger stared' rhythmically rocking herself.

The third method was to allow June into a restricted room where she would sit or lie and 'finger stare' and rock on a couch or chair. Often June screamed and hit herself as the staff went through this repertoire of methods attempting to console her. On days when June was very disconsolate she abused herself. She bit her hands, hit the wall with her head, or hit the staff.

June, was put in her bedroom when nothing consoled her. The bedroom had all the walls panelled so she could not put holes through the wall. She hit the walls and gradually settled down. At this point June laid on her bed and rocked rhythmically. Each night before bed time for June entailed bathing, grooming, and getting into her night gown. The staff helped her undress, wash, brush her teeth, and dress her in pajamas. June presented no problem in going to bed. She followed the staff to her room, got into her bed and sleep came almost immediately to her.

A typical weekend day for June was not dissimilar from a weekday. June rhythmically rocked and finger stared. Often she went into the yard and laid in the sun. June rocked and finger stared for most of the day. From time to time she got up, screamed and grabbed a staff member's hand. The staff led by June came back into the house where June went to the couch, office, or kitchen. Once June found an area she wanted, she laid down and the screams changed as she started her rhythmic patterned movement. Inexplicably, a smile came to her face. Evenings in the group home followed the same routine as the week day evenings. June went to bed at approximately nine o'clock and slept until the morning.
Participant Three: May

Age: 37 years
Height: 5' 4"
Weight 105 lbs

a) Physical Description

May is slight person with a very sore looking red rash that covers her face. The rash is the result of tuberoschorsis. These polyps that cover her face are also present in her brain, growing on the brain cells. It is the cause of her retardation. The rash on her face is unpleasant to view and gives her a grotesque but pitiful look. May always walks on her tip toes with her hands constantly going in her mouth, nose, and over her face, while she vocalizes a sound similar to a small motor, grrgrr, hour after hour. May, overall, appears small, unusual, and somewhat pitiful to the observer.

b) A Typical Day in the Life Of May

May seldomly slept during the night. She stayed up with the over night staff and was always awake in the morning. She was the first person to be washed and dressed. May loved to sit in the kitchen on a chair and 'grrrr' and rub her hands over her face. If left unattended May would engage in coprophagy. She would eat her feces and pick her anus until it bled. The over night staff always allowed May to stay in the kitchen where they could watch her. May, if the staff left out a coffee cup or ashtray, would drink the coffee and eat the ashes and cigarette butts out of the ashtray. May also exhibited the behavior known as pica, (eating of non-nutritional items, e.g., cigarette butts).

May was a gentle person and every morning was in the kitchen in 'her' chair drinking a cup of tea and grring, face fingering, and rocking rhythmically.
Another participant entered the kitchen, touched May on the top of the head. May got up and moved to another chair as the participant sat in her chair. May’s grrs often changed in pitch. She sounded sad, cried, and hit the fist of her right hand into her left. May’s rocking increased in speed and intensity. Often she jumped up and went into the front room. There she laid on the long bench couch grring. The grrs and tears changed to laughter for no apparent reason.

May came to the dining table when the staff called her name and sat at her place. She ggrred and rocked while she ate her breakfast. May ate her breakfast off a regular plate with a fork. The other participants seated beside her stole the food from her plate while she ate. The theft never appeared to bother May.

After breakfast May was let into the kitchen by the staff where she sat in her chair, grred, ‘face fingered,’ and rocked until it was time to go to the day program.

May went immediately to the kitchen door on her arrival at the day program. One of the staff let her into the kitchen. May sat in a chair in the kitchen and performed her pattern of stereotypic movement. May checked out all the coffee cups, ashtrays and anything that might be edible. The staff said ‘Sit down May’ and she sat down with a grr. May, when she drank the staffs’ coffee, noticably changed her behavior. The stereotypic motion became faster, more intense, and often resulted in tears and emotional signs of anguish. The caffeine from the coffee appeared to affect May in this manner.

May participated in the small group sessions with total disinterest and continual stereotypic movement. The staff used hand over hand with May so the
task was accomplished by her. May never looked at a task that she was engaged in by the staff. Often she jumped up, grrred, and attempted to leave the room. The staff said ‘Come back and sit down May’ and May sat down and waited grring, rocking, and face fingering.

The return to the group home at the end of the day program was the next event in May’s life. May entered the group home and waited by the kitchen door to be let in. She waited crouched on the floor outside the kitchen door on her hands and knees grring and rocking rhythmically. A staff member let her in and she sat in her chair in the kitchen. Often she took a staff member by the hand, led them to the kitchen counter, and put their hand on the kettle. The staff said to her ‘Do you want some tea May?’ Sometimes they made her a cup of tea. May touched the cup. If it was hot she took her hand away. Occasionally May retouched the cup and finally drank the tea.

May moved from the kitchen to the bench couch in the front room where she laid stretched out grring and face fingering. Often Dan or Tim came by and touched her head. May got up and went to another couch while the other participant took her spot on the bench couch. May grrred, rocked, and face fingered until dinner. She occasionally napped. There was no sign of stereotyped movement during her naps.

May was called from the kitchen to the dining table for dinner. She sat at her place. May’s dinner was served on a plate and she ate with a fork. The participants on either side of her stole food from her which she ignored. The stereotypic movement and sounds continued throughout the dinner. After dinner May went back to her chair in the kitchen and sat in it. She grrred and performed her stereotypic patterns. Occasionally May took the staff to the kettle,
or suddenly got up and drained one of the staffs' coffee cups. May frequently ate from an ashtray someone had left out.

May stayed seated in the kitchen or moved to the front room to lay on the couch. Her ever present search for coffee or tea, or ashtrays was always evident and if cups or ashtrays were left unattended May would take advantage and drink or eat whatever was available.

May loved to have her back rubbed by a staff member. At these times May would cease the stereotyped motion and ggring and enjoy the massage. When the person stopped massaging May she would take their hand and put it on her back. May appeared to possess an outstanding quality to May was her receptive language. May would ‘understand’ verbal directions and came to the staff when called, pulled up her pants on verbal prompt, or went to the bathroom when told to do so.

May never went to bed. She stayed in the kitchen and ggrred and face fingered all night. She occasionally napped. The last sound heard as the ASWs left the house each night was the night staff in the kitchen with May ggrring in the background at midnight.

May’s weekend was not disimilar to the weekdays except for May going on outings. May went to the park and ggrred as she walked on her tip toes. She sat down and ate grass when the staff was not watching her. Often the staff tickled her and she laughed. May responded to music. Rock and roll music on the stereo system meant May’s stereotypic movements were fast and pronounced. During classical music, especially flute music, May slowed down to the point of sleep. May sometimes changed from sounds of anguish to laughter, which was infectious and the staff laughed too because of May’s mirth.
Participant Four: Tim

Age: 36 years
Height: 5' 8"
Weight: 153 lbs.

a) Physical Description

Tim’s ears are badly cauliflowered. His eyebrows and chin are badly scarred. These scars were apparently the result of his time spent on a back ward where the other ‘inmates’ and Tim fought. Tim had blue eyes and sandy brown hair. He was muscular and seemed unaware of his surroundings. There was a quality of aloofness and of Tim not attending to changes in his physical surroundings. Tim spent hours walking in circular patterns with his eyes opening from time to time. He often bumped into other people due to his lack of attention to the ‘outside’ world. Tim’s expression, ears, and scars gave him the appearance of being mentally retarded.

b) A Typical Day in the Life of Tim

Tim was up early in the morning, dressed, and taken into the front room by the staff. Tim appeared to love the mornings. He ran a circle pattern in the front room/dining room area every morning with a big smile on his face and made small noises. Tim stopped occasionally, held up his arm so the sun touched his hand, laughed, and then continued his circular run.

The breakfast was brought to the table and Tim took his seat when called by the staff. He ate from a training bowl with a spoon. Tim was a very messy eater and his food fell on his shirt, the table, and the bench he was seated on. He had a hearty appetite and usually ate second and third bowls of cereal. Tim frequently took food from May and April. At the end of a meal
Tim ate the food that had fallen on the table and bench. He also ate anything that was on the floor, food or otherwise if left unattended.

Tim gazed at his fingers for hours at a time. He stared at his index finger and his thumb oblivious to the world around him. Often he was incontinent. He, at these times, removed the wet and soiled clothing, and went back to staring at his finger and thumb. The staff were discouraged with constantly changing Tim's clothes. There were times when the staff sat Tim on the toilet for an hour and Tim would not urinate or have a bowel movement. Then fifteen minutes to an hour later Tim soiled himself. Tim usually wet himself and had to be changed before leaving for the day program despite the staff's effort to seat him on the toilet before breakfast.

Tim arrived at the day program and went to the front room to 'circle walk.' If it was sunny and warm Tim found the sunniest warmest spot and sat and basked in the warmth finger staring. On other mornings, Tim pushed either another participant, furniture, or a staff member. Tim's pushing behavior was a problem. He approached a person and pushed their arm or leg. If the person resisted Tim applied more force. The actions were never violent, rather he used a slow, steady, applied pressure, just enough to move the arm or leg. If the person pushed back Tim pushed harder. If the person left Tim either went to another person and started to push, or followed the person and when they stopped moving he pushed them again.

This pushing behavior had various responses from the person being pushed. If it was June she screamed, curled into a ball, and rocked rhythmically. If Tim continued to push June she flailed him and kicked him (very hard) with her feet. Tim appeared as if he did not even felt the blows
hitting him. He kept right on pushing her despite the forceful kicks and punches. June screamed and hit herself while Tim pushed her leg until the staff came in and took June out of the room. Tim got up and looked for someone else to push. If no else was available to push Tim circle walked and stared at his thumb and index finger. The day program staff often complained of the unruly mood June was in due to Tim.

Tim appeared to have no interest in any of the activities at the day program. The staff had to use hand over hand. Tim seemed to live in a world of his own. On occasion, Tim sat down and would not move. The staff wanted him to attend a program. This posed a problem for Tim would not move. At these times if the staff tried to move him he went limp, refused to stand up, and if pushed held on to anything within reach. It appeared to be total passive resistance. Tim never pushed or hit. He just let his body go limp and made it difficult to move.

Tim's favourite activity was lying in the sun without moving except to finger stare hour after hour. The staff had to be careful not to let Tim sit in the sun if they wanted him to attend a program for his passive resistance techniques went into effect upon attempts to remove him.

Tim usually soiled himself three times during the day despite the best efforts of the staff to monitor his liquids and take him to the toilet. Tim, however, was not unpopular with the staff. His behaviors while upsetting were compensated by his gentleness. Frequently, he sat with a staff person and played a touch game where the staff would touch his fingers. Tim looked up and smiled. This game could be played for hours with Tim.

After the day program Tim returned to the group home. He started his
circle walk, or laid in the sun until dinner. His incontinence continued. On cloudy
or rainy days Tim circle walked under the flourescent lights in the front room,
held his arm up to the light from time to time and smiled. He vocalized ‘aboo’
softly with his broad smile.

Tim’s behavior during dinner was much like the behavior exhibited at
breakfast. He ate two or three helpings with a spoon from his training plate
followed by some theft from May’s and April’s plates.

After dinner Tim circle walked, finger stared, or laid in the sun on the
porch until it was his bath time. Bath time was another of Tim’s favourite
times. He followed the staff when called to the bath, took off his pants, and got
into the tub on his own. He usually had to be helped out of his shirt before he
sat in the tub. Once in the tub Tim got as close to the tap filling the tub with
warm water. Tim stayed in the tub for over an hour.

After the bath Tim was dressed in his pajamas and put into bed. Tim
willingly got into bed with a big smile on his face. Two of the staff played
‘peek a boo’ with Tim. He hid his face under the covers and peeked out. The
staff caught him and said ‘got you.’ Tim smiled. Once the staff turned the
lights out Tim was asleep in minutes until he was awakened the next day.

The weekends for Tim were spent lying in the sun when it was warm
and sunny outside. If it was cold or rainy he circle walked and ran around the
front room. Tim, as during the week, enjoyed going to bed at night and
sleeping.
Participant Five: April

Age: 39 years
Height: 5' 6"
Weight: 125 Lbs.

a) Physical Description

April's most immediately noticeable feature was her lack of teeth. Many of her teeth have been removed. This was because April sometimes bit people. In the past while she was institutionalized certain of her teeth were removed as a result of this behavior. April also walked on her toes. These two features made April appear immediately different to the observer. She appeared to be taller than she really was because of the toe walking. April constantly vocalized and picked her nose, vaginal area, or her sweater. April ate the fluff from the sweater. Her brown hair was cut quite short. Pink and purple were the colours April chose to wear. She was always dressed in these two colours. April, due to these physical features and behaviors, was noticeably mentally retarded.

b) A Typical Day in the Life of April

April was the last person awakened up by the staff in the morning and came to the breakfast table last. In the morning her skin tone was very pale. April appeared visibly tired and sleepy. She did not eat a lot of food and was characterized as a picky eater. However, the foods that April liked she really liked, and stole them from the other participants. April's breakfast was left almost untouched. She spun her plate and threw most of the food onto the table. April liked her tea in the morning and had two or three cups, plus she stole tea from May and Tim. Celia (staff) came to April and had her leave the
April went down the hall to her bedroom.

April liked to hug the staff and came right up, hugged them ‘eeahhing,’ and pushed her face into the person that she hugged. Often she picked her nose and slurped while she did this behavior. April bit or hit the staff when they forced her to do things she was opposed to doing. April was forceful about what she liked. Both tea and coffee are liked by April. She stole the staffs’ and other participants’ tea and coffee. April was an extremely fast cup thief and gulped down whatever was in a cup in seconds. If someone tried to remove the cup from April while she was holding it she would bite them.

After breakfast April returned to her room, sat on the bed, stared out the window, and rubbed her vagina. She picked and ate the fluff from her sweater. April loved to carry sweaters and socks in her right hand. This morning the laundry room door was left open. April went in and took two sweaters and carried them around under her arm. Celia (staff) gave her a cup of tea. April took the cup and let the sweaters fall. Celia grabbed them and returned them to the laundry room. Then the laundry room door was locked.

After breakfast, the staff prepared April and the other participants to walk to the day program. April stopped to eat grass for she, like May, exhibits pica. The staff watched April carefully while she crossed the yard to the day program. Once inside April walked into the dining and living room. Next she went into the bathroom and emptied the contents of the cup board onto the floor if the cup board was not locked. She then appeared in the front room, naked except for her shoes. The staff took her and reclothed her in the bathroom.

April during the circle exercise rolled the balls without looking at them for her favourite food, which was weiners. Sal, made her roll a ball in the hand
over hand method and April bit her other hand during this process. Another participant had a sweater on, and April attempted to pull it off the person. The other person, Tim, resisted and was bitten. The staff interceded and moved Tim away from April. Despite April’s missing teeth her bite marks were noticeable on the other participants and staff.

April hugged the other participants as well as the staff. The hugs lasted a short time and were gentle. This morning April hugged Dan. April was very astute at opening many of the lock systems the staff have invented. April stripped to her shoes this morning. She got out of the day program and wandered naked across the lawn ‘eeahhing.’

One of the staff ran out, brought April back, and took the grass from her mouth. April joined a group of higher functioning people in another building at the site. Larry accompanied her and they sanded items. April was taken hand over hand by Larry through the sanding exercise. April constantly bit her other hand during the hand over hand routine. The weiner bits given at the end of the session appeared to keep her at the table and she didn’t bite Larry.

When she returned from the day program April checked out the group home and every cup that was out for tea or coffee. April then went to her bedroom to sit on the bed, rub her vagina, pick her sweater and eat the fluff while ‘eeahhing.’ It was not uncommon for April to spend thirty or forty minutes in her room alone sweater picking and staring out the window.

April patrolled the house, checked doors to see if they were open and looked for cups with tea or coffee left in them. The kitchen door was open April went in, opened the fridge door and tried to take food out. The staff evicted her for being a nuisance. April wandered down the hall into a bathroom, opened a
cupboard, threw the contents onto the floor and then left. Kurt (staff) saw the mess on the bathroom floor. He took April to her bedroom. Kurt then cleaned the bathroom. April sat on her bed and picked fluff from her sweater.

April was a fussy eater at dinner as well as breakfast. She spun her plate, and found the potatoes and ate only the potatoes. She threw off the plate any vegetables or meat that were in the potatoes. April stole May’s potatoes but the staff stopped her before she ate them all. April stayed for tea at the table after dinner. She had four cups and tried to steal Tim’s tea but the staff moved Tim away from her.

April then went back to her bedroom, sat on her bed, ‘eeahhed,’ rubbed her vagina, and ate fluff from her sweater. She occasionally patrolled the house looking for tea, coffee, open doors, or sweaters to carry. When the other participants’ bedroom doors were open April went in and threw their clothes on the floor and emptied their dressers. April went to bed early and slept without disturbance until awakened the next morning. She was a sound sleeper.

A weekend day for April was much the same as a weekday except for an outing to a park. April moved about twenty feet away from the group. She sat and ate grass. Sal (staff) went over to her and ‘wrestled’ with April who ‘eeahhed’ and playfully wrestled her back. April appeared to enjoy the contact and hugs from Sal. April appeared to kiss the top of Sal’s head while they played.

June went over to April and tried to sit on her. April pushed her away. June left and ran back to the main group. The staff started to return to the van and April was called by a staff member. April got up and followed the group to the van. They returned to the group home and April went to her
bedroom. Later April appeared naked in the front room. This was another typical weekend day for April.

E. DISCUSSION AND ANALYSIS OF THE PARTICIPANTS

The preceding descriptions indicate a number of severe deficits in all of the participants' functioning including; intellectual, adaptive behavior, and independent living skills. The participants are disabled people. A list of the major deficits would include;

1. They have no verbal language, (not one word)
2. They do not dress themselves
3. They are incontinent, (at least on occasion)
4. They cannot prepare any meals or serve themselves a liquid beverage
5. They perform a high degree of stereotyped movement
6. They lack accepted social skills (public masturbation, stripping, anal picking)
7. They require almost total supervision for their safety and survival.

In other words the participants are, what's archaically referred to as, 'idiots' (MacAndrew & Edgerton, 1964). The participant groups' everyday needs for survival are met by the staff. Without the presence of the staff, the participants would likely perish in a very short time. The participants apparently lack common sense, and seem to, need constant supervision to ensure their needs for food, shelter, and general well-being are met.

On the other hand, the participants exhibit some fairly sophisticated behavior. Each participant recognized and used many objects in their environment, (ie. the swings, trampoline, radio, musical instruments, certain furniture, rooms, partiality to certain staff members). Each participant has curiousity, likes, and
dislikes in their environment. Pleasure and displeasure are expressed through each person's overt emotional responses and these emotional responses are consistent across both settings and through time. Staff members have responses from different participants that are consistent through time.

The participants appear to be aware of their place and role in the social pecking order of this group (i.e., Dan will touch May's head and have her move, but ignores Tim's aggression). The participants utilized different coping strategies to maintain their position in the social order. Dan was not aggressive towards the staff or the other participants. June was aggressive towards the staff and other participants. The adaptive behavior the participants exhibit in preserving the social order (Dan ignoring aggression by Tim, May's avoidance of confrontation by moving places when touched by the other participants) seemed on the surface to be reasonable and successful strategies. The social order appeared to follow a hierarchy that placed April in the number one position. Tim was the next most powerful. Dan was number three in the pecking order. June was in the number four position. May was at the bottom of the order. These social rankings were not altered throughout the time the researcher was in the setting.

April took food, clothing, and places from any of the participants. Tim could push Dan, May, and April from their places. Dan could move June and May from their places. June could move May from her seat in the kitchen or living room. May was at the bottom of the participants' pecking order.

The participants each have individual likes that are consistent across time and settings, (i.e., Dan's walks, June's puzzle, Tim's sun bathing, May's kitchen sitting, April's sweaters). Each participant liked certain staff members. They sought out and made these likes known within the context of their environment.
Dan appeared to learn, through observation, the use of objects he liked, for example, the use of the radio. June had sensitized the staff to her need for privacy from the other participants. Tim was allowed to sun. The participants did communicate their wants and likes to the staff.

The participants overall, appeared to tolerate the formal programs that the staff had set up. The participants did not display a great interest in these programs, they were not often violent or aggressive toward the staff who made them perform these tasks. The participants did make their likes and dislikes known to the staff through their emotional responses and behavior. Each participant had a pattern of behavior that was understandable within the context of their environment and they were, after observation, predictable.

The participants' behavior can be divided into three main categories of (1) inside, (2) outside, and (3) boundary overlaps. Each of these categories will be reviewed below with examples cited in the following section.

1. Inside

The inside category refers to behaviour a person performs with him or herself. This type of action and activity does not involve other people or environmental stimuli. Everyone from time to time exhibits inside behavior such as day dreaming, rubbing themselves, or fussing with their clothes. These behaviors are exhibited when environmental stimulation is low, while waiting, or as a response to boredom. Inside behavior may be viewed while observing people in traffic tie-ups, waiting rooms, or when a person is alone in a public place. Inside activity is a common activity.

The coding of inside behavior has been divided into two subcategories:
inside physical behavior and inside reticular behavior. The distinction between these categories is the intensity and degree of self-involvement. The inside physical behavior was exhibited in the participants through actions such as ear and nose picking; penis, vagina, and finger rubbing; and sweater picking. The second category, inside reticular behavior, was observed in the participants' performance of stereotypic behavior. This category appeared more intense and self-absorbing than behavior coded as inside physical behavior.

Each of these classifications will be discussed in the following paragraphs. Examples of participant behavior will be provided and the definitions and theoretical bases explored.

a. Inside Physical Behavior

All the participants exhibited inside physical behavior. April rubbed her vaginal area, picked her nose and picked her sweater. Dan rubbed his groin and picked his ear. May rubbed her face in pattern. Tim held his penis and picked his fingers. June rubbed her head and vaginal area.

These actions are private behaviors and usually not performed in public places. As previously stated, these behaviors are associated with boredom, waiting, and detachment from the environment. These activities are self-involving and are not externally focused. However, the person is not totally withdrawn into him or herself while performing these activities. This classification reflects mild detachment and a mild degree of reliance of self for stimulation.

The participants engaged in prolonged periods of inside physical behavior. April sat in her bedroom for long periods and picked wool pills from her sweater. Dan rubbed his penis for extended periods on the window seat. Each
participant had a favored unique repertoire of inside physical behaviors.

A staff member was able to draw the attention of the participant through a verbal prompt when they exhibited inside physical behavior. This behavioral repertoire was easily disrupted and the participant's attention focused on the staff member.

b. Inside Reticular Behavior

This classification refers to visible behavior that was intense and completely self-absorbing for the participant. Stereotypic behavior was the observable manifestation of inside reticular behavior. Each participant had unique ritualistic stereotypic movement patterns. Tim circle walked and finger stared. May rocked and grred. June rhythmically rocked from side to side. Dan waved his arms and shook his head. These behaviors were rhythmic and repetitive. The behavioral patterns were deeply ingrained in the participants.

The intensity of self-absorption was observed to include emotional responses during the performance of stereotypic movement by the participants. The emotional responses did not appear to be the result of external factors: either other people or environmental stimuli. The stereotypic behavior and the emotional responses seemed inexorably linked and unified. The participants appeared totally self-absorbed during the performance of stereotypic movement.

The participants spent a majority of their time performing stereotypic movements. The environment did not appear to interest the participants while engaged in this activity. The staff were unsuccessful when they attempted to intercede, through verbal prompts, to have the participant focus on them.

The evidence from sensory deprivation experiments indicates that the
reticular area of the brain develops its own data and sensation in a monotonous environment. This creation of data may be viewed as an adaptation to monotony. This data developed includes retinual visual phenomena (a form of mild hallucination), childish emotional responses, and audio hallucinations (Burney, 1961; Heron, 1957; Robertson, 1961; Schultz, 1969; Suedfeld, 1980; Zubek, 1969). The inner generated sensory data is not observable nor environmental. The inside category of reticular behavior is based on this theoretical construct.

2. Outside

The outside category refers to behaviors the participants exhibited which involved interactions with other participants, the staff or the environment. These actions were directed externally and were interactive between the participant and external objects, stimuli, or people. The outside category represented the antithesis to the inside category. This category of behavior coded behaviors which the participants exhibited that were externally focused.

The outside behavioral category has been subdivided into two classification: outside interpersonal behaviors and outside environmental behaviors. The distinction between these two categories is that the interpersonal classification involves activities and actions the participants initiated with objects that were in the physical setting.

Each of these classifications will be presented below. Examples of participants' behaviors and details of each category will be presented.
a. Outside Interpersonal Behavior

All the participants exhibited outside interpersonal behaviors. Dan hugging Maria was a typical example of his manifestation of this classification. April took staff members by the arm and led them to a given room. May placed staff members' hands on her back. Tim engaged in a finger touching activity with Lidia. April hugged and kissed staff members. These are all examples of participant/staff outside interpersonal behaviors.

Examples of participant/participant outside interpersonal behavior was April hugging Dan and leading him by the hand. Tim pushed Dan's arm or leg. Dan touched the top of May's head and May left the seat for Dan to sit in.

These actions were self-initiated by the participants. The outside interpersonal classification was an observable manifestation of a participant seeking interpersonal contact. The examples given above were frequent, repeated, and unique to the individual participant. The interpersonal actions were not random but rather represented an order that was observable across different protocols.

Each participant exhibited unique interpersonal behaviors. These were interpreted by the observer as orderly, meaningful, and purposeful to the participant. This classification represented the social behavior of the participant group.

b. Outside Environmental Behavior

This classification refers to participant activity which involved an environmental objective as the focus of the participant's attention. The behaviors were self-initiated by the participant. All participants exhibited unique repeated
actions in this classification.

Dan went to the radio, turned it on, and altered the volume and station. April went into the bathroom and removed all the miscellaneous toiletry items from the cabinet. June searched for her puzzle to carry and look at. Each participant was observed initiating behavior which was externally focussed on an environmental object.

These behaviors indicated to the researcher that the participants each recognized certain objects and chose them for a reason. The repeated selection indicated recognition and preference of certain objects. In a sense the objects selected had a meaning for the participant.

The theoretical construct used to ground the outside behavioral category was intrinsic motivation and curiosity. The participants when not involved in inside behavior appeared to exhibit curious and exploratory activity. The outside behavior was possibly based on an intrinsic need for sensory input and stimulation. The participants were apparently motivated to interact with the environment.

3. Boundary Overlaps

The boundary overlap category refers to behavior that involved a mutual understanding between the participants and the staff. This category involves activities that participants exhibited when prompte by the staff. The boundary overlap category has been subdivided into two classifications: conforming positive behaviors and conforming negative behaviors. The distinguishing feature between these two classifications is the degree of independence and social adaptability of the actions and activities.
Each of the classifications will be presented below. Examples of participant behaviors will be given and details of each subcategory will be provided.

a. Positive Conforming Behavior

This classification of behavior encompassed observable actions and activities that the participants exhibited which were considered acceptable. Behavior classified in this category included participant compliance to the directions of staff members such as responding when their names were called, performing a task when prompted (e.g., 'Pull your pants up.'), and performing tasks they were trained to do (e.g., eating dinner with a fork and not stealing food).

This behavioral classification represented social behavior that was viewed as acceptable by the staff. These behaviors are critical for community living in the PMR population. Many of the behaviors listed in previous categories were negative and represented barriers to community acceptance of the PMR. The conforming positive behaviors were an area of importance to the staff since they represented apparent recognition and understanding between them and the participants.

b. Negative Conforming Behavior

This behavior classification represented observable actions that were considered as unacceptable social activities. The participants stripped at inappropriate times. Yet, at bedtime or in the bathroom the staff assisted them in removing their clothing. Stripping in public was coded as negative conforming behavior. Dan urinated in the toilet near the greenhouses when he went out for a walk. Dan was incontinent when in the group home or day program.
Incontinence was coded as a negative conforming behavior.

The researcher hypothesized that the participants had developed a learned helplessness. This concept of learned helplessness is worth consideration. Could the participants have developed a dependency on the staff? Information gathered from observations of the participants' behavior appeared to support this notion. The participants performed many behaviors inappropriately (e.g., stripping, opening doors, trying to leave the house). These behaviors, from one frame of reference, are functional, yet in fact are dysfunctional and inappropriate as they are performed by the participants.

4. Discussion

In summary, the participants exhibited intelligent behavior and learned new behavioral repertoires. The participants did not need to have specific programs set up to learn these behaviors, they appeared to learn through trial and error. The issue of relevance and whether or not compliance to staff initiated programs was the 'best' method of instruction for the participants is at issue. The staff devoted a lot of time and energy to programs that did not appear to have an impact on the participants. On the other hand the participants learned new skills (ie. Dan to use the radio, trampoline and swings, May to lead the staff to the coffee pot or kettle) on their own.

The participants, through their stereotypic behavior, were able to cut themselves off from the staff and outside world. They were in, it appears, a world of their own. At those times juice, or walks, or music, did not seem to bring them back. The link between boredom and stereotyped movement as an answer within the person to boredom seems hypothetically possible. The
participants’ stereotyped movement is reduced during times of activity in events they ‘like.’ Dan tried to ‘get out’ of the house. He often, after trying to open the door to get out, turned back when it was locked and either stereotyped or ‘humped’ the couch. June ‘understood’ the symbol for ‘walk’ is her coat. May would get a cup and present it to the staff to communicate that she wanted a drink of coffee or tea. The staff did not ‘read’ these clues as a statement of self-motivation and interests by the participants.

The concept of learned helplessness in the participants created by staff induced dependency is a factor worthy of consideration. The dignity of risk (allowing the participants to learn through more trial and error on their part) might offer more efficacy. The participants can learn, as the protocols illustrate. They did not seem to learn many of the essentials for their survival; the question is: why?

The use of the perspective of symbolic interactionism is important. Have the participants learned to be ‘idiots’ through internalizing in themselves the views the staff have of them? Did the institutional staff and now the community staff, treat the participants like ‘idiots’? Did the participants, in the end, internalize this view of themselves? Does the treatment of the participants, both in the ‘institution’ and the community create the dependency and ‘idiocy’?

The use of the analytic abstractions of inside, outside, and boundary overlaps might lead to a new perspective on programing in the PMR. The alteration in the theory of the participants being totally dependent, by the staff, and the use of trial and error might greatly facilitate the growth of independent living skills for the participants. The staff dressed and undressed the participants, yet the participants ‘inappropriately strip’ their clothes off when they wanted to
disrobe. At other times the participants needed assistance from the staff to disrobe. The symbolic interactionist perspective offers a unique view of the participants 'playing a social role' expected of them.
CHAPTER V. ANALYSIS AND INTERPRETATION OF THE DATA

This chapter will present the analysis and interpretation of the data. The major coding categories presented in Chapter IV were: (1) inside, (2) outside, and (3) boundary overlap. Table 8 on the following page is a schematic representation of the coding categories, subclassifications, and behavioral manifestations for each of these categories. The observable, understandable, and orderly behavior of the PMR participants will be developed for each category. The emotional responses of the participants will be presented.

The initial observations of the participants' behavior by the researcher appeared devoid of meaning, purposeless, and random. These initial observations were predictable given the literature cited in Chapter I. The PMR are noted for their highly aggressive, unusual, and stereotypic behavior (Baumeister, 1978; Bricker & Campbell, 1981; Cleland, 1979; Rago, 1976). Beyond noting the aforementioned traits, the literature does not discuss the social order or interactions of the PMR. The observations and analysis of the data from this study provide evidence that the PMR do have predictable patterns of behavior and at least a rudimentary social order. Presented in the following pages is the analysis of the data to support the interpretation of the data.

The categories will be presented in order of amount of time the participants spent engaged in the behavioral manifestations. The inside category was the most frequent, then the outside, and finally the boundary overlap.
Table 8: Schematic Diagram of Coding Categories

<table>
<thead>
<tr>
<th>Inside</th>
<th>Outside</th>
<th>Overlap</th>
</tr>
</thead>
<tbody>
<tr>
<td>(A) Reticular</td>
<td>(B) Physical</td>
<td>(A) Negative</td>
</tr>
<tr>
<td>(i) stereotypic behavior</td>
<td>(i) bodily self stimulation</td>
<td>(i) learned dependency</td>
</tr>
<tr>
<td>(a) emotionality</td>
<td>(a) autoeroticism</td>
<td>(a) incontinence</td>
</tr>
<tr>
<td>(B) Environmental</td>
<td></td>
<td>(b) stripping</td>
</tr>
<tr>
<td>(i) seating arrangement</td>
<td></td>
<td>(ii) staff initiated activity</td>
</tr>
<tr>
<td>(ii) possession recognition</td>
<td></td>
<td>(A) Positive</td>
</tr>
<tr>
<td>(iii) object oriented behavior</td>
<td></td>
<td>(i) familiarity of routine</td>
</tr>
</tbody>
</table>

### Outside

<table>
<thead>
<tr>
<th>(A) Interpersonal</th>
<th>(B) Environmental</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i) social order</td>
<td>(i) seating arrangement</td>
</tr>
<tr>
<td>(ii) staff preferences</td>
<td>(ii) possession recognition</td>
</tr>
<tr>
<td>(iii) sexuality</td>
<td>(iii) object oriented behavior</td>
</tr>
<tr>
<td>(iv) intimacy</td>
<td></td>
</tr>
<tr>
<td>(v) SIB</td>
<td></td>
</tr>
</tbody>
</table>
A. THE INSIDE CATEGORY

This category was divided into inside physical behavior and inside reticular behavior. The inside category accounted for a majority of the participants' behavior observed by the researcher, as the literature suggested. The inside physical category which has been divided into body self-stimulation and autoeroticism was not as predominant nor as self-absorbing as the inside reticular category.

1. The Inside Reticular Category

Stereotypic behavior was exhibited by all the participants. It was an outstanding, noticeable pattern, and a dominant characteristic in the participants. Stereotypic movement was ever present across contexts and time in all the participants. Stereotypic behavior is a characteristic of the PMR (Baumeister, 1978; Cleland, 1979; Hollis, 1978; Snell, 1982).

The researcher observed that the participants' stereotypic movements were exact movements for each participant. Each participant exhibited stereotypic movements that were different from the other participants. The movement was similar to a part of their personality and like personality, each participant had their own unique and definite pattern of stereotypic movement. The degree and intensity of the movement varied within the individual but the pattern of movement did not vary.

June exhibited a stereotypic motion that required her hands be placed at eye level on either side of her head, the fingers curled in to the palm of her hands, and she moved her head from side to side, staring at each hand in a rhythmic motion. The researcher labelled this stereotypic movement 'finger
staring.' At other times, June lay on the floor on her back, pulled her knees into her stomach, crossed her ankles, and rolled her head from side to side. This movement the researcher labelled the 'prenatal rock.' June performed this motion so frequently that the hair at the back of her head was matted from the continual rubbing on the floor. June also rocked back and forth while seated in a chair. This movement was labelled 'body rocking.' This form of short hand for the participants stereotypic movement was incorporated by the researcher rather than continually write each movement each time the participant exhibited the stereotypic pattern.

Dan's stereotypic movement was completely different compared to June's. Dan exhibited stereotypic behavior that involved large motor movement of his arms while he shook his head vigorously. This pattern of movement resembled a rock musician playing an imaginary guitar and was called 'rock star' by the staff. Dan frequently spun himself around on one foot as he walked. This behavior was labelled 'whirling dervish.' Dan also used a stereotypic movement of his hand that usually involved watching the movement in the reflection of a window or seeing the motion of his hand in the shadows. This was called 'reflection waving.'

Tim was a 'circle walker.' This stereotypic behavior of Tim's frequently lasted for sixty minutes. Tim walked circle patterns around furniture in the living/dining room area. Tim's circle walking patterns were very intricate patterns as illustrated by protocol #15 that was typical of Tim:

47. Tim walks a circle around the dining room table 4 complete times.
48. He stops and picks up a crumb from the table and eats it. Tim then reverses his direction around the table and again
49. reverses direction, and stops by the patio door, turns again and
50. circles the dining table. Kurt puts the front room lights on
51. and Tim circles the dining table and into the front room, he moves
through the furniture, very close to it but not touching it and circle walks under the over head light in the front room. He stops and "finger picks" under the light. Kurt turns the light off and Tim circles the dining table and stops and "finger picks" under the dining room light. After three minutes of staring Tim circles through front room furniture. The pattern is intricate as the furniture is close together and Tim's eyes are often closed. Tim moves between furniture without opening his eyes and changes circle patterns with never touching the furniture. He stops under the over head light and "finger stares"...........

Diagram A (Appendix D) shows Tim's pattern of movement and the furniture lay out in the group home. Tim sat in the sun for hours and performed a motion, identical to one observed during his circle walk behavior, that involved his index finger and thumb. This was called "finger picking."

May's stereotypic movement involved her voice which 'ggrred' and her body rocked forwards and backwards as her hands ran over her face, into her mouth and nose, then back through the sequence again. May exhibited an almost constant 'grrr' and body rock. There were very few times that May was quiet or still. Flute music quieted May. However, even at meals she rocked and 'ggrred.'

April's stereotypic movement involved her voice which made an 'eeaaah' sound. April would pick her nose, pick pills of wool from her sweater and eat both commodities. April slurped noticeably while she ate, then 'eeaaahhed' again.

The stereotypic behavior of the participants' became predictable and personalized to the researcher. The stereotypic movements were not random patterns but very personal individual patterns and movements specific to each participant. Stereotypic behavior is individualistic and unchanging except for degree and intensity within the person.

The researcher observed that the participants varied the speed and intensity of stereotypic movement. The specific muscles motions were the same, it
was the rate of movement that changed. The example of Tim's circle walking, cited in the following section, is one case. Tim walked faster and became happier. The speed of the stereotypic movement increased in relation to the degree of happiness he exhibited.

The emotional responses of the participants appeared to be reflected in the stereotypic behavior they exhibited. Another example of this correlation between emotional response and stereotypic behavior is illustrated by Protocol #26 which describes May:

34. May is seated sideways in the green chair in the kitchen. She is
35. gurring quietly. May taps the chair, table, and her teeth with her
36. index finger. May’s movement starts to speed up, her hand moves
37. faster, her body rocks quicker. She starts to laugh at apparently
38. nothing, she rocks, moves more, and more, and becomes very loud
39. to the level of shouting, clapping her hands together, and sucks her
41. fingers. Then the laughter starts to diminish and her movements
42. slow as she quietens down..............

The participants all exhibited this correlation between stereotypic motion, intensity, and emotional responses. The researcher regarded this phenomena as indicative of a relationship between stereotypic behavior and emotional responses in the participants. The emotional responses that were observed did not appear to be a result of external environmental changes or people interacting with the participants. The stereotypic motion, it appeared, was a manifestation of the degree of emotional response in the participant. These actions occurred in both the day program and in the group home. The stereotypic behavior of the participants was both their most frequent behavior and the most self-involving behavior.
a. The Emotional Reticular Category

Inner directed emotional responses were also manifested by all the participants. This, according to one researcher, is important knowledge for the understanding of the PMR:

Have you ever noticed a PMR sitting all alone, in relative solitude, break into a broad grin or laugh? For, if we had unequivocal affirmatives on both these questions, we would have evidence that some among them have the capacity of self, or other regard or that a thought crossed their mind and caused them to smile (Cleland, 1979, pp. 80-81).

The researcher noted emotional responses in the participants as in the above cited example of May. Tim provided another example of the interaction between stereotypic movement, intensity and emotional response. Protocol #8 contains an example of Tim's emotional response:

39. Tim, circle walks while finger staring.............
41. Tim runs' and opens his mouth wide in an almost smile. He runs
42. fast circles around the dining table, he is laughing, and making
43. a cooing sound. He continues to run the circle, four times, he is up
44. to ten times. He continues to run the circles are larger and he
45. laughs. Tim lets out an 'aaabouuu' sound as he runs a circle into
47. the living room as he circles back to the dining room he laughs.
48. Tim appears so happy....................

All of the participants exhibited emotional responses when alone. The researcher was careful to note if there had been any change in the external environment to prompt this change in the participant. No external changes in the environment were noticed by the researcher. There were not only changes to smiles, at other times, especially in May, a tear came to her eye and crying was seen and heard by the researcher.

This category of behavior observed in the participants did not appear to be dependent on the environment or on other people. The inside category of behavior was observed by the researcher as intra-individual. Since this category
of behavior represented a majority of the behavior of the participants, it is important. The researcher's classification of behavior observed in the participants was predicated on the basis that the participants had developed coping strategies (inside physical and reticular behaviors) as an adaptation to the institutional environment that they had lived in throughout a majority of their lives.

Now that the participants were in a smaller setting with a larger staff-participant ratio, these coping mechanisms were so ingrained and habitual that they did not stop because of the new environment. The origin and maintenance of stereotypic behavior is unknown (Baumeister, 1978; Baumeister and Foreman, 1976; Hollis, 1978). Stereotypic movement as a characteristic of the PMR and representative of a major part of their behavioral repertoire has been documented by many authors (Baumeister, 1978; Cleland, 1979; Snell, 1982).

The stereotypic movement and emotional responses of the participants engaged in stereotypic behavior led the researcher to infer that there was a direct correlation between the two. The literature on sensory deprivation (Heron, 1957; Heron, Hebb, Doane, Scott and Bexton, 1956; Suedfeld, 1980; Zubek, 1969) indicates that there are behavioral changes due to a prolonged exposure to a monotonous environment. These changes included hallucinations, childish emotional responses, and an increase in activity in the reticular area of the brain.

The researcher, after three months of observation, inferred that the participants reacted to the institutional environment with behavior similar to that exhibited by subjects of sensory deprivation. They experienced hallucinations and childish emotional responses due to the reticular area of the brain. The participants, in effect, develop their own sensory data which is as, if not more,
involving as the environment. The researcher hypothesized that stereotypic behavior and the observed emotional responses were a manifestation of this phenomena. The participants, due to sensory deprivation, not mental retardation, had become self-reliant for sensory stimulation.

The physical and autoerotic subclassifications were less intense manifestations of this adaptation to self-reliance. These two subclassifications are more common in the entire population except for the public nature of the participants in these socially unacceptable behaviors. The social rules of society dictate masturbation to be a private act. To a lesser extent the behaviors of bodily stimulation of the nose and ears are also seen as inappropriate in a public place.

The participants were unaware of the social taboo of their behaviors. The deeply ingrained pattern of self-reliance for sensory stimulation was paramount. The participants occupied themselves for a majority of the time with inside physical and reticular behavior.

2. The Inside Physical Category

The body self-stimulation behavior included April's picking and eating wool pills from her sweater, picking her nose, and vocalization of 'eeaah.' Dan's body stimulation included picking his ears and nose. Tim was on medication which prevented him from regurgitating his food. Regurgitation of food would have been coded in this category as it provides a body sensation of taste. He also picked his fingers. May rubbed her face, nose, mouth, and ears. She vocalized 'grrrrs.' June picked her fingers. Each participant had unique body self-stimulation behaviors.
This category, as previously mentioned, appeared to the researcher to be similar to behavior associated with monotony, waiting, and boredom. Body self-stimulation, whistling, singing, and vocalizations are common behaviors for people coping with monotony. The participants engaged these behaviors for prolonged time periods.

The interpretation of these behaviors was that the participants had become self-reliant for stimulation. Years of living on large wards had created a self-sufficiency in the participants. They did not seek external stimulus, not due to profound retardation, but rather as an adaptation to a monotonous environment.

a. The Autoerotic Category

The autoerotic behavior of the participants was interpreted by the researcher as a reliance on oneself for stimulation. The literature on PMR available to the researcher did not discuss autoeroticism. April, Dan, and June were observed stimulating their genitals. The behaviors these three participants exhibited were noted as masturbation by the researcher. A description and discussion of these behaviors is given below.

Dan manifested sexual tendencies and became sexually aroused after physically hugging and dancing with female staff members. This activity produced autoerotic behavior in Dan. A description of Dan engaging in masturbation after hugging Maria was given in the last chapter. Dan was frequently observed by the researcher to stimulate his penis to erection. A description of this in Protocol #44 was as follows:

10. Glynda comes in the kitchen. Dan hugs her and grabs her hair.
11. She says 'You, let go!' Dan lets go after a minute. Dan goes to the
12. fridge and takes out the juice container and hands it to Glynda.
13. She pours him a drink. Dan drinks the juice and hugs her. They
do ‘a two step dance.’ They disengage and Glynda pats his chest
he makes an ‘YAAYAA’ Tarzan-like yell. Dan hugs her again and
they ‘dance’ yet again. Glynda disengages herself and has Dan
leave the kitchen..................
21. Dan is in the front room with his hands down the front of his pants
22. He is lying on his stomach ‘humping’ the couch with his rear end
23. bobbing up and down...................

April was observed by the researcher in her bedroom masturbating. The
researcher one day went to observe April in her bedroom. Upon entering the
room April was naked on the bed as she rubbed her vagina. The researcher
immediately left the room to allow the participant privacy. April appeared in the
kitchen five minutes later dressed in a skirt and sweater. April approached the
researcher hugged him and ‘kissed’ the top of his head.

April frequently rubbed her genitals with her hands. This activity was
performed by her rubbing her vaginal area with her hands outside of her
clothing. April often sat on her bed and rubbed her vagina in this manner.

June exhibited autoerotic behavior in the bath tub. The researcher
observed on occasion when, as participant observer, he was assigned to bath
June, that she smiled at him then lowered her hands to her vagina and rubbed
up and down. Protocol #34 illustrates this behavior:

18. June now lies back in the tub. I wash her neck and lift her neck
19. to wash her shoulders. She lies back again. She is smiling and
20. not performing stereotypic behavior. She smiles at me and plays
21. with her vagina occasionally..................

May and Tim were significantly different from the other three participants
with respect to autoerotic activity. The researcher questioned the staff concerning
Tim. The staff were unaware of Tim having an erection or masturbating. The
researcher during the observation period was also unaware of Tim having an
erection or masturbating. Tim held his penis on occasion, but it did not become
erect nor did he rub it. He merely held it. This was coded as physical self-stimulation.

May was not observed by the researcher to exhibit autoerotic behavior. May did during the observation period engage in coprophagy (eating feces).

The autoerotic activities of Dan, April, and June were interpreted as self-reliance. The participants utilized their own bodies to create pleasure for themselves. The researcher developed an awareness of the participants as self-sustaining people who did not seek environmental stimulation or interactions with other people to the degree they relied on themselves. The staff and researcher were unaware if the autoerotic acts led to orgasm.

B. THE OUTSIDE CATEGORY

This category was divided into interpersonal interactions and environmental interactions. The outside category accounted for the participants' behaviors and actions that involved another person or object in the environment. This category represented the participants seeking stimulation from outside themselves. The original perception of chaotic behavior by the participants observed by the researcher became ordered as the researcher noted the predictable behavior in the classification. The outside category will be presented under two subclassifications: (a) environmental and (b) interpersonal.

The participants' outside environmental behavior included seating arrangement, recognition of objects that were owned by a participant, and the use of objects in the environment for stimulation. The initial observations of the participants' behavior by the researcher appeared devoid of meaning, purposeless, and random. The patterns of behavior and movement of the participants became
familiar and repetitive to the researcher over time spent in the setting. The first observable pattern was the seating arrangement of the participants. Each participant had a favourite and usual place to sit. This seating pattern was observed and recorded by the researcher. The participant during nonstructured free time had specific places where they chose to sit. The seating arrangement was not random or varied.

Dan sat most frequently on the window seat. May sat on the green chair in the kitchen. June sat on the T.V. couch. April sat in her bedroom on the bed. Tim seldomly sat down. He preferred to ‘circle walk’ in the dining room/front room area. This pattern of seating and movement was consistent throughout the research period.

The participants, at least June and April, also recognized their clothing. June expressed that she wanted to go for a walk by taking her coat and dropping it at the feet of a staff person. When she was ill, June took her coat and sat on her TV couch hugging the coat. April was very definite about sweaters. April preferred two sweaters in particular, one was pink the other was purple. In the morning if April was not given both sweaters by the staff she grabbed the staff member’s arm and took them to the laundry room. She was most insistent about this and escalated in aggressive behaviors until she had both her sweaters.

The concept of ownership and seating arrangement began to become a very definite and observable phenomenon of the participants. They recognized certain places, furniture, and articles as ‘their own.’ Further examples of this are present in the data in respect to seating as mentioned above, as well as their bedrooms. Each participant went to their own bedroom (except May) to sleep and
when they 'chose' to be alone. April frequently spent a large amount of time in her bedroom. When June was ill or suffering from her allergies she went to 'her' bedroom. Dan, always went to his bedroom after a shower or bath.

The physical world of the PMR was patterned to the participants and they 'knew' where they liked to sit, which bedroom was theirs, recognized certain possessions, and where to sit at dinner. The orderly nature of the PMR was clear in the above terms of actions, seating arrangement, and possessions.

The other subclassification of the outside category was interpersonal behavior observed by the researcher between participants and participants, and participants and staff. The observations revealed that certain participants were dominant and others submissive consistently through time and across settings. May was the most submissive participant. Dan, Tim, June, and April were all observed to touch May when she was seated. May then got up and left her seat for the other participant. Protocol #12 records one such incident that is typical of this displacement activity:

2. May is seated in her usual green chair quietly gurring. Tim comes in and touches May gently on the top of her head. May gets up and goes and sits on the telephone table next to the green chair. Tim sits on the green chair.......................
10. Tim leaves the chair and May sits in it again now that it's vacant.

Dan when pushed by Tim would never exhibit aggression and often left the seat he was in to avoid a confrontation. April was the most dominant in the group. She once removed a sweater from Tim and when he would not co-operate, bit him. Tim never 'pushed' April. June, who was the most physically powerful and most aggressive towards the staff was not the most dominant of the participants. Tim pushed June, Dan twisted her hair, and April took her food and clothing. June exhibited the fewest coping strategies to the advances of
other participants. June had three strategies: leaving, screaming, and hitting.

Protocol #13 illustrates one example of a June and Dan interaction:

12. June is seated on the yellow chair in the kitchen and May is in her usual green chair. Dan comes up to the observation window and puts his hand through the small pass through opening in the window and touches June. She stands up immediately and 'finger stares' and 'head nods.' Kurt looks over and says 'Sit down June' but she won't. Dan moves away and June sits in the chair again.

Neither of June's other two responses were particularly effective. The participant who pushed June generally ignored her screams and hits. June usually wound up hitting herself and biting her hand. The other participants continued to push, grab, and take from June. The pecking order placed April at the top she could move May from her seat, hug Dan and lead him around by the hand, take Tim's clothes, and steal June's food. Tim was next in the pecking order: he could move Dan, and May from their places. Tim frustrated June by 'pushing' her until she hit herself and screamed.

Dan could move May from her seat and tug June's hair. June hit May and could make May leave her chair. May was at the bottom of the pecking order and was not observed to have dominance over any of the other participants.

The observations and coding developed a number of definite characteristics not previously recorded for the PMR. First, there was a definite pattern to the places and furniture the participants' preferred and it was as if there was an ownership to certain seats for each participant.

Second, there appeared to be a rudimentary social hierarchy in the participants. The hierarchy did not appear to be based on physical strength or prowess. The dominant person, April, was also the participant who displayed the most affection to the other participants and was the initiator of the affectionate
actions. The activities of this group of PMR was orderly and comprehensible in terms of predictable seating arrangements, participant ownership, and their response to routinely planned activities, and a pecking order. Further studies of other groups of PMR should yield information as to the degree of generalization of this rudimentary social order across other PMR groups.

The participants all manifested an attachment to a specific staff member. The emotional response and the degree of compliance the participant exhibited when with that staff member was noteworthy. The example of June’s relationship was cited in the previous chapter. June smiled when Larry came in the room, went to him first, and when agitated often sought Larry’s company.

Dan’s relationship with Maria was also an exceptional relationship. Dan smiled when he heard Maria’s voice, hugged her before Glynda or Diane (two other full time female staff). Maria was sought out by Dan, he came immediately when called by her, and was more compliant with Maria than the other staff members.

Tim and Lidia exhibited the same type of relationship. Tim sat and played a ‘finger’ game with Lidia that he did not do with any other staff member. Lidia, in turn, ‘understood’ Tim more than the other staff members and at staff meetings emphasized Tim’s strengths and positive attributes. Tim came to Lidia on his own initiative and when called by her.

May did not manifest this type of personal relationship with any one staff member. May maintained a relationship with all staff members. The researcher recorded her taking each staff member’s hand and placing it on her back for a back rub. It is only hypothetical that due to May’s coprophagy, rectal digging, and grotesque appearance that staff members and other participants did not
develop a relationship with May. An alternative hypothesis is that May was the most inward participant and did not seek interpersonal interactions with other people.

April maintained a relationship with Sal. It was Sal who wrestled and tickled April. Sal engaged in activities with April that were met with agreeable emotional responses by April. The wrestling and tickling were not utilized by other staff members with April. The relationship between April and Sal was not as frequent as Tim and Lidia, Dan and Maria, or June and Larry.

The literature on the PMR does not discuss the sexual patterns of this group. The researcher observed manifestations of sexual awareness and expression in three of the participants: Dan, April, and June. These three participants, to varying degrees, expressed autoerotic and/or sexual attention to others.

A description of Dan’s behavior towards Maria was detailed in the last chapter. Glynda occasionally received hugs and overt gestures of affection from Dan, though in less degree and intensity than Maria. Dan exhibited masturbatory behavior and frequently had an erection. This was not true of Tim. The researcher during the observation period was not aware of Tim having an erection or engaging in masturbation.

Dan frequently sought out female staff members and rubbed his body against them. At the end of a session of hugging and rubbing his body against a female staff member Dan went to the front room and played with his penis.

The sexual expression and activity of Dan was the most developed and directed towards Maria. Dan appeared to be aware of Maria in a sexual sense and was attached to her. April and June were more autoerotic and did not act or behave towards male or female staff members in a sexual manner. The fact
that Dan was the youngest participant, at least ten years younger, may be a significant factor.

The participants also displayed times of tenderness with each other. On one occasion June was ill and seated in her bedroom April sat with her for over an hour. They just sat side by side on the bed. June was disconsolate and screamed while April sat beside her and made gentle 'eeaah' sounds. April was also observed on several occasions hugging Dan. April at other times held Dan's hand and walked with him. June and May were observed on several occasions sleeping nestled up to each other.

The PMR are noted for their self injurious behavior (SIB) (Baumeister, 1978; Cleland, 1979; Hollis, 1978). All of the participants exhibited SIB. The context and the events that preceded the display of SIB in the participants is relevant to the topic of SIB.

April exhibited SIB by biting her hands. This was not an uncommon practice for all of the participants. A close examination of the participants' hands revealed callouses on the areas they placed in their mouths and bit. April’s SIB involved this hand biting and is illustrated in protocol #41:

42. Larry seats April at a table. He is going to have her use a sanding block. Larry takes her hand and places it over April's hand and
43. lifts her hand up and puts it on the sanding block and moves his hand backwards and forwards, thereby making April's hand move
44. backwards and forwards. April puts her other hand in her mouth
45. and bites it and vocalizes 'eeaah!!' with vehemance.
46. Larry has a food reinforcer that he gives her. Larry again uses
47. hand over hand and April bites her other hand...........

The researcher observed on many occasions the participants bite their hand when the staff used the technique of hand-over-hand training. The use of hand-over-hand training resulted in self injurious behavior by the participant. SIB appeared to be the result of external stimuli and not as self stimulating
behavior.

June exhibited the most profound degree of SIB. There were several occasions when June required medical attention, usually stitches to her face, as a result of SIB. June hit herself with her hands, bit her hands until they bled, and hit her head into walls. One example of June’s SIB was illustrated in the description of a day in her life. June had tried to take the meal cart into the front room and when it became stuck on the door, had hit herself. June also exhibited SIB as illustrated in protocol #21:

15. June tries to leave the dining table but Dan is seated on the outside seat so she cannot leave. She stands up on the dining bench. June
16. screams and pounds her head with her fists. She tries to walk
17. over him but cannot do this, so she sits down again, screams and
18. pounds her head on the table. One of the staff move Dan and June
19. runs to the TV couch screaming. Dan has not shown any reaction
20. at all.............................................

SIB in the participants did not appear randomly or without an observable event or reason. The SIB was related to external factors. The PMR, and in this case, the participants exhibited this behavior and the researcher observed many incidents of SIB with the participants. All of the incidents noted were environmental in nature and appeared ‘explainable’ and rational to the researcher. June exhibited SIB when pushed by Tim, when the food cart was blocked by the door frame, and when Dan was seated on the bench so she could not leave the dining table.

SIB appeared to the researcher to be correlated to frustration in the participants. The participants when forced to perform tasks exhibited SIB and when they were unable to achieve an activity, such as pushing the food cart, abused themselves.
C. THE BOUNDARY OVERLAP CATEGORY

The boundary overlap category included behavior noted by the researcher that exhibited reciprocity or mutual expectations between the participants and the staff. This category has been divided into two subclassifications: (a) negative boundary overlap and (b) positive boundary overlap. These two subclassifications will be presented in the following paragraphs.

The negative boundary overlap was interpreted as learned helplessness by the participants. The concept of learned helplessness is based on the idea that people become dependent upon other people when they continually are treated as incompetent (Nirje, 1980; Wolfensgerger, 1980). The two behaviors exhibited by the participants which the researcher coded as learned helplessness were stripping and incontinence.

All the participants stripped their clothes off during the observation period. It was a common sight to see one of the participants naked in the group home or day program. The researcher was aware that the participants were able to undress themselves. What was interesting was that the participants needed assistance to strip for baths and bed at night. The negative or anti-social behavior of public stripping by the participants was in fact a skill. The participants most commonly used the skill inappropriately.

The researcher recorded many observations of the staff undressing the participants. The staff with very little assistance from the participants removed the clothing of the person. The inference the researcher made was that both the staff and the participant expected this behavior of each other. It was not due to incompetence in the participants but rather it seemed based on mutual expectations.
The incontinence exhibited by the participants was another behavior the researcher coded as learned helplessness. All the participants, except Tim, were observed using the toilet on their own without the aid of staff. The researcher observed June, April, May, and Dan go into a bathroom and independently use the toilet. Yet, all the participants were incontinent a majority of the time. The researcher inferred that, again as in the stripping example, both the staff and the participants expected this behavior from each other.

The positive conforming boundary overlap category was behavior that the participants exhibited which indicated they were aware of social rules, the requests of the staff, and the expectations of the daily routines. The participants manifested an understanding of the times of day as exhibited in their behavior before meals, waiting for the day program to start, and bed time. Each of the participants manifested an expectation for dinner at a specific time. The researcher recorded each evening that the participants, who were not in the kitchen, gravitated to the observation window and stared into the kitchen at meal time. The nightly routine consisted of May, in the kitchen, staring at the stove; June sitting on the dining table and staring in; and April and Dan at the observation window intently staring at the stove. The bathing schedule was recognized by the participants who would, at the sound of their names called by a staff member, go right into the bathroom.

Other examples of positive conforming behavior included June pleasure when having her nails clipped by the staff. Tim laughed and played peek-a-boo with a staff member. These actions indicate a knowledge of the activity and rules that were mutual and reciprocal for the staff and the participants. These activities seemed to represent mutual enjoyment by the staff and the participants.
D. DISCUSSION OF THE CODING CATEGORIES

The inside coding category contained the majority of the participants' behaviors. Overall the researcher at the end of the observation period left the setting with the impression that the participants were people who preferred their own individual company. The other two coding categories did not represent a large percentage of the participants' behavior.

The participants, certainly through institutionalization, had experienced separation from their mothers, lack of early childhood stimulation, and a monotonous boring environment. There is support in the literature that deprivation in animals and humans results in stereotypic behavior, coprophagy, childish emotional responses, and hallucinations (Baumeister, 1978; Baumeister & Foreman; Berkson, 1973; 1976; Cleland, 1979; Hollis, 1978; Heron, 1957; Heron, Hebb, Doane; Scott, & Bexton, 1951). These behaviors were all displayed by the participants.

Theoretically, the stereotypic behavior, childish emotional responses, and preoccupation with self that the participants exhibited may have been a result of the institutional environment and not as a function of profound mental retardation. The effects of sensory deprivation or restricted stimulation conditions are reliable and powerful to the individual.

Actually, stimulus reduction is a powerful way to elicit changes in a variety of psychological and behavioral processes. Even stripped of melodrama, it produces a range of reliable effects (Suedfeld, 1980, p. ix).

The past twenty-five years of studies on sensory deprivation or restricted environmental stimulation technique (REST) research has shown that visual phenomena occur for the subjects during restricted stimulation periods:
There is certainly no doubt that subjects in restrictive stimulation conditions experience perceptual phenomena. Among these are vivid dreams, day dreams, fantasies, hypnagogic and hypnopompic (that is experiences that occur in the borderline state from wakefulness to sleep and vice versa), spontaneous firing in the retina, and the perception of endogenous, residual, or low-intensity stimuli of which the experimenter is not aware (Suedfeld, 1980, p. 150).

This evidence supports the hypothesis that long term exposure to restricted environmental stimulation results in hallucinations, a dream-like existence, of which other people are unaware.

There is support for the theory that people who have experienced sensory deprivation focus more and more on themselves and less on the environment (Robertson, 1961). Usually a person focuses on environmental stimuli. However, as environmental stimuli become restricted the conscious mind focuses increasingly on stimuli from within the person. The environmental input becomes less important as the person focuses on inner material (Robertson, 1961). The person begins to react emotionally to their inner thoughts:

As the individual becomes more and more preoccupied with his own consciousness, the thoughts, emotions, and residual stimuli become increasingly separated from context and other structural anchors (Suedfeld, 1980, p. 389).

The behavioral patterns of the participants coded as the inside category seem to fit this pattern. The institutional environment is restricted. Their mothers were not present. There was no stimulation from families, emotional attachments, cuddling, nurturing, playing, or other normal stimulation as experienced by children in a family.

The experimental evidence from Heron, Hebb, Doane, Scott, and Bexton (1951), Suedfeld (1980), and Zubek (1969) supports the hypothesis that the participants, as victims of long term restricted environmental stimulation, may
well experience retinal visual phenomena of which the staff are not aware. This perceptual phenomena was classified by the researcher as the 'inner' analytic category which acted as a boundary to the actions and behavior of the participants to the exclusion of the staff. The inner category was the non-observable internal imagery or thoughts that the participants experienced. There is support for people focusing their attention on inner material and becoming disinterested in environmental stimuli.

The theory that stereotypic behavior was the result of deprivation and the creation of inner mental imagery fit the pattern exhibited by the participants. The inner/outer analytic category was also congruent with the analytic categories for the participants behavior. The participants did exhibit interactions with the staff and objects in the environment but a majority of the time they did not exhibit interest in anything other than themselves. The participants had become accustomed to focusing on their own inner thoughts and vivid dreams (Suedfeld, 1980).

The times that the participants did exhibit interest in the environment the stereotypic behavior either was not present or diminished in degree and intensity. This observation is supported by the research on stereotypic behavior in the laboratory where the subjects, who were frequent exhibitors of stereotypic behavior, were offered a toy. The subjects preferred the toy and did not exhibit stereotypic movement (Baumeister, 1978). The environment and the 'interest' of the participant in the environment appears to have an effect upon the amount of stereotypic behavior exhibited by the participants. Thus, theoretically the more stimulating an environment is the less stereotypic behavior should be present. Stimulation, however cannot be simplistically interpreted. The researcher observed
the staff engaged in one to one activities with the participants which involved art and music. The participants still exhibited stereotypic behavior. It would appear from the data collected in this study that stimulation must be interpreted in consultation with the individual preferences of the participants.

The staff of both the group home and day program had designed activities for the participants. These activities appeared insufficient in either stimulation or interest to the participants and they continued to exhibit stereotypic movement. The researcher-coded activities the participants appeared to prefer and exhibited an interest in on their own or with a staff member.

Dan appeared to prefer walks, the trampoline, and rock music. Dan learned on his own to turn on the radio, change the station, and alter the volume. It was observed that Dan received no instruction for this accomplishment. Dan was ‘interested’ in the radio and music. The staff did not view the radio as a program for Dan. The staff emphasized arts and crafts. Dan exhibited stereotypic behavior and did not look at the tasks in the arts and crafts.

April wanted walks and tried to open the door of the home to leave and was usually denied. April spent a majority of time in her bedroom performing stereotypic behavior. The staff did not notice the clue of self-initiated curiosity and activities or the degree of stereotypic behavior as interference in the progress of the participants.

May appeared to enjoy certain classical music tapes and her stereotypic behavior was not present when she listened to these tapes. The researcher observed that May did not perform stereotypic behavior when the staff massaged her back.
June's stereotypic movement was greatly reduced when country and western music was played. June also enjoyed a hot bath and a small child's puzzle which she held and stared at. The arts, crafts and music in the day program did not appear to interest June.

Tim seemed to enjoy the finger game with Lidia. He played peek-a-boo with the staff and did not exhibit stereotypic behavior when engaged in these activities. Two other activities which Tim enjoyed were hot baths and walks. Tim did not exhibit stereotypic behavior during these activities.

The participants appeared to display preferences for specific activities. When engaged in preferred activities each participant exhibited a decrease in stereotypic movements. The activities the participants preferred were observable to the researcher by the participants self-initiating the behaviour, the reduction in stereotypic behavior, and their emotional responses.

The observations of the researcher in the setting support the hypothesis that the participants were focusing on inner material. The times that this was most apparent was at times when the activity was not of interest to the participant, or when there was unstructured free time. The individual participants when engaged in self directed activities that were outer focused exhibited less stereotypic behavior.

The theoretical combination of the emotional responses, stereotypic behavior and the deprivation of the institutional experience as an explanation of the behavior of the PMR is a new approach. There are theoretical positions which support the belief that stereotypic behavior is a result of deprivation in humans and non-human animals (Baumeister, 1978; Baumeister and Foreman, 1978; Hollis, 1978; Lewis and Baumeister, 1982). There has not been a theory which
incorporated the emotional responses exhibited during stereotypic behavior.

E. THE ROLE OF EMOTIONS

The coding categories of inside, outside, and boundary overlap are a continuum which moves from a complete focus on self (inside), to gratification of self from the environment and other people (outside) to reciprocal relations with other people (boundary overlap). Emotional responses from the participants were observed in all categories.

Cleland (1979), as quoted in previous chapters, hypothesizes that emotions are an indicator of intelligence. The view that in order to have an emotional response there must be a thought or an appraisal of the environment has support from a number of authors:

They (emotions) are, as I have been arguing, judgements, and they are intentional and intelligent. Emotions, may therefore be said to be rational in precisely the same sense in which all judgements may be said to be rational; they require an advanced degree of conception of self and at least some ability in abstraction (Solomon, 1976, p. 240).

The researcher observed the PMR participants exhibiting emotional responses throughout the observation period. The observation protocols recorded a high degree of emotional responses in the participants across all the coding categories and in all participants. The interpretation and understanding of emotions is important to a theoretical understanding of profound mental retardation and the participants.

The researcher reviewed support for a cognitive theory of emotions by Arnold (1960), Lazarus (1968), and Plutchick (1980). All of these authors offer evidence to support the hypothesis that emotions are judgements and judgements are the result of appraisal and rationality. A cognitive theory of emotions was
an accepted theoretical construct. The PMR participants appeared to be communicating through their emotional responses.

If emotions were rational then there should be a rational reason that the participants laughed and cried. A review of the literature on stereotypic movement and deprivation were instrumental in developing a theoretical explanation of the inner/outer directed emotional responses observed in the participants.

F. SUMMARY

The day-to-day life of the PMR participants was ordered and understandable through analysis of their behavior using the coding categories. The participants exhibited behavior that was rational and based on social order. The behavior of the PMR is not unfathomable when viewed from this perspective.

The inside category was interpreted as a result of sensory deprivation. The physical and reticular subclassifications contained the major activities of the participants. Suedfeld (1980) presents data that long term exposure to restricted environmental stimulation results in hypnagogic and hypnopompic states in the person. These are borderline states between wakefulness and sleep, where the person is immersed in fantasies of his/her own creation.

The outside category represented the participants' awareness of the environment and other people. This category of behaviors was not as prevalent in the participants. However, the interpersonal and environmental subclassifications were observable and represented behavior that was orderly, rational, and structured. This classification suggests that the participants did recognize possessions, have social order, and were aware of environmental stimulation and
other people.

The boundary overlap category represented reciprocity and mutual awareness between the staff and the participants. This coding category displayed the social awareness of the PMR participants.

Finally, the emotional responses displayed by the participants was viewed by the researcher as a system to understand the individual preferences and dislikes of the participants. The cognitive theory of emotions (Arnold, 1960; Lazarus, 1968; Plutchick, 1980; Solomon, 1976) provided the theoretical base for this model. The participants' behaviors could be understood across all the coding categories when emotions were viewed as rational and cognitive appraisals of events or experiences.
CHAPTER VI. THEORETICAL IMPLICATIONS OF THE STUDY

The analytic category of ‘inside/outside’ was developed on the fourteenth day in the field. The category was tentative at that point and was emergent as the research and the coding progressed. The initial concept of inside/outside was that the inside was an adaptation on the part of the participants to the deprived circumstances of the institution. The participants in their early childhood were understimulated and as a result ‘went inside’ themselves. The category had an intuitive appeal, but little else to support the notion that this was in fact the experience of the participants. The severity of their retardation was a significant factor in their behavior, perhaps the stereotypic movement they displayed, was the only behavior they ‘were capable’ of performing.

The emergence of the inside outside category received support from the literature on stereotypic movement. The literature supported the appearance of stereotypic motion in humans and non-human primates as a result of restriction of activity, captivity or caging, and as a result of restricted environmental stimulation. This theory was not accepted by all the authors on the topic of stereotypic movement. However, it was presented and noted as worthy of further research.

The literature on institutionalization also pin-pointed institutions as ‘depriving’ environments. The literature presented a higher frequency of stereotypic behavior in institutionalized PMR than in non institutionalized PMR. Further, a study of PKU, offered support to the concept that retarded children separated from their mothers showed lower intellectual and adaptive behavior skills than a control group who had not separated from their families.

The deprivation literature also supported the concept that in clinical
conditions with a normal population that deprivation resulted in a state where the subject experienced a change in behavior, and hallucinations, or more accurately retinal visual phenomena. In essence the results of long term restricted environmental stimulation created an inner world that appeared to the subject that it was outside. The autobiographical account of a prisoner in solitary confinement supported this phenomena. The inside/outside category was supported from a number of sources in the literature.

The reading of the above mentioned literature resulted in the concept of inside/outside taking on a meaning that was larger than the researcher initially thought was possible for this category. The inside/outside experience was not present in just the PMR participants but was present in the normal population and animal studies. The adaptation to deprivation regardless of retardation was documented in clinical and experimental conditions across diverse populations.

The adaptation to monotony was adaptation and not maladaptive behavior in the PMR. The literature and measurement of adaptive behavior on the retarded lists stereotypic behavior as maladaptive and depresses a person's score. In other words, adaptation to restricted environmental stimulus is is interpreted as maladaptive. The cause for the development of stereotypic behavior is not known. It appears that one condition for the onset of stereotypic behavior in humans and primates is separation from their mothers and restricted environmental stimulus (Baumeister, 1978; Hollis, 1978).

The extension of the experience of 'normal' humans to the PMR intuitively was more appealing than using non human animals for comparison. Certainly the PMR participants exhibited more emotional reaction than the researcher had initially expected. Cleland (1979) had wondered whether the PMR emoted while in
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solitude. The researcher observed many such displays of emotionality in the participants.

The theoretical explanation of emotions in the participants was the next emergent step in the development of the theoretical position from the observations and the literature. The cognitive theory of emotions the researcher included in the literature review became salient in the development of the inside outside category. It became apparent that the PMR did experience emotions and that the outside, or external causes were not always present to account for the shift in their emotional responses. Thus, the researcher hypothesized that the causal factors resided inside the participant. The concept that ideational reasons were the cause seemed difficult to explicate in light of the intellectual development of the participants. However, given the theory of Robertson (1961) of the effects of deprivation and the retinal visual phenomena that accompanied long term SD. The researcher hypothesized that the participants were viewing inside hallucinations that appeared real, and caused pleasure or distress depending on the reaction of the participant. That this was hypothesized by SD researchers for the normal population provided credibility to the inside outside category developed by the researcher. The behavior and actions of the PMR participants were understandable and indeed, logical from this theoretical perspective.

The category of inside/outside became a central tenet to the theory of the behavior and actions of the deinstitutionalized population of non verbal PMR. The inside phenomena was the result of understimulation and the recticular area of the brain provided its own patterns to compensate for the monotonous and restricted environmental stimulus of the institution. The feasibility that all people, regardless of retardation, needed environmental stimulation was well grounded in
the stereotypic behavior literature, the deprivation literature, and the institutional literature. The emotional reactions of the participants were congruent to the theory, the participants were displaying reactions to the internal mental images that appeared to be 'real.' The participants were not schizophrenic. They were responding, as any other person would, to the results of long term restricted environmental stimulus.

The emotional reactions of the participants were the cognitive appraisals of those images as pleasurable or distressful. This is confirmed by Heron (1957), Robertson (1961), and Suedfeld (1980) that long term deprivation creates such a phenomena.

A. CONCEPTUALIZATION AND THE NATURE OF HUMANKIND

Cochrane (1986) states that the theoretical assumptions of a therapist are paramount in how the therapist conceptualizes the clients problem, and the resulting treatment the therapist gives the client. The PMR have been conceptualized as 'vegetables,' 'idiots,' and 'sub humans.' The institutions developed programs formulated on the bases that the PMR did not require the same environmental stimulation that normal children required and hypothesized that in fact stereotypic behavior and aggression were inherent in the PMR. The self fulfilling prophesy, was a fact of life. The PMR were expected to act this way, the environment was perfect for such behavior to develop (under stimulated, monotonous, and over crowded). The behavior developed and the conceptualization was that the PMR as defectives naturally exhibited this behavior.

The observations from this study warrant another theoretical perspective to be considered. The PMR participants in this study exhibited behavior that was
not expected, but was adaptable, curious, social, and understandable. The perspective that many stereotypic behaviors of the PMR are an environmental product of understimulation and misunderstanding is warranted. It is time to consider a reconceptualization of the theoretical assumptions regarding the PMR.

The nature of intelligence is often conceptualized as global. Thus, the PMR without language, score between 0 and 20 on standardized intelligence tests. The intelligence tests are cognitive linguistic exercises. Without language this group is bound to be relegated to the bottom ranks of humanity. The treatment the PMR receive in terms of institutionalization only exacerbates the obvious deficits of cognitive linguistic skills. It is time to recognize that possibly the PMR require increased environmental stimulus techniques in order to facilitate their growth and development.

Gardner (1976) has theorized that intelligence is not global. Gardner has hypothesized a domain based intelligence system which consists of six separate domains: (1) cognitive linguistic ability, (2) tactile kinesthetic ability, (3) spatial visual ability, (4) auditory, (5) mathematical ability, (6) musical ability. Gardner’s domain based intelligence theory accounts for the ‘idiot savant’ in mathematics and music found amongst the PMR population. The global intelligence theory cannot explicate this phenomena. The PMR might well have other domains that are intact and functioning if the conceptualization of profound mental retardation were altered to account for the effects of stimulus deprivation and domain based intelligence.

This study does not provide empirical evidence for the theoretical understanding of the cause of stereotypic movement in the PMR. However, the data from the study are adequate to raise the spectre that the nature of
profound mental retardation has been misunderstood, mistreated, and misinformed. The research data reveal a pattern of action and behavior in the PMR that is definable, comprehensible, and ordered. The care and treatment of the PMR will not change from custodial services without a concomitant change in the theoretical conceptualization of PMR.

Tregold (1937) believed the PMR were a group that were beyond comprehension and were an entire negation of humanity. Sontag, Burke, and Yorke (1973) believed the PMR were untrainable. Berkson and Landesman-Dwyer (1976) empirically demonstrated that the PMR do learn with the principles of behavior modification. They state that unless theoretical growth occurred that behavior modification and aversive conditioning might be more detrimental to the PMR than helpful. The researcher believes the work of Berkson and Landesman-Dwyer was instrumental in a reconceptualization of the PMR.

Cleland (1979) has been a major influence on the reconceptualization of the PMR. He advocates empathic understanding of the PMR, environmental stimulation, and developing an awareness of the interests of the PMR. Cleland hypothesizes that these interests might include music, dancing, walking, and that the emotions are areas of interest to the PMR. The researcher’s observations are in accord with Cleland’s view.

It is possible to demonstrate that the PMR have been the victims of understimulation, maltreatment, and misdiagnosis. The data from this study are a start to the development of the phenomenological understanding of the PMR. It is hoped that further research will provide greater insights into the nature of intelligence and optimal environmental stimulus for this group.
B. LIMITATIONS OF THE STUDY

The PMR are a very heterogenous group. This makes it very difficult to generalize across previous studies. The etiologies of the participant group included: phenylketonuria, Rett syndrome, and tuberosclerosis. These widely varied metabolic disorders limit the generalizability not only between across studies but even among individuals in the same study.

The PMR are varied not only in etiology but also in ability. The exact functioning level and I.Q. of the participants were unknown due to their 'untestability.' The lack of specific I.Q. scores, adaptive functioning levels, and social skills is another barrier to generalizability.

A further barrier to generalizability is the 'group home' variable. Each group home is varied in terms of the staff training, philosophy, programs and number of residents. Some group homes offer very little change from the custodial practices of the institutions (Bercovici, 1983). The physical size, staff/resident ratio, and community access that the residents receive is also very divergent between group homes.

The generalizability across studies becomes very limited given the above complicating factors. The need to develop accurate accounts of the lives of the profoundly mentally retarded in the community should not be limited due to these difficulties.

C. IMPLICATIONS OF THE STUDY

The data and analysis from this study have ramifications for the care, treatment, and theoretical understanding of the PMR. The data collected revealed that the participants engaged in stereotypic or inside behavior for a majority of
their time. However, the participants also exhibited behavior that was self-initiated with the environment and other people or outside behavior. There was also participant behavior that was indicative of mutuality and reciprocity with the staff. The implications of these findings will be discussed in this section.

The theoretical understanding of stereotypic behavior appears to be paramount for the care and treatment of the PMR. The data from this study and Arkell (1982) suggests that stereotypic behavior and SIB is a withdrawal technique employed by the PMR. This perspective of stereotypic behavior is critical to developing intervention strategies for the successful training and education of the PMR. This study suggests that the PMR are capable of learning new behaviors, developing greater independent living skills, and benefiting from educational training.

The important component necessary to achieve the goals of increased dignity and advancement of the PMR is an empathic understanding of this group. It is necessary to develop awareness and understanding of the PMR and their communication system. This study utilized emotional responses from the participants as a communication of their appraisals of acceptance or rejection of activities, situations, and people.

This perspective of the emotional responses of the PMR as a language allows increased awareness of the phenomenology of those labelled PMR. The analysis of the data suggests the PMR have a desire and motivation to explore the environment, exhibit curiosity, and to acquire new skills. The findings of this study indicate the PMR have been misunderstood theoretically and denied optimal opportunities for development.

The researcher suggests, on the basis of the data collected, that staff
training in developing empathic regard for the PMR is essential. The staff must develop a bond with the PMR. The bond would allow the staff to increase the 'boundary overlap' category of behavior. Staff must utilize the inner motivation of the PMR in activities such as walking with the PMR. Staff need to recognize the musical likes and dislikes of the PMR to maximize the amount of time the PMR focus on the environment and minimize the time spent performing stereotypic behavior.

The staff must engage in behavior that is appraised by the PMR as motivating and desireable. This will aid in forming a bond and reciprocity between the PMR and staff. The bond may lead to increased reciprocity. The staff need to avoid creating dependency. The expectations of the staff for the PMR are extremely low. The symbolic interactionist perspective appears to be valid with the PMR. The staff expect very little and the PMR in turn become dependent and internalize the low expectations of the staff.

This study suggests that the abilities of the PMR need to be reconceptualized and that the development of empathic understanding is the first step to achieving this goal.

D. IMPLICATIONS FOR FUTURE RESEARCH

Despite the above mentioned difficulties with generalizability of studies with the PMR, there are a number of important areas in need of further research. The first, is the development of descriptive studies of the PMR in their natural settings. Studies with detailed descriptions of the degree of stereotypic movement in the participants in different settings, during different activities, and with different people. Stereotypic behavior in the PMR is an important research
concern. The literature documents the presence of stereotypic behavior in the PMR regardless of organic or specific metabolic disorder. The genesis of stereotypic behavior and the maintenance of this behavior needs further research to explicate the phenomena. It is possible that with greater understanding there will be the development of intervention strategies to eliminate this behavior.

Descriptive studies which detail the emotional responses of the PMR is another important area of future research. Emotionality and the concomitant development of empathic understanding for the PMR is in need of studies concerning the inner/outer causal explanations of the reaction. The environments, activities, and people that create emotional responses in the PMR are an important area of future research.

Levels of environmental stimulation which elicit the optimal behavior in the PMR are in need of recognition, definition, and description. Cleland (1979) notes the activities of walking, music, and dancing. These activities are primarily auditory, spatial, and body-kinesthetic activities. Information on the generalizability of these activities and others is an important research area. The activities of interest to the PMR might generate increased theoretical consideration of a domain based intelligence model in general and assist in program development for the PMR. The multiple intelligence or domain intelligence model proposed by Gardner (1983) states the domains are, linguistic, musical, logical-mathematical, spatial, body-kinesthetic, and personal intelligences. These intelligences or domains are in need of research not only in the PMR but in the general population to ascertain their applicability as a model. The PMR with their impaired linguistic and logical-mathematical domains are an excellent population to study the other domains.
There is clearly a need for more ethnographic descriptions of the PMR in community settings to develop a data base for developing awareness of their social, cognitive, and adaptive behavior in a natural ecological context. The need to develop a theoretical model for the PMR has been cited (Berkson & Landesman-Dwyer, 1977). This study does not claim to resolve the dilemma of the meaning of emotions and their presence in the PMR.

This study does offer a description of the daily lives of the PMR in a group home setting. Further, through empathetic understanding of the phenomenology of the PMR, utilizing a cognitive theory of emotions might benefit the PMR and the literature on the emotions. More research of the emotional responses is needed and the development a model for interpreting the emotional responses of the PMR.

The development of a more extensive literature on the ‘likes’ and ‘dislikes’ of the PMR is important for program development for this group. The awareness of the sensory modalities that the PMR utilize for enjoyment and ‘learning’ would have positive benefits in understanding more on intelligence and motivation. It is possible that the utilization of specific sensory modalities and their role in how an individual ‘learns’ lead to increased empirical evidence through studies with the PMR. These studies might be generalizable to the general population.

The deprivation literature discusses the use of sensory deprivation as a therapeutic tool. The effects of deprivation on infant PMR appears to be detrimental and life long in it’s effect (Friedman, Sibinga, Steisel, & Sinnamon, 1968; Robertson, 1962; Suedfeld, 1980). The literature suggests that sensory deprivation especially for PMR is deleterious. The deprivation literature can also be a source of information for experimental conditions to define optimal
environments for the victims of childhood deprivation.

Therapy for the non-verbal PMR must, of necessity, be a non-verbal therapy. Empathy has been recognized as a factor in therapy (Carkhuff, 1969; Egan, 1982; Rogers, 1957). This study is a beginning to developing an empathic understanding of the PMR through their emotional responses, intensity and degree of their stereotypic movements, and identifications of their likes and dislikes. There is a need to develop a wider data base in all of these areas. Cleland (1979) recognizes the lack of empathy for the PMR and this study offers some observations as to possibilities for the development of a systematic model for developing empathy. This is another area for further research.

The present trend of deinstitutionalization of the PMR population will require more data on optimal environments for the PMR in order to facilitate their transition from the back wards to the community. The development of increased information on the boundaries that divide and overlap the PMR and the staff are needed to develop strategies to enhance the development of the PMR in community settings.

There is a need to develop a theoretical model of the PMR that will benefit them in programs, quality of life, and as citizens. The Canadian constitution declares that the mentally retarded are full and equal citizens. The realization of that idealized statement will not materialize without increased research into the hopes, fears, wants, and potentials of the PMR. It is untenable that theoretical models which equate the PMR to vegetables, sub-humans, or idiots will result in non-discrimination. Research is the only method to develop an indepth knowledge base.
REFERENCES


Canadian Association for Community Living. (1986). Report to the membership. Ontario.


APPENDIX A

RESEARCH CONSENT FORM
APPENDIX B

OBSERVATION SCHEDULE
APPENDIX B

Observation Schedule: March - May

<table>
<thead>
<tr>
<th>Date</th>
<th>Type</th>
<th>Time</th>
<th>Place</th>
<th>Person</th>
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## Appendix B

**Observation Schedule continued**

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<tr>
<td>May 22</td>
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<td>12pm-3pm</td>
<td>Day program</td>
<td>Tim</td>
<td>#53</td>
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<td>May 23</td>
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<td>4pm-7pm</td>
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<td>Tim</td>
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<td>May 24</td>
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<td>May 25</td>
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APPENDIX C

EXAMPLES OF OBSERVATION PROTOCOLS
APPENDIX C

EXAMPLES OF INFORMAL AND FORMAL OBSERVATION PROTOCOLS

INFORMAL OBSERVATION PROTOCOL

Protocol #1

Week one

Researcher Lee

Place Hse#2

Date April 6, 1987

Time 3:00

1. Here come the guys. It's 3:00. June is in the door first
2. followed by May who, I note, goes straight to the bench
3. couch gurring, then in comes Dan, & he makes a bee
4. line straight for the table where Carmen has the tea out.
5. April and Tim are circle walking. Dan joins May
6. on the couch. He gets up moves up and touches her head.
7. She moves further down the couch as if to make room for
8. him and he lays on the couch too [first time I’ve seen
9. couch sharing, I think]. Now Tim sits up against Dan.
10. Tim worms in behind him and starts to gently push
11. him. Dan re-adjusts for the pushing. May gets
12. pushed by Dan as Tim keeps pushing him. Dan
13. gets up and leaves and comes to sit at the dining room
14. table. May follows him. Tim gets up and circle
15. walks. May, now the couch is empty, goes back to the
16. couch and lies down. June sits at the table and hasn’t
17. moved. April is still sitting there too. Carmen is
18. sitting there too. Dan goes back to the couch where
19. May is. They share, lying on the couch about two feet
20. apart. It's quiet. Dawn & Ken come into the kitchen.
21. May gets up and goes and stands next to where Carmen
22. is seated. The group is mellow tonight. May after a
23. few minutes sits down next to Carmen. June gets up and
24. comes into the kitchen she checks out the top of the
25. fridge [looking for her puzzle, I think, because that’s
26. where it’s usually kept]. I ask her to sit down and she
27. does. Dan is still on the couch & Tim goes & sits
beside his head and starts to push his shoulder. Dan doesn’t react until Tim pushes him onto the floor. All Dan does is get up and sit instead of lying. Dan then gently places his hand on Tim’s head. Tim touches lightly Dan’s arm. Dan gets up and leaves. Tim follows him. They both come and peer thru the glass into the kitchen. Then they do a circle walk. Dan goes to the window seat as Tim continues walking. Then Dan gets up, his hands thrust thru his shirt collar, and starts walking, the neck becoming stretched. Tim stands finger staring. June is next to me sharing my tea with me. May is gurring, coming to and fro in the dining room. Ken is reading a log book while May goes around draining the tea cups on the table. Carmen is in the kitchen now. Classical music is on the stereo on low volume. Dawn is in the office.
1. Dan is back on the bench couch lying spread out. Tim goes over and sits by his feet and pushes his legs.
2. Dan doesn’t react except to shift his position for balance. Dan turns and sits, Tim now reaches down by the floor and pushes at Dan’s calves. Dan still does not react. June is still beside me. Dan gets up
3. Tim gets up & follows him & pushes him from behind as they walk past the kitchen window, Dan trips and falls but merely recovers his balance. Ken says, “Hey Tim don’t push.” The kitchen door is open and May comes running in and sits in the vacant chair by June.
4. Dawn comes in and June gets up & takes her hand & goes to the cup board where her puzzle is sometimes kept, but it’s not there. They go out looking for it but come back in still looking. I look up & Ken is seated on the couch by the T.V. with Dan twirling the bells and touching them to make the noise. Dan is not all that interested. May, June & I are in the kitchen. Carmen is at the table, Tim is circle walking. Ken is getting Dan to touch the bells as they spin with his fingers to make the noise. Dan seems more interested and leans over to hear the sound. I haven’t seen April since she left the table so I go to check her bedroom.
5. She is in it with the “yellow” sweater on making noises & picking at it. She eats the bits she picks. She looks up at me & vocalizes then looks out the window. I go back into the front room. Dan is on the T.V. couch; Tim is circle walking; Ken & June are at the dining table. June has some of her puzzle pieces. Tim still circle walking & Dan stays on the couch. Ken talks to me about the guys. June has the puzzle pieces on the slate board she brings them to me. I re-arrange them and give them back. Tim puts on a burst of speed, humming.
6. Ken gets up & leaves. June & I sit at the table. Tim stops and stares out the window then finger stares. June gets up and goes to the couch Dan is on & puts her head in his lap. He doesn’t react, they lie there together. She rocks her head in his lap. Dan just sits there.
7. After a few minutes June gets up but her puzzle falls apart & she gets upset. I find some scotch tape and tape them on. June is again happy & lies back on the bench couch. Carmen has been toileting; 1st Tim, & then Dan. I sit at the dining room table & June comes over & sits too, nodding her head from side to side & looking at me. She screams, I look up & she stops screaming.
8. We are the only 2 in the front room. Dawn, who is in the kitchen, says, “who’s doing meds? It’s 4:05?” I haven’t seen
INFORMAL OBSER#7

1. June being toiletted. May is still in the kitchen. I look in
the kitchen window and Dan's pants have not been
done up after toileting. Ken has put Dan's med's in
a cottage cheese spoon but he's not taking them. He
finds yogurt & makes a med yogurt spoon which Dan
takes willingly. Ken says, "He doesn't like cottage cheese."
7. Carmen does his pants up. He gets a glass of juice and
they send him out of the kitchen. May gets a med
yogurt spoon & gladly eats it. Tim wanders by the open
kitchen door & tries to get in but Ken sends him away.
11. Carmen asks May to follow her but has to physically
prompt her. April wanders in & sits down. June is still
at the table with her beloved puzzle; Dan is on the
bench couch lying with his feet up; Tim sits at his feet
and starts to push them. Dan does not react. Tim
keeps pushing and pushing. Finally Dan gets up and
Tim gets up and follows him. Tim makes a circle past
June and then sits by Ken at the table. June is on the
other side of Ken. Those three stay at the table and
Dan comes over to the kitchen window and bangs his
head on it. Dan then goes back to the bench seat.
22. Tim gets up and circle walks around the table twice &
then he goes into the front room. Ken stands up and
starts to leave the room. Dan gets up and goes to
him; takes his hand; gets behind him and gives him a
two arm gentle hug. He hugs Ken for awhile then goes to
the window seat. Dan gets up but lies right down
again. Tim still sits next to his feet and pushes them
off again but Dan still doesn't react except to alter
his feet to compensate for the pushing. Finally Dan
gets up and leaves; so does Tim, who follows him.
Dan sits down again, Tim sits next to him. Tim
then starts to move Dans hand. He starts to push on
Dan's feet. Each time Tim pushes his foot off, Dan
puts it back up again. Finally once again Dan gets
up and leaves. Tim stands up & then sits again.
37. Dan comes to the kitchen window & peers in. Then
moves back against the dining bench & just moves back
& forth & then goes to the green couch & leans on it.
41. Dan comes back to the window with his hand inside
the back of his pants, moves right by & over to the bench
couch & lies down. May comes in & lies on the same
couch. Then Tim moves over & sits next to her. She
gets up & goes over to the T.V. couch & lies on it. Tim
moves up & starts pushing Dan. Dan gets up and
Tim follows him. Tim then goes to where May is &
1. pushes her; she gets up & goes over to the bench couch &
2. lies on it. Tim now circle walks. Dan goes over to
3. the bench couch by May & without even touching her
4. she gets up & leaves & goes to the window seat. Tim
5. continues to circle walk. June for the past 30 mins. has
6. been at the table with her puzzle nodding away. Dan
7. gets up & then lies down again. Carmen, Ken, & I are all
8. in the kitchen. Carmen starts to make dinner. The
9. people in the front room are quiet. June at the table,
10. Dan on the bench couch, & May on the window seat.
11. April is seated in the kitchen. There has been no staff
12. in the front room for about 25 mins. Dan gets up,
13. goes over & touches May on the head, he takes her seat
14. she goes to where he was. Tim continues to circle
15. walk. Dan gets up & checks out the kitchen activity.
16. He circle walks the dining table 3 times, disappears for
17. a second, comes back into view, circle walks the table slowly.
18. He stops in peers thru the window. April gets up & Ken
19. helps her out of the kitchen. She doen't appear in the
20. front room [I guess she's in her bedroom]. June is still
21. seated with puzzle, Dan at the window seat, May on
22. the bench couch, & Tim circle walking. I check
23. April's bedroom out, she's there, seated on her bed. I go
24. to the front room. June gets up & goes with her puzzle to
25. the T.V. couch & lies down. Dan is walking, Tim
26. goes & sits on the same couch as June & starts to push
27. her feet. She doesn't react. He pushes her feet off the
28. couch. She still doesn't react. He starts to push her
29. rear end. She gets up and heads to the dining table &
30. goes to Ken who is there & pulls him to the kitchen door
31. [great coping strategy]. He lets her in June sits down in
32. the chair. Tim picks up a pillow that was on the floor,
33. moves it, then circle walks. Dan goes over to the
34. bench couch touches May's head, she gets up & runs to
35. the open kitchen door & comes in, then Robert comes in
36. & April, who touches his waist with both hands, but
37. Dawn steers her out after she steals a carrot. But
38. April comes right back in & makes a bee line for the
39. hot stove I steer her out; Tim & Dan last two in the
40. front room. Dan at his window seat, Tim circle
41. walking. June gets up & steals a carrot & munches away
42. on it. Dawn makes her sit back in her chair. Dan
43. comes over and stares in the window, then goes away.
44. The activity level subsides. Dan sits at the table,
45. June leaves the kitchen & goes to the rocking chair,
46. April peers thru the window, Tim stands finger
1. staring, May on the floor on her knees pronated beside
   2. him. The room stays like this for around 10 or 15 mins.
   3. No mad panic for dinner [shift to day light savings?].
   4. Dinner tonight is sausages, potatoes au gratin, carrots,
   5. cauliflower, tossed salad, milk, juice, & ice cream. And it
   6. is dinner time. The guys with my verbal prompting seat
   7. themselves. Dawn & Carmen bring out the dinner trolley.
   8. Everyone seems very well behaved tonight. May tries to
   9. eat with a spoon but Dawn stops her & gives her a fork.
   10. There has been no stealing so far tonight. It's quiet. Oh,
   11. oh, Dan just stole from May, June now steals from
   12. May too. The eating is much neater than I thought it
   13. would be. It feels good, soft music is on the radio. June
   14. gets up and goes to the frontroom, stands & looks back
   15. in around. Carmen is between May & April. June goes to
   16. the book shelf to get the puzzle parts & brings them to
   17. me in the kitchen. I re-scotch tape them onto the slate
   18. board & she sits next to me in the kitchen. I look up.
   19. April is stealing May's potatoes, Ken makes her leave
   20. the table. Dawn says, "She got it from both sides, Dan
   21. & April." Ken lets April back to the table for tea.
   22. Dan gets up & leaves the table. Tim & April are
   23. still eating. Dan tries to steal Tim's juice, Ken
   24. stops him mid reach. Dan finishes his ice cream. Ken
   25. sits between April & May so May won't have all her
   26. food stolen. April tries to steal Tim's glass but Ken
   27. stops her. June is still with me. April goes to the tray
   28. & has more milk but after an extra glass Dawn moves
   29. her away. May finally finishes her supper and no one
   30. is left at the table so I take my leave.
Formal Observations

PROTOCOL #22  PAGE#1

Place: Hse#2 & Day Program.

Date: April 21, 1987.

Researcher: Lee.

Time: 8:00 - 10:00 am.

Clients: June, Dan, Tim, May, Mike, April, & Sharon.

Staff: Hse#2 – Curt [o.n. relief], Val-Dean.

Staff: Day Prog – Val-Dean, Debbie, Anne, Lome, Karen.

8:00am
1. I come in. June is in the green chair in the kitchen, Dan at the
2. window looking in, Tim circle walking the cooking area in
3. the kitchen. April is having a bath. Val is making spumoni
4. med spoons. The T.V. & radio are both on. Dan reflection
5. waves. May is very active this morning, lots of noisy
6. guurrs and movement. She is right now on the bench seat in
7. the front room and she comes into the kitchen to the yellow
8. chair. Then she goes back to the bench seat and back again
9. to the yellow chair. Val gives June the spumoni med spoon.
10. Dan does “air guitar.” June is quiet. April and Dan have a big
11. hug. Dan is very neutral to it. Tim is in the kitchen and
12. knocks over the foot bench as he circle walks and has his
13. pants unzipped and his hands on his penis. May is now in
14. “her” green chair. June is on the yellow chair. Dan gets a
15. glass for juice and the juice from the fridge. Curt helps
16. him with it. April hugs me and eeaahhs!! She then hugs
18. Tim reopens his zipper and tops of his pants after Curt
19. does them up for him and he reholds his penis. April is
20. holding two sweaters, a pink one and a brown one. Tim
21. continues his kitchen circle walking. Curt calls Tim and
22. Tim goes to him. April checks every cup for coffee dregs
23. to drink. Dan opens the fridge again. May is calm now,
24. [meds??]. June screams and cries when Val tries to clean
25. her face, June vaguely swats Val’s hand away. May checks
26. every coffee cup for dregs. Everyone is now in the kitchen.
27. Dan alerts the staff to his need for the toilet [I don’t know
28. how but he is praised for it]. Everyone was ready to go so
29. we wait while Dan is helped with the toilet. June screams at
30. the door and pounds her head on the special glass in the
8:50am
door. Tim starts to push people. We walk to the day
program house about thirty feet away. May is allowed in
the kitchen [the only one who is let in]. Tim goes to the
front room and immediately does circle walking and running.
May is agitated in the kitchen. Dan stands in the front
room and does “air guitar.” Sharon rocks on the hassock.
Tim does furniture pusher on the large arm chair. June is
taken to the music room by Lome. April strips & is taken
to the bathroom to be reclothed. Dan does “whirling
dervish.” Stops, puts his hand down his pants and “picks his
seat.” Mike comes into the front room and sits on the
couch. Dan is circle walking and seat picking. I’m in the
same spot as I usually am in Hse#2. Lome has toiletted
Tim and Tim hits the front room, circle walking, penis
holding and starts to run his pattern. Dan is circle
walking, which he doesn’t do at Hse#2. April comes
1. in naked again except for her sneakers. Tim is moving the
couch with Mike sitting on it. Dan does a very exaggerrated
“air guitar.” Tim moves the couch again with Mike still in it.
Mike is non-plussed. Tim pushes chairs. Dan spins and
shouts. Tim again moves the couch with Mike in it. Dan is
circle walking and “air guitaring” like crazy. April walks
thru on tip toes. Mike gets up and goes to the piano and
plays a few notes, then runs off. Tim picks up a stuffed
animal drops it, picks it up and drops it. He moves the arm
chair around. He runs circles. Dan & Tim are the only
two in the frontroom now. Tim circle walks and moves
the couch. Dan circle walks and does “whirling dervish.”
April comes back in the frontroom and passes thru
without stopping. Lome has Dan follow him. Tim
continues to furniture move. Dan comes back in the front
room and does an incredible “whirling dervish” with a big
smile, one arm extended, the other arm in. June comes into
the front room but doesn’t stay. Dan comes to the kitchen
window and circle walks. Tim pushes the couch hither and
yon. Val gets June to bring in two excercise mats, and they
both go for more mats. Debbie, Karen, Val, & Lome get
bowls of candy and go into the front room. June comes in
with two more mats. May sits on the couch in the front
room. Tim sits beside her and pushes her. She moves and
gets up. Tim pushes the couch around. June and Dan sit on
the mats. Then Mike is seated. Lome prompts May into
sitting on one. There is now a circle (see diagram). The
staff have 3 tennis balls, one basket ball, 2 beach balls.
Tim is the last one seated. April gets up and leaves and
is brought back by Val. The balls are then pushed between
the members of the circle. Candies and praise are given
when people participate. Tim pushes a ball, finger stares
and has a huge smile on his face. Lorne rubs June, has her
push a ball, rubs her hair, says “Good Girl.” April rolls. June
is finger staring. Debbie hand over hand has Dan roll a ball.
Mike gets up to retrieve a ball that has gone out of the
circle and throws it without looking, hits June in the head, but
instead of being upset she starts to laugh. Mike gets
another ball and takes it back to the circle. April throws a
9:20am
tennis ball that goes all the way into the dining room. June
gets a candy, this “game” goes on with candies, praise and
pats. Dan hand waves and “air guitars.” Lorne takes Mike
to the washroom. June gets up and follows Lome, I have
ever seen her like and obey anyone like she does Lome.
The ball game ends at 9:50. I leave.
APPENDIX D

FLOOR PLAN OF GROUP HOME AND DAY PROGRAM
APPENDIX D

FLOOR PLAN OF GROUP HOME AND DAY PROGRAM

Protocol #14: Tim's Patterns, April 13, 1987

BA  Bathroom
BR  Bedroom
CL  Closet
D   Dryer
DT  Dining Table
RF  Refrigerator
SH  Shower
SL  Shelves
W   Washer