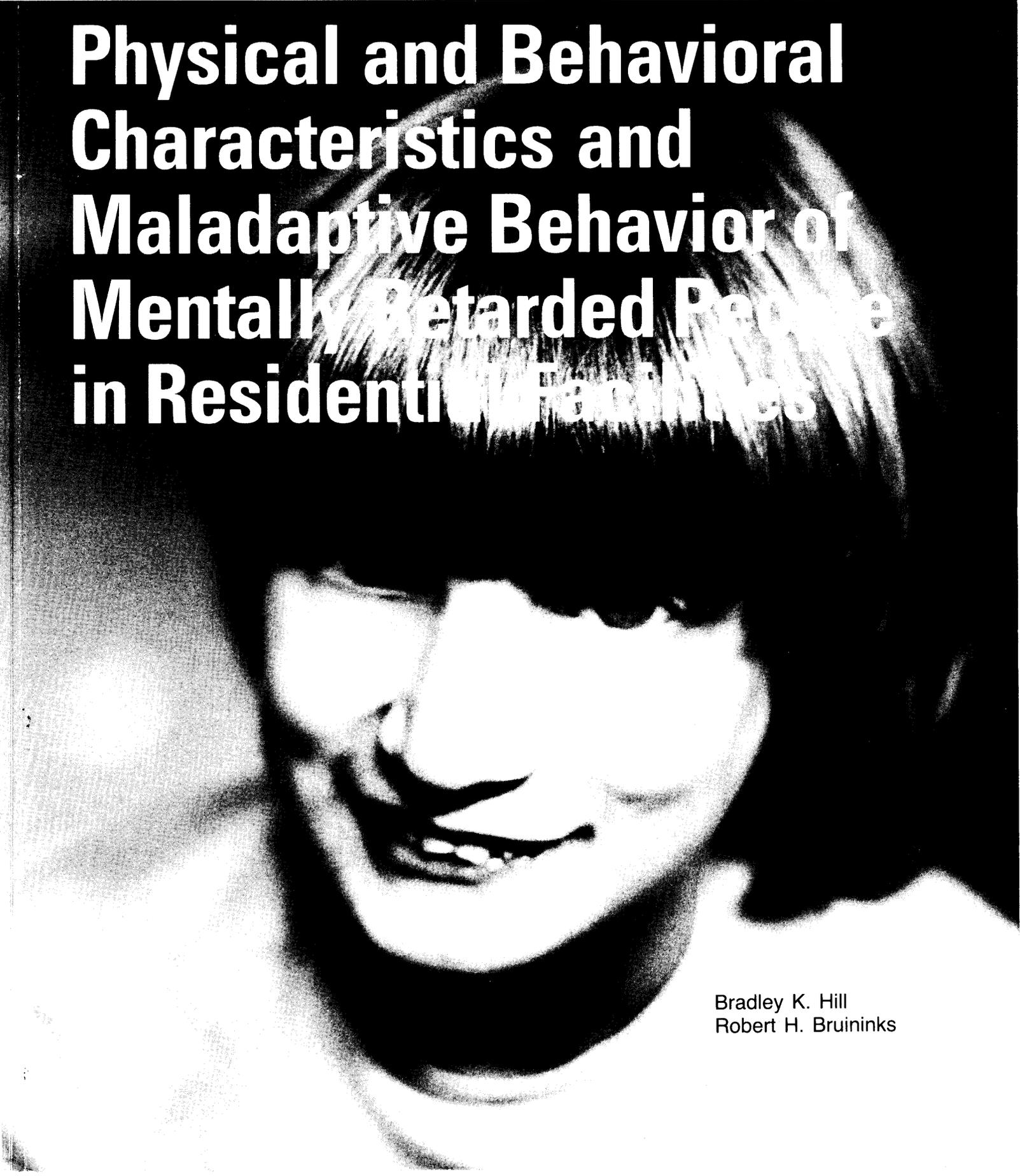


# Physical and Behavioral Characteristics and Maladaptive Behavior of Mentally Retarded People in Residential Facilities



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Robert H. Bruininks

The Developmental Disabilities Project on Residential Services and Community Adjustment is conducting a nationwide study of mentally retarded persons in residential programs. Information is being collected on (a) the administrative and general characteristics of residential programs for mentally retarded individuals, (b) the behavioral and physical characteristics of mentally retarded people in residential programs, (c) factors related to admission of former residents of state residential facilities to community residential settings, and (d) community adjustment.

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DEVELOPMENTAL DISABILITIES PROJECT  
ON RESIDENTIAL SERVICES AND  
COMMUNITY ADJUSTMENT

Project Report No. 12

# Physical and Behavioral Characteristics and Maladaptive Behavior of Mentally Retarded People in Residential Facilities

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## ABSTRACT

Descriptive information is presented about the physical characteristics and health problems, behavioral characteristics and maladaptive behavior of a national sample of mentally retarded people living in public and community residential facilities. Sample groups included 965 current residents of community residential facilities, 953 current residents of publicly operated residential facilities, 211 residents newly admitted to public residential facilities, and 192 residents readmitted to public residential facilities after previous release.

Behavioral characteristics were assessed using a model that incorporated specific levels of independence. Residents of community residential facilities were generally more independent than residents of public facilities, although sizable proportions of both populations were severely handicapped and required one-to-one assistance for most activities.

The prevalence of health problems was similar among public facility residents and community facility residents. Residents of community facilities exhibited the same types of physical handicaps and maladaptive behaviors found among residents in public residential facilities, although the prevalence of physical handicaps and maladaptive behavior was higher in public facilities. Maladaptive behavior was analyzed according to prevalence, frequency, and severity. Implications for the deinstitutionalization process are presented.

## ACKNOWLEDGMENTS

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We would also like to thank the staff of the Survey Research Center of the University of Michigan, who collaborated on sample selection and field work. Finally, we sincerely appreciate the help and information we obtained from administrators, staff, and residents of the public and community residential facilities in our sample, who contributed their knowledge and time in answering our questions.

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## I. INTRODUCTION

The decade of the 1970s brought widespread changes in residential services for mentally retarded people. This change is reflected dramatically in release statistics compiled for publicly operated facilities. During the past 13 years, the number of retarded people in state institutions has declined by approximately 30%, since reaching a peak population of 194,650 residents in 1967 (Lakin, 1979). Statistical indicators of population movement, however, provide only partial information on changes that have taken place in the residential service system. Recent surveys of community-based residential programs and foster homes specially licensed for retarded people have shown that their numbers increased exponentially during the 1970s. They currently serve in excess of 65,000 retarded people (Bruininks, Hauber, & Kudla, 1980; Bruininks, Hill, & Thorsheim, 1980).

Detailed information about the needs of residents is necessary for effective planning, development, and evaluation of residential services. The need for information is particularly evident in states in which the courts have ordered the release of hundreds, even thousands, of residents from public residential facilities to settings that are judged to be less restrictive (Halderman vs. Pennhurst, 1977; Welsch vs. Likens, 1974; Wyatt vs. Stickney, 1972).

There have been several investigations of the characteristics of mentally retarded people in public and private residential facilities

(Eyman, 1975; Frohlich, Burdette, Cormier, & Matthews, 1974; O'Connor, 1976; Payne, Johnson, & Abelson, 1969; Scheerenberger, 1979). Many people residing in state operated institutions have been shown to present physical handicaps and limited abilities. The previous studies indicated that approximately one-fifth of the residents could not walk or feed themselves; half could not talk, were not toilet trained, or could not get dressed without help. Retarded people living in community facilities had relatively higher abilities and fewer physical handicaps compared to those in institutions; they were somewhat younger; and only 10% could not talk or needed assistance with basic self-help skills such as getting dressed.

Mental retardation is often accompanied by physically handicapping conditions (Hardman & Drew, 1977), limited motor skills (Bruininks, 1974), or health problems (Nelson & Crocker, 1978; Smith, Decker, Herberg, & Rupke, 1969). Although it is not clear that there is a direct relationship between physical characteristics and health care needs, past surveys of the health characteristics of retarded people in publicly operated institutions have also indicated a high incidence of medical problems (Wright, Valente, & Tarjan, 1962) and mortality rates (deaths per thousand persons per year) that are far above those for the general population (Balakrishnan & Wolf, 1976; Forssman & Akesson, 1970; Tarjan, Eyman, & Miller, 1969).

Although neither physical handicaps nor health-related problems have been clearly identified as reasons for initial institutionalization (Maney, Pace, & Morrison, 1964; Saenger, 1960), they have often been

cited as reasons for reinstitutionalization of released residents. Pagel and Whitting (1978) studied 117 readmissions to a large state institution for retarded people. Among all reasons for readmission, 25% of the group were reported by social workers to have returned because of health problems, 45% because of maladaptive behavior, 10% for a combination of health problems and maladaptive behavior, and 22% for other reasons. Similarly, Keys, Boroskin, and Ross (1973) reported that of 126 readmissions to a public institution, 28% returned for medical reasons, 6% because of uncontrollable seizures, 30% because of behavior problems, and 36% for other reasons.

Behavior problems have long been considered a major factor in successful community placement and adjustment (Sternlicht & Deutsch, 1972; Windle, 1962). Next to severity of retardation, behavior problems may be the single most important factor in determining initial placement in an institution (Maney, Pace, & Morrison, 1964; Saenger, 1960; Spencer, 1976). Readmission rates to institutions, moreover, suggest that some community residential facilities may be unable to cope with certain behavior problems. Although the total number of institutionalized retarded people has decreased at a fairly constant rate, smaller numbers of first admissions to state operated facilities have been offset by larger numbers of readmissions (Conroy, 1977; Lakin, 1979). In 1979 readmissions actually outnumbered first admissions to public residential facilities (Krantz, Bruininks, & Clumpner, 1979).

There have been several efforts to establish the prevalence of maladaptive behavior among retarded people. Eyman and Call (1977) used

selected items from the Adaptive Behavior Scale (Nihira, Foster, Shellhaas, & Leland, 1974) to investigate the prevalence of maladaptive behavior in samples of retarded people living in institutions, in community facilities, and with their parents. A high percentage of individuals in each sample, especially males and people living in institutions, were reported to exhibit maladaptive behavior. For example, approximately 45% of the institutionalized sample, 20% of the people in community facilities, and 20% of those living with their parents were reported to threaten or do physical violence to other people.

The relative basis by which society determines what behavior is considered to be unacceptable makes it difficult to judge the severity of maladaptive behavior among retarded people. Goroff (1967) used a critical incident technique to identify specific behavioral events that had precipitated reinstitutionalization of a sample of reinstitutionalized residents. An impressive finding was that the majority of critical incidents that included behavior problems would have been considered inconsequential if they had been performed by a nonretarded person (e.g., a nonretarded person would not be institutionalized for missing work). Another frequently cited study (Nihira & Nihira, 1975) indicated that of 1252 incidents of problem behaviors among 424 retarded residents of community residential facilities (problems that were considered to be bothersome, unacceptable, or beyond the threshold of community acceptance), only 16% were considered to jeopardize the health, safety, general welfare, or legal status of residents.

Purpose of the Study

Deinstitutionalization involves placing mentally retarded people in the least restrictive residential alternatives which appropriately meet their special needs. To effectively plan and evaluate the residential service system, it is necessary to possess accurate information about the characteristics of people in need of residential care. Although there have been previous studies of the physical and behavioral characteristics of mentally retarded people in residential facilities, none has been as comprehensive in describing resident characteristics on a national scale. Previous studies have gathered data from either public or community facilities; resident characteristics have often been assessed in a general manner that has not yielded information in a form useful for planning and evaluation purposes; and methodologies have often confused health care needs with physical handicaps.

This study included a detailed examination of characteristics of residents sampled from a large number of public and community residential facilities throughout the United States. The purpose of this report is to present data about the health, physical, and behavioral characteristics and maladaptive behavior of mentally retarded people living in public and community residential facilities.

## II. METHOD

Previous studies of residential services for mentally retarded people have focused on specific topics such as the size of facilities, the cost of services, the adaptive behavior of residents, the maladaptive behavior of residents, or on specific populations, specific geographic areas, or specific types of facilities. Methodologies have usually been restricted to mail questionnaires, examination of records, or self report forms.

The present study attempted to overcome many of these limitations. It included a national sample and used a combination of on-site interviews, examination of records, self report forms, observation, and telephone follow-up procedures. The many topics investigated permit concurrent comparison of many types of information. A more complete description of the methodology for the study is contained in a report by Hauber, Bruininks, Wieck, Sigford and Hill (1980).

### Sample

The study included 2271 retarded individuals in 236 residential facilities. A two-stage probability sample design for the study was developed in cooperation with the Sampling Section of the Survey Research Center at the University of Michigan's Institute for Social Research. In the first stage, a sample of facilities was selected in such a way that the probability of a facility's selection was proportionate to its size

(i.e., number of residents) and so that the distribution of sample facilities across census regions and size classes was in close agreement with the distribution of the national resident population (Hess, 1979a, 1979b). The following criteria were used to define facilities:

A community residential facility (CRF) is any community-based living quarter(s) which provides 24-hour, 7 days-a-week responsibility for room, board, and supervision of mentally retarded persons as of June 30, 1977, with the exception of: (a) single family homes providing services to a relative; (b) nursing homes, boarding homes, and foster homes that are not formally state licensed or contracted as mental retardation service providers; and (c) independent living (apartment) programs which have no staff residing in the same facility.

A public residential facility (PRF) is any state sponsored and administered facility which offers comprehensive programming on a 24-hour, 7 days-a-week basis.

Public facilities were sampled from a complete 1977 list of public residential facilities maintained by the National Association of Superintendents of Public Residential Facilities. Community facilities were sampled from among 4,427 facilities that participated in a 1977 national mail questionnaire survey (Bruininks, Hauber, & Kudla, 1979).

In the second sampling stage, a sampling fraction of residents within each facility was determined so that the total sample size would be approximately 1000 PRF and 1000 CRF residents. This design was intended to provide an unbiased representation of all mentally retarded residents in public and community residential facilities in the United States in 1978.

Five sample groups of residents were selected independently. The two primary groups were current residents of CRFs and current residents of PRFs:

Current Resident. Any mentally retarded person on the rolls of a facility as of the night prior to preparing the sample list, and for whom a bed was held on a 24 hour-a-day basis, even though he or she might have been temporarily away on overnight leave or in a hospital. Residents on trial placement at another facility were excluded.

With PRFs three additional samples were selected:

New Admission. A mentally retarded resident who had been admitted for the first time to a sample facility during the time period of July 1, 1977 through August 31, 1978.

Readmission. A mentally retarded resident who had been admitted for the second time or more to a sample facility during the time period of July 1, 1977 through August 31, 1978.

Released Resident. A mentally retarded person who had left, been transferred, formally released or discharged from a sample facility (for reasons other than death) during the time period January 1, 1978 through August 31, 1978. The person was no longer officially on the rolls of the facility; or the facility no longer maintained a bed for the person's use.

This report includes data on CRF current residents, PRF current residents, and on new admissions and readmissions to PRFs. Information about PRF released residents is discussed in a related project publication (Sigford & Bruininks, 1981).

#### Response Rate and Sample Weighting

Tables 1 and 2 present a summary of response rates in the study. Several facilities that declined to participate or had closed after the time of original selection were replaced by other facilities of the same size and from the same geographic region. At the time of the study there were six community residential facilities in the United States that had more than 400 residents. Only one of these facilities agreed

Table 1

## Summary of Facility Selection

Facilities	Originally selected	Participants	Replacement facilities	Final participants
CRFs	180	154	7	161
PRFs	78	72	3	75

Table 2

## Summary of Resident Selection

Group	Originally designated	Participating residents	Weighted <sup>a</sup>
CRF current residents	1024	965	964
PRF current residents	983	953	997
PRF new admissions	220	211	286
PRF readmissions	210	192	244
PRF releases	497	478	494

<sup>a</sup>Weighted for facility non-response and disproportionate sampling.

to participate in the study. After an extensive but unsuccessful effort to recruit these non-participating facilities, project staff decided to keep the one participating facility in the study, make no adjustment for non-response of the other large facilities, and report that CRFs with more than 400 residents are underrepresented.

The sample design specified the appropriate number of residents to sample within each facility. No adjustment was made for non-response

of individual residents or non-response on individual questionnaire items because it was not felt that the relatively limited number of non-responses was biased in a particular direction. A weight adjustment of resident data was made for facility non-response and for disproportionate sampling (cf. Hauber, et al., 1980). This adjustment, although minor, assured that each resident represented the appropriate proportion of residents in the population as a whole.

Descriptive data presented in this report are weighted. All statistical analyses, however, are based upon unweighted data in order to assure probability values based upon actual sample size.

#### Survey Instruments

The eleven instruments used in the study were based upon research issues identified in the literature and reviewed by a national panel of 30 people knowledgeable about services for mentally retarded persons. Many sources were used in the development and review of specific questionnaire items, and each item was again reviewed by outside experts. Field procedures and interview content were pilot tested in a sample of Canadian residential facilities, and some interview questions were revised as a result of the pilot test. A second field test was conducted in a group of United States facilities to assure that final survey instruments and procedures were optimal.

An administrator interview questionnaire, financial questionnaire, staff composition list, staff separation list for a 30-day period, and physical plant description self-report forms gathered information about each facility and its administrative characteristics.

Demographic information about individual residents, including date of birth, date of admission, previous type of residential placement, age, height, weight, and diagnosed degree of retardation, was obtained from each resident's records and recorded on a Personal Record Sheet (see Appendix A).

Interviews about residents were conducted with direct-care staff persons who had known each resident selected for the sample for at least two months. Each interview, which lasted approximately one hour, covered topics such as program plans, day programs, leisure time activities, family and social contact, specialized services, characteristics of the residential environment, and physical, health, and behavioral characteristics of each resident. Questionnaire items were designed to make maximal use of the care person's knowledge. Although care persons sometimes consulted residents' records, they were not required to do so.

Each resident's behavioral characteristics were assessed with the Behavioral Characteristic Assessment, a 65-item booklet completed by a care person (Hill & Bruininks, 1980). Existing behavior scales had been judged to be inappropriate for use in this study because of their length, detail, limited content, means of administration, or because of difficulties in inferring residential service needs from their results (Hill & Bruininks, 1977). The Behavioral Characteristics Assessment, presented in Appendix B, was specially developed to satisfy the requirements of this research effort, which included time constraints that permitted approximately 10 minutes for the assessment of behavioral characteristics.

The Behavioral Characteristics Assessment was based upon the assumption that residential programs should strive to promote normalization and independence while at the same time providing special treatment or assistance that residents need. These two interactive elements --special care and opportunities for independence--provided the framework for a model that related the behavioral characteristics of retarded people to the residential environment in which they live. It was hypothesized that there are specific behavioral characteristics that differentiate the way in which retarded individuals interact with other people, including residential staff, and that these characteristics could be identified with various skills and abilities. Knowledge about specific behavioral characteristics could help in determining the type and amount of specialized assistance as well as the opportunities for social interaction and independence that a residential facility should be able to offer its residents.

Figure 1 depicts a model of behavioral characteristics in terms of six levels of independence. The Behavioral Characteristics Assessment identifies six specific points along a continuum. At one end of this continuum are retarded people whose abilities are so limited as to make them passive and nearly totally dependent; they require a great deal of care, and their social interaction is minimal. As these individuals learn and develop, there is a point at which they may begin to respond cooperatively to gestures and manual guidance. This is a first level of independence, designated as level 1 in the Behavioral Characteristics Assessment, and identified by the first item in each of the assessment

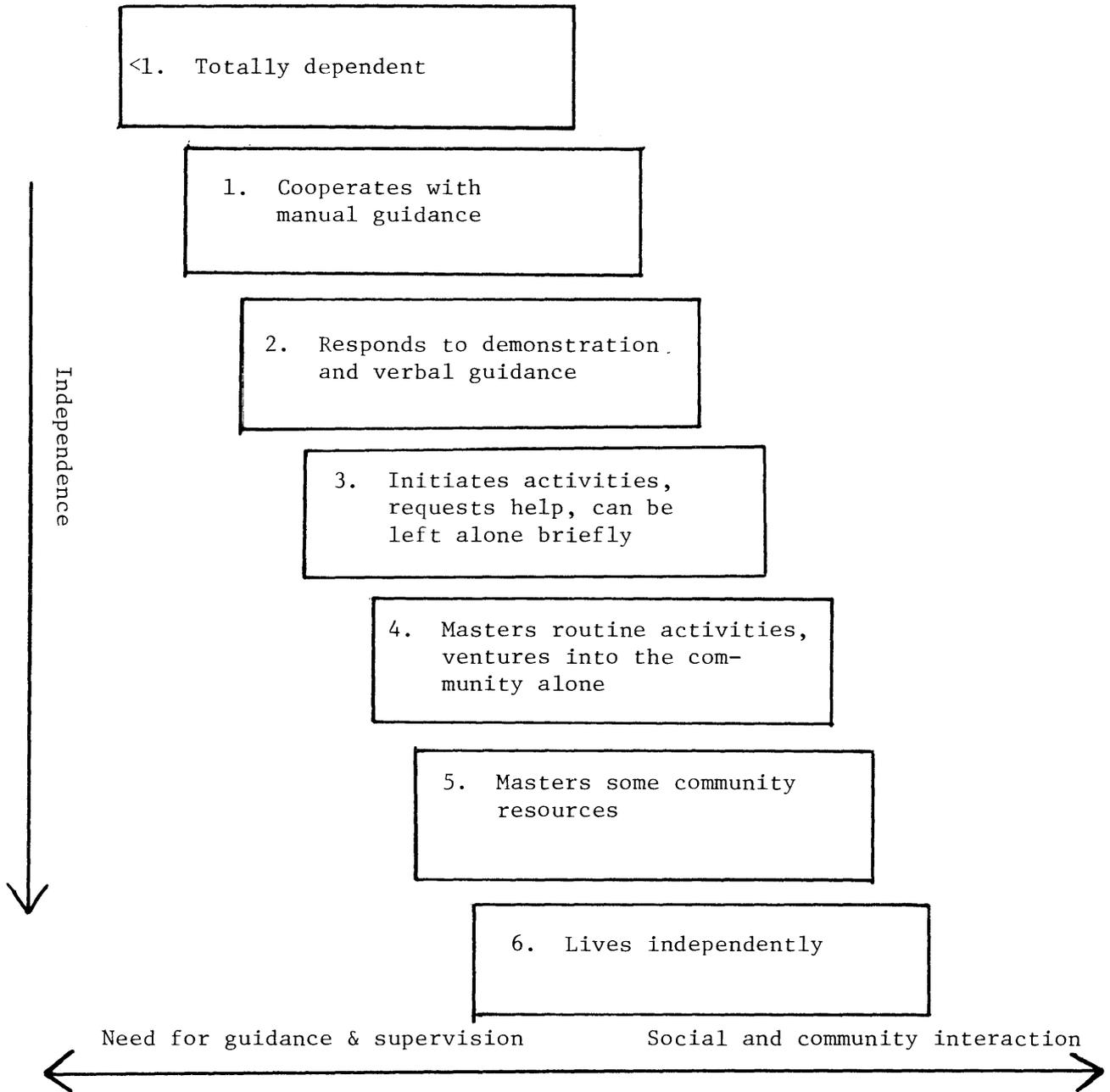


Figure 1. Levels of Independence in a Residential Setting

instrument's behavioral domains. As abilities further increase, there is another point at which demonstration and verbal instruction can be used as effective forms of guidance and interaction with other people (level 2). A third segment of the continuum is signified by the point at which an individual begins to initiate his/her own activities, begins to actively seek help when it is needed, and can get along without direct supervision for short periods of time. A fourth level of independence is attained when an individual begins to venture alone into the community near the residential facility. A fifth level is reached when an individual can actually live and work in the community semi-independently, and at the sixth level independent living in the community is possible. These levels of independence provided a meaningful and economical basis for scale construction requiring only a limited number of scale items to discriminate levels of independence within each domain.

Behavioral assessment scales customarily, if somewhat arbitrarily, group functionally related behaviors into categories called domains. Past studies of community programs have often included domains related to domestic skills and community living, whereas studies of institutionalized residents have placed more emphasis on basic self-help skills. The Behavioral Characteristics Assessment, which addresses all levels of independence, incorporated domains from both of these commonly used areas. Since it is useful to make comparisons with data collected from other studies, the Behavioral Characteristics Assessment was designed to be as compatible as possible with previous studies and data base models. After reviewing many behavior scales and questionnaires (Hill &

Bruininks, 1977), eleven domains were selected for inclusion in the assessment: (1) Eating and meal preparation, (2) Dressing, (3) Toileting, (4) Personal self care, (5) Language comprehension, (6) Language expression, (7) Social interaction, (8) Domestic activities, (9) Community orientation, (10) Value and money, and (11) Reading and writing. Each domain of the Behavioral Characteristics Assessment contains five or six hierarchically arranged items which correspond to the levels of independence in Figure 1.

The assessment was produced as a booklet to be filled out by direct-care staff under standardized directions provided by a trained interviewer (see Appendix B). After field testing, various statistical analyses indicated an average item interrater agreement of 83%, domain-total correlations ranging from .87 to .94, and total scale scores which correlated highly with other adaptive behavior scales (Hill & Bruininks, 1980).

The Behavioral Characteristics Assessment was intended to be a measure of actual day-to-day performance. Residents were considered to pass an item if they performed it well on a regular basis, without having to be assisted or coaxed, or if the staff member completing the assessment form was certain that a resident would routinely perform the behavior described by an item if not prevented from doing so solely by constraints of the present environment. These environmental constraints might have been rules (e.g., no residents in the kitchen) or characteristics of the physical environment (e.g., no kitchen in the building).

Motivation is a second factor that was expected to influence the expression of behavior among residents. In order to determine the difference between typical performance and potential performance, data were gathered on the number of scale items that a resident "could" perform, "but only if coaxed or repeatedly reminded." Residents were not considered to pass such items, however.

The number of items passed in each domain corresponds to a specific level of independence. The total scale score divided by 11 (the number of domains) yields an overall level of independence score.

Information about physical ability, additional handicapping conditions, and health characteristics was obtained through a series of interview questions, some open ended, and some with fixed response categories. These questions are included in Appendix C. Responses were recorded verbatim, individually coded, and later categorized during data analysis.

Care persons were asked if residents had "any long-term health problems such as heart trouble, diabetes, and so on." Although staff frequently referred to residents' records or consulted with other staff members, they were not required to do so, and could respond that they did not know. Temporary illnesses were not included. Down's Syndrome and other diagnoses for which mental retardation is a primary symptom were not themselves considered health disorders, but specific disorders such as heart problems that often accompany Down's Syndrome were recorded for residents who evidenced them. Health disorders were categorized during data analysis in a manner consistent with the International

Classification of Diseases (ICD-9-CM, 1980). It is possible that some residents had conditions that were not known to care persons. However, since the care person interviewed had been responsible for the resident's direct care for a considerable period of time and was likely to be familiar with any treatment and medical or nursing consultation, the underestimation of incidence of health problems was expected to be minimal, and similar for all sample groups.

The care person questionnaire also included a section which assessed residents' maladaptive behavior (see Appendix D). Several research efforts have approached the assessment of maladaptive behavior through the use of categorized checklists (Eyman, 1975; Payne, Johnson, & Abelson, 1969; Nihira et al., 1974). Checklists, however, have often been difficult to interpret because various behaviors are not necessarily equally problematic or severe (Auger & Auger, 1974; Clements, Bost, DuBois, & Turpin, 1980) or because behaviors occur at varying frequencies (Abelson & Payne, 1969; Isett & Spreat, 1979; King, Soucar, & Isett, 1980; McDevitt, McDevitt, & Rosen, 1977; Taylor, Warren & Slocumb, 1979). The present study attempted to determine the type, frequency, and severity of various behaviors.

The maladaptive behavior section of the care person questionnaire combined a series of open-ended and fixed response questions about four major categories of maladaptive behavior (self-injurious behavior, behavior injurious to others, behavior that damages property, and unusual or disruptive behavior), as well as additional questions about other behavior problems. In a set of open-ended questions for each major

category, a staff person was asked to list specific behaviors evidenced by a resident. Up to three behaviors were later coded within each category. If a resident evidenced several different behaviors within a single category, staff were asked to identify the single most prominent behavior or group of similar behaviors (the "biggest problem") and to indicate the frequency at which episodes of the behavior usually occurred. The frequency of behavior was recoded into five levels ranging from less than once per month (level 1) to one or more times per hour (level 5).

Staff were also asked ". . . what you usually do" when the resident exhibits this behavior? It was felt that staff response would be an indicator of the severity of a maladaptive behavior on the assumption that the problem a particular behavior presented would be reflected by the amount of disruption it caused and by the type and amount of staff time that was allocated to responding to it. Five levels of staff response were analyzed. The least serious level of staff response was considered to be elicited by behavior for which staff reported that they "did not do anything." The infrequency at which this level of response was reported indicates that staff had seldom reported a behavior problem unless it actually was a problem that they responded to. The second level of staff response included an organized effort by staff to ignore the maladaptive behavior, to withhold any possible social reinforcement, and to reinforce other more adaptive behaviors. Verbal responses constituted a third, and more intrusive level of staff response: staff responded verbally by asking a resident to refrain, to leave the room,

or to make amends, or staff verbally reasoned with the resident, stated the consequences that would follow, etc. Physical responses constituted response level 4. Staff physically redirected residents or physically led them from the room. Physical restraints such as straps or calming medication administered directly in response to an incident were considered to be physical responses. The fifth and highest level of staff response was elicited by behaviors so serious that one staff member alone could not control the behavior or its consequences, requiring the immediate assistance of at least one additional staff person. It was hypothesized that residents who exhibited maladaptive behavior that required this level of staff response could not be tolerated in some residential facilities that did not have two staff members on duty at all times.

#### Procedure

Interviews were conducted between September, 1978, and April, 1979, at 236 facilities. Trained interviewers of the Survey Research Center of the University of Michigan, working under supervision of the Center's field office, followed step-by-step instructions included in training materials. At each facility interviewers selected a predetermined number of mentally retarded residents according to a pre-specified random sampling procedure. A staff person most familiar with each resident was then identified and interviewed about the resident, with certain information obtained from the resident's records. Completed interviews were returned to Michigan for editing and coding in collaboration with Minnesota staff.

### III. RESULTS

#### Demographic Characteristics

Table 3 presents basic demographic information summarized from the records of the four samples of residents: CRF residents, PRF residents (including appropriate proportions of new admissions and readmissions), PRF new admissions, and PRF readmissions. Independently selected samples of PRF new admissions and readmissions provided detailed information specifically about these two groups.

Males outnumbered females in both CRFs and PRFs, as they have in earlier studies (O'Connor, 1976; Scheerenberger, 1979). The proportions of males among PRF readmissions was particularly high, 64.3%, though only 54.5% of the residents released from PRFs were male (Sigford & Bruininks, 1981).

CRF residents were relatively younger than those in PRFs. Almost 17% of CRF residents were less than 16 years old, compared with only 10.2% of all PRF residents. PRF new admissions and readmissions, however, were relatively younger than PRF residents in general; 29.7% of new admissions and 16.7% of readmissions were less than 16 years old.

Racial minorities composed 12.6% of CRF residents and 18.4% of PRF residents. Among new admissions to PRFs, 28% were minorities, and 20.2% of the PRF readmission sample were minorities.

Table 3

## Demographic Characteristics of Residents

Characteristic	CRF		PRF		PRF		PRF	
	<u>residents</u>		<u>residents</u>		<u>new admissions</u>		<u>readmissions</u>	
	N	%	N	%	N	%	N	%
Sex								
Male	579	60.1	552	55.4	171	59.8	157	64.3
Female	385	39.9	445	44.6	115	40.2	87	35.7
Age in years								
< 6	12	1.2	7	.7	15	5.2	2	.8
6-10	44	4.6	29	2.9	40	14.0	14	5.7
11-15	106	11.0	66	6.6	30	10.5	25	10.2
16-20	172	17.9	143	14.3	55	19.2	46	18.9
21-30	265	27.5	336	33.7	68	23.6	85	34.8
31-40	176	18.2	192	19.3	45	15.7	40	16.4
41-50	81	8.4	81	8.1	22	7.7	22	9.0
51-61	71	7.4	87	8.7	8	2.8	9	3.7
62+	37	3.9	56	5.6	3	1.0	1	.4
Race or ethnic background								
White	837	87.4	805	81.6	206	73.0	194	79.8
Black	88	9.2	140	14.2	58	20.7	39	16.0
Hispanic	22	2.3	33	3.3	16	5.7	10	4.1
Asian or Pacific Islander	4	.4	5	.5	2	.7	0	-
American Indian or Alaskan Native	7	.7	3	.3	0	-	0	-
Level of retardation								
Borderline (IQ 69-84)	97	10.1	14	1.4	10	3.5	13	5.3
Mild (IQ 52-68)	229	23.8	78	7.8	46	16.1	52	21.3
Moderate (IQ 36-51)	276	28.7	150	15.0	62	21.7	61	25.0
Severe (IQ 20-35)	248	25.8	287	28.8	83	29.0	56	23.0
Profound (IQ < 20)	113	11.7	468	46.9	85	29.7	62	25.4

Nearly every resident's record (98%) contained either an IQ score or a diagnosed level of retardation. The most recent diagnosis or IQ score was used, although neither the source of the evaluation nor the specific test of intelligence was recorded by interviewers. In order to calculate sampling errors, information on this item was imputed for the 2% of the total sample whose records did not indicate a level of retardation. It is apparent that PRF residents were generally more severely retarded than CRF residents. Nevertheless, 37.5% of CRF residents were either severely or profoundly retarded. Almost 34% of CRF residents were borderline or mildly retarded, compared with 9.2% of PRF residents. PRF new admissions and readmissions included greater proportions of mildly handicapped individuals than did the PRF population as a whole. The distribution of intelligence among PRF readmissions is similar to that for CRF residents and parallels the distribution for residents released from PRFs (Sigford & Bruininks, 1981).

#### Behavioral Characteristics

Detailed information about the behavioral characteristics of residents was gathered through the Behavioral Characteristic Assessment scale. Table 4 summarizes residents' level of independence scores on the Behavioral Characteristic Assessment.

Of CRF residents, 7% were nearly totally dependent (level <1) and an additional 8.4% were cooperative but nevertheless required one-to-one assistance with all activities (level 1); 33.7% took an active role in attempting to perform most self-help skills and initiated many day-to-

Table 4

## Residents' Level of Independence

Level of Independence	CRF residents		PRF residents		PRF new admissions		PRF readmissions	
	N	%	N	%	N	%	N	%
<1. Abilities are limited to the extent that this resident is passive & nearly everything must be done for him/her by direct physical manipulation.	68	7.2	185	18.8	49	17.2	28	11.7
1. With manual guidance or if physically & gesturally prompted & helped, this resident cooperates in attempting to perform most activities.	79	8.4	220	22.3	45	15.8	34	14.2
2. With verbal guidance & reminders, & if shown what to do, this resident takes an active role in attempting to perform some self-help skills & everyday activities without physical help.	133	14.0	201	20.4	47	16.5	28	11.7
3. This resident takes care of some self-help needs independently, often finds things to do or play with, seeks help when it is needed, & can be trusted without direct supervision (e.g., in the yard) for short periods of time.	186	19.7	168	17.0	45	15.8	32	13.3
4. This resident needs only occasional reminders to perform most everyday household & self-help activities independently, but relies on instruction for more complex activities such as meal preparation, learning to use appliances, money management, & learning to use community resources. This person can make short routine trips into the nearby community independently (or if accompanied only by peers).	236	24.9	139	14.1	49	17.2	51	21.3
5. This person performs most routine domestic activities independently, & finds his/her way around the community. However, he/she needs intermittent supervision & access to a responsible adult present in the same building, but not necessarily in the same living unit.	177	18.7	61	6.2	34	11.9	46	19.2
6. This individual demonstrates skills necessary to live independently in the community without direct supervision. He/she knows where to get assistance from time to time when the needs arises.	67	7.1	12	1.2	16	5.6	21	8.8

day activities on their own (levels 2 and 3); 24.9% had mastered most routine household activities and could venture into the neighborhood on their own (level 4); 18.7% had mastered most routine domestic skills and many community activities necessary for semi-independent supervised living (level 5); and 7.1% demonstrated most of the abilities needed for independent living (level 6).

The PRF resident sample was considerably less independent than residents in the CRF group. Nearly one-fifth (18.8%) of all PRF residents were virtually totally dependent (level <1). For these residents the traditionally used term "total care" might apply. They were unable to feed themselves, even with their fingers; they did not use the toilet even if placed on one; they were unresponsive to language or gestures; and outwardly appeared to be oblivious to people and activities around them. An additional 22.3% of PRF residents were actively cooperative, but still required manual guidance and one-to-one help for their daily activities (level 1); 20.4% of PRF residents responded to language and demonstration (level 2); 17% had mastered some self-help skills (level 3); 14.1% were independent enough to perform most self-help and everyday household activities on their own and could venture into the nearby community alone or with peers (level 4); and 7.4% had mastered at least some of the skills that would be necessary to live semi-independently or independently in the community (levels 5 and 6).

PRF new admissions were relatively more independent than PRF residents in general, but more limited in ability than CRF residents. Although the PRF readmission group included some very dependent

residents, the proportion of readmissions at levels 5 and 6, semi-independent and independent (28%), was actually larger than the proportion of CRF residents at these levels.

A one-way analysis of variance on average level of independence for the four groups showed statistically significant differences ( $F = 86.32$ ;  $p < .0001$ ). The results indicated that PRF residents were most dependent, followed in terms of increasing independence by the PRF new admissions, PRF readmissions, and CRF residents.

Domain scores based upon the number of scale items passed in each domain of the Behavioral Characteristics Assessment are presented in Table 5. One-way analysis of variance among resident sample groups on domain scores revealed a consistent pattern of statistically significant differences ( $p < .0001$ ). Total scale scores for the CRF residents were significantly higher than those of PRF residents ( $t(1837) = 16.7$ ,  $p < .001$ ) and of PRF new admissions ( $t(1155) = 5.7$ ,  $p < .001$ ), but not significantly higher than PRF readmissions. A similar pattern of results was found for each domain.

Table 6 reports specific abilities of each group of residents in terms of the percent of residents passing each scale item. On eating and meal preparation, 79% of CRF current residents, 72.4% of PRF readmissions, 57.4% of PRF new admissions, and 52.6% of all PRF residents could eat a complete meal with a knife, fork, and spoon with little spilling.

A similar pattern emerged among groups in self-help skills (dressing, toileting, and personal self-care). In dressing, 79.1% of

Table 5

Residents' Level of Independence by Domain<sup>a</sup>

Domain	CRF <u>residents</u>		PRF <u>residents</u>		PRF <u>new admissions</u>		PRF <u>readmissions</u>		<u>F</u>
	M	SD	M	SD	M	SD	M	SD	
A. Eating & Meal Preparation	3.0	1.7	2.0	1.5	2.4	1.8	2.8	1.8	51.97*
B. Dressing	3.3	1.7	2.2	1.7	2.6	1.9	3.1	1.9	58.06*
C. Toileting	3.6	1.7	2.4	1.8	2.9	1.9	3.5	1.8	65.84*
D. Personal Self Care	3.2	1.9	2.0	1.9	2.5	2.0	2.8	2.2	59.18*
E. Language Comprehension	3.4	1.8	2.3	1.8	2.7	2.0	3.3	2.1	53.55*
F. Language Expression	3.6	2.0	2.2	2.0	3.0	2.2	3.5	2.2	77.72*
G. Social Interaction	3.5	1.7	2.5	1.6	2.9	1.8	3.4	1.7	54.66*
H. Domestic Activities	3.3	2.1	1.7	1.9	2.2	2.1	2.9	2.2	98.07*
I. Community Orientation	3.5	1.8	2.2	1.9	2.7	1.9	3.3	2.0	76.13*
J. Value & Money	3.1	1.8	2.0	1.7	2.6	1.9	3.0	1.9	63.87*
K. Reading & Writing	3.0	1.8	1.5	1.5	2.0	1.8	2.6	1.9	114.42*
Total Scale	36.5	17.5	22.9	16.6	28.3	19.4	34.2	19.6	86.32*

<sup>a</sup>The level of independence per domain is equal to the number of items passed per domain.

\*  $p < .0001$

Table 6

## Residents' Behavioral Characteristics

Item	CRF		PRF		PRF		PRF	
	residents		residents		new admissions		readmissions	
	N	% pass	N	% pass	N	% pass	N	% pass
<b>A. Eating &amp; Meal Preparation</b>								
1. Feeds self with fingers	879	92.6	837	85.1	236	83.1	218	90.5
2. Eats a complete meal with a knife, fork, & spoon with little spilling.	755	79.0	523	52.6	163	57.4	176	72.4
3. Prepares a snack that doesn't require cooking (such as a sandwich or bowl of cereal) without supervision.	574	60.0	337	34.0	133	46.8	135	55.8
4. Mixes & cooks simple foods such as scrambled eggs or hamburgers on a range without direct supervision.	312	32.8	149	15.0	78	27.6	73	30.4
5. Cooks a complete hot meal with help only in planning.	182	19.1	76	7.7	41	14.4	44	18.2
6. Independently plans, shops for groceries, & cooks complete hot meals.	135	14.2	63	6.4	40	14.1	35	14.5
<b>B. Dressing</b>								
1. Cooperates by holding out arms & legs while being dressed.	868	91.8	776	78.3	225	79.5	211	86.8
2. Dresses self completely & correctly except for some fastenings such as zippers or shoelaces.	753	79.1	565	56.9	185	65.1	174	71.9
3. Dresses self completely & correctly including buttons & belts & shoelaces.	636	66.7	377	37.9	136	47.9	143	59.1
4. Independently selects appropriate clothing for various situations & weather conditions.	506	53.0	267	26.8	101	35.6	123	50.8
5. Independently selects & buys correct size & style of clothing & accessories in a store.	193	20.3	84	8.5	49	17.3	55	22.8
6. Independently sews back on buttons that have fallen off clothing.	160	16.8	84	8.5	36	12.7	46	19.1
<b>C. Toileting</b>								
1. When taken to the bathroom at appropriate times, uses the toilet, but may still have frequent accidents unless reminded.	859	89.9	774	78.2	220	78.0	211	87.6
2. Uses the toilet independently with few reminders (including removing & replacing clothing), with less than one accident per month.	784	82.0	615	61.7	199	70.3	188	78.0
3. In new surroundings, finds or asks where the bathroom is.	696	73.0	472	47.4	172	60.8	170	70.2
4. Always closes the bathroom door when bathing, using the toilet, or in need or privacy.	599	62.7	368	37.2	134	47.4	149	61.8
5. Locates & properly uses the correct men's or women's rest-room in a restaurant or public building.	496	52.0	205	20.7	96	34.0	118	49.0
<b>D. Personal Self Care</b>								
1. Holds hands under running water for washing.	832	87.0	666	67.1	209	73.6	181	75.0
2. When asked, applies toothpaste, brushes teeth & rinses mouth & toothbrush.	697	73.0	453	45.8	163	57.4	150	62.0
3. Adjusts water faucets for proper temperature in sink or bathtub.	647	67.6	381	38.4	139	48.9	140	58.1
4. Prepares & completes bathing, including washing & drying hair, at regular intervals or as needed without reminder.	425	44.4	208	21.0	89	31.7	93	38.4
5. Without reminders, keeps self clean & well groomed overall (hair cuts, make-up, filing nails, etc.)	306	32.1	134	13.5	54	19.0	66	27.3
6. Independently goes to doctor, dentist, clinic as needed for routine health care or illness.	164	17.2	109	11.0	54	19.0	54	22.3

Table 6 (continued-2)

## Residents' Behavioral Characteristics

Item	CRF		PRF		PRF		PRF	
	residents		residents		new admissions		readmissions	
	N	% pass	N	% pass	N	% pass	N	% pass
<b>E. Language Comprehension</b>								
1. Responds appropriately to simple words & gestures such as "sit down" or "come here."	859	89.9	779	78.1	225	79.2	204	84.3
2. Follows simple one part directions which include a preposition such as "Put your coat in the closet."	800	83.8	617	61.9	188	66.2	186	76.5
3. Follows two part directions in order. For example: "First hang up your coat & then find the book."	649	68.2	416	41.8	140	49.3	157	64.9
4. Follows verbal directions about how to put things together or take them apart, how to operate appliances, & so on.	401	42.0	247	24.9	91	32.2	114	47.1
5. Could summarize a story or what happened in a movie or TV program.	327	34.4	143	14.4	77	27.2	85	35.3
6. Understands & remembers information presented by a speaker to a group of about 20 people, such as in a classroom or at a club meeting.	235	24.8	110	11.1	50	17.7	66	27.4
<b>F. Language Expression</b>								
1. Shakes head or otherwise indicates yes or no in response to a simple question like "Do you want some milk?"	848	88.6	714	71.6	219	77.1	200	82.6
2. Says at least ten words that can be understood by someone who knows him/her.	735	77.0	496	49.9	177	62.3	174	71.9
3. Speaks (or signs) in short sentences.	717	74.9	453	45.5	168	59.2	172	71.1
4. Uses complex sentences containing "and," "because," etc. For example: "I'm not going outside today because it's raining."	505	52.8	268	27.0	130	45.8	133	55.4
5. Carries on a meaningful ten minute social conversation with someone he/she knows casually.	398	41.6	202	20.4	97	34.2	101	41.7
6. Calls the landlord or a repairman if something major around the house breaks down.	265	27.7	89	9.0	52	18.3	69	28.5
<b>G. Social Interaction</b>								
1. Responds to the presence of another person by smiling or turning head.	897	93.9	852	85.5	248	87.3	228	94.2
2. Plays catch or another simple game with another person.	719	75.4	570	57.3	187	65.8	176	72.7
3. Takes part in simple group games & social activities such as parties.	710	74.3	538	54.2	158	56.0	173	71.5
4. Acts appropriately (does not draw people's attention) when alone in a routine public situation, such as in a store.	562	58.8	384	38.9	131	46.8	127	52.9
5. Uses a telephone independently, including finding the numbers & placing the call, to get information or talk to friends.	235	24.6	76	7.7	53	18.7	66	27.3
6. Plans & entertains others in own residence--provides food, beverage or appropriate activity.	195	20.5	77	7.8	53	18.7	52	21.6
<b>H. Domestic Activities</b>								
1. If handed an empty dish, will set it down on a table or sink in appropriate circumstances.	785	82.1	536	53.8	170	59.9	177	73.1
2. When given a damp cloth, wipes a counter or table in appropriate circumstances.	690	72.1	440	44.2	154	54.2	154	63.4
3. Finds something to do or asks if there is something to do when he/she is unoccupied for more than 15 minutes.	503	52.7	235	23.7	89	31.3	103	42.6
4. Demonstrates the physical & mental ability to get out of the house safely alone in case of a fire.	568	58.9	244	24.5	105	36.7	120	49.2
5. Independently determines by looking at a clock when it is time to go to school or work, eat, or to be home.	351	36.7	151	15.2	62	21.8	84	34.9
6. Independently loads & operates an automatic clothes washer & dryer, including correct settings & appropriate amount of detergent.	308	32.2	111	11.2	56	19.7	70	28.9

Table 6 (continued-3)

## Residents' Behavioral Characteristics

Item	CRF		PRF		PRF		PRF	
	residents		residents		new admissions		readmissions	
	N	% pass	N	% pass	N	% pass	N	% pass
<b>I. Community Orientation</b>								
1. Finds favorite toys or objects that are always kept in the same place.	842	88.4	655	66.2	206	72.8	206	85.1
2. If asked to go to a certain room at home or in a familiar building, finds own way correctly.	787	82.5	571	57.6	196	69.3	177	77.8
3. Goes outside unsupervised in an unfenced yard for ten minutes without wandering away or getting lost.	741	76.9	511	51.3	170	59.4	161	66.0
4. Goes four blocks from home, school, or work alone or with peers without getting lost.	490	50.8	281	28.2	102	35.7	127	52.0
5. If lost, asks directions, telephones for help, or otherwise regains sense of direction & finds planned destination.	361	37.9	135	13.6	63	22.4	87	36.0
6. Locates or follows directions to a specific street address several miles away.	163	17.1	66	6.7	38	13.4	43	17.8
<b>J. Value &amp; Money</b>								
1. When given a choice between two objects or toys, usually points at or otherwise indicates which of the two he/she prefers.	848	88.6	686	68.9	211	74.5	200	82.3
2. Persistently points at or names things that he/she sees or wants.	789	82.5	585	58.9	193	68.2	191	78.6
3. Shows that he/she knows money or tokens have value because will trade something for them or do something to earn them.	558	58.5	359	36.3	135	47.9	141	58.8
4. Without supervision, uses money to make minor purchases at local stores or fast food restaurants (but need not count change correctly).	432	45.3	229	23.1	104	36.9	110	45.5
5. Budgets transportation &/or recreation money to last an entire week.	184	19.3	71	7.2	39	13.8	43	17.8
6. Counts out exact amount of change for a purchase of \$5.00 or less.	185	19.4	61	6.2	43	15.2	45	18.6
<b>K. Reading &amp; Writing</b>								
1. Looks at pictures in a book or at a TV program for at least a few minutes at a time.	848	88.7	746	75.1	227	80.2	207	85.2
2. Identifies a printed example of his/her first name from a group of names; for example on lockers or over coat hooks.	633	66.2	309	31.2	121	42.8	143	59.1
3. Prints own first name with an example to look at.	609	63.8	221	22.5	99	35.6	114	47.3
4. Prints or writes first & last name with no example to look at.	493	51.6	146	14.7	75	26.7	98	40.7
5. Reads & understands written sentences & simple instructions well enough to follow directions; for example, on a box of cake mix.	170	17.8	42	4.2	25	8.9	42	17.5
6. Completes short application forms.	116	12.1	32	3.2	20	7.1	22	9.1

CRF residents, 71.9% of PRF readmissions, 65.1% of PRF new admissions and 56.9% of all PRF residents could dress themselves completely and correctly except for some fastenings such as zippers or shoelaces.

Language comprehension and expression, social interaction, domestic activities, and community orientation also showed that CRF residents and PRF readmissions were most independent and PRF residents were least independent. Approximately three-fourths of CRF residents could communicate in at least short sentences, whereas less than half of institutionalized residents communicated at this level. Three-fourths of CRF residents and one-half of PRF residents could safely occupy themselves within their facility's immediate locale, i.e., in the yard, but only 50.8% of CRF residents and only 28.2% of PRF residents could go beyond the yard without direct supervision. Of the institutionalized residents, 13.6% could reliably find a planned destination in the community, whereas 37.9% of CRF residents were reported to have this ability.

With regard to value and money and reading and writing skills, 45.3% of the CRF residents and 45.5% of PRF readmissions could use money to make minor purchases without supervision. Only 17% of residents in these two groups could read and understand written instructions. Among all PRF residents, 23.1% could use money independently and 4.2% could read.

Table 7 reports the percentage of scale items on the Behavior Characteristics Assessment that were reported to be passed, but could not be performed because of constraints in the residential environment.

Table 7

Percent of Behavioral Characteristics Assessment Items Passed  
But Not Performed Due to Environmental Constraints

Group	M	Median	SD
CRF residents (N = 946)	4.3	0.0	8.1
PRF residents (N = 986)	7.0	0.0	12.3
PRF new admissions (N = 285)	7.2	3.6	11.0
PRF readmissions (N = 240)	8.7	5.4	13.8

The average proportion of items passed but not performed because of environmental constraints was higher in PRFs than in CRFs ( $t(1508) = 5.94, p < .001$ ). Nevertheless, the proportions were relatively small for all groups and settings. Median values of 0.0 indicated that for the majority of each group of residents there were no behaviors included in this particular scale that they were capable of performing but were precluded from doing by the residential environment. It is possible, nevertheless, that environmental limitations had prevented the acquisition of some skills that might have been learned in alternate environments. PRF new admission and readmission sample groups included residents whose current PRF placement had been less than approximately 18 months. Higher median values for these groups suggested that new residents tended to have higher percentages of environmental constraints, perhaps indicating that their facilities had not yet fully adjusted to their abilities.

Residents were not considered to pass a scale item if staff reported that in order to perform it the resident had to be coaxed or repeatedly

reminded. The proportion of items potentially within a resident's ability but not performed without coaxing was calculated to obtain an index of motivation. Because even one behavior not performed for this reason could drastically affect this index for severely handicapped residents who passed only a few items, it was necessary to adjust the index for degree of mental retardation. Using one-way analysis of variance, controlling for level of retardation, there were no differences among CRF and PRF groups with regard to the proportion of items they "failed" because of an inferred lack of motivation. Among all residents (N = 2233), score on the 65 items of the Behavioral Characteristic Assessment was 20.5% below what it would have been under optimal performance (i.e., if residents had been given credit for passing items that they did not actually perform on a routine basis). There was wide variation among individuals (SD = 21.5%).

The language domains of the Behavioral Characteristics Assessment were expanded upon by a separate interview question about mode of communication. Table 8 details the manner in which residents usually communicated as reported by direct-care staff. The communication modes of CRF residents were similar to those of PRF readmissions, with approximately 75% of each sample communicating through the use of speech. Consistent with findings reported in earlier tables, PRF residents were more limited in communication abilities. Approximately 29% of PRF residents did not communicate, except perhaps through crying or gestures. Less than 50% communicated through use of speech. Most residents who communicated but did not talk, did so by pointing or using

Table 8

## Residents' Usual Mode of Communication

Communication Mode	CRF <u>residents</u>		PRF <u>residents</u>		PRF <u>new admissions</u>		PRF <u>readmissions</u>	
	N	%	N	%	N	%	N	%
Does not communicate except to cry or smile	99	10.2	286	28.7	62	21.4	41	16.8
Points, gestures	94	9.8	213	21.4	33	11.4	24	9.8
Talks								
Is easily understood	449	46.6	229	23.1	102	35.7	112	45.9
Can usually be understood	209	21.7	168	16.9	58	20.3	60	24.6
Is very difficult to understand	84	8.7	56	5.6	24	8.4	5	2.0
Formal sign language	17	1.8	19	1.9	4	1.4	1	.4
Symbol board	5	.5	10	1.0	0	-	1	.4
Prints, types, writes	1	.1	1	.1	0	-	0	-
Other	5	.5	5	.5	3	1.0	0	-

gestures. Approximately 1.9% of PRF residents and 1.8% of CRF residents used a formal sign language system, and a small proportion (.5% of CRF residents, 1.0% of PRF residents) used symbol boards to communicate.

### Physical and Health Characteristics

#### Handicapping Conditions

Table 9 presents data about residents with handicaps in addition to mental retardation. Statistically significant differences were found among groups of residents with regard to the prevalence of epilepsy, physical handicaps, and the total number of additional handicaps exhibited by each retarded individual. Comparisons among groups on the prevalence of cerebral palsy, visual disorders, hearing disorders, and behavior disorders (alcoholism, chemical dependency, autism, mental illness) were not different at a statistically significant ( $p \leq .01$ ) level.

Many residents received medication to control seizures. The number of residents who had had an epileptic seizure during the preceding year was approximately half as large as the number whose records indicated a history of epilepsy. Seizures had been observed for 12.9% of CRF residents and for 22.2% of PRF residents during the year prior to the interviews.

It was difficult for direct-care staff to differentiate between cerebral palsy and physical handicaps such as contractures which may or may not have been related to cerebral palsy. Either cerebral palsy or a physical handicap were reported for 21.2% of CRF residents and for 25.5% of PRF residents. Of the CRF residents, 6% were blind or had

Table 9

## Handicaps in Addition to Mental Retardation

Handicap	CRF residents		PRF residents		PRF new admissions		PRF readmissions		F
	N	%	N	%	N	%	N	%	
Epilepsy									16.86**
Recorded history	244	25.3	425	42.8	126	43.8	101	41.4	
Medicated for epilepsy	200	20.8	360	36.3	93	32.2	85	34.8	
Seizure observed within last year	124	12.9	221	22.2	56	19.3	61	25.1	
Cerebral palsy	101	10.5	110	11.0	20	6.9	30	12.2	.74
Physical handicap <sup>a</sup>	103	10.7	145	14.5	26	9.0	18	7.3	5.23*
Vision									2.21
Severely impaired <sup>b</sup>	32	3.4	45	4.6	14	5.0	5	2.0	
Blind	25	2.6	40	4.0	13	4.6	8	3.3	
Hearing									3.73
Severely impaired <sup>c</sup>	16	1.7	27	2.7	7	2.5	2	.8	
Deaf	12	1.3	26	2.6	8	2.8	2	.8	
Behavior disorder <sup>d</sup>	15	1.6	7	.7	2	.7	4	1.6	2.06
Number of handicaps <sup>e</sup>									13.07**
None	573	59.5	440	44.3	160	55.9	123	50.4	
One	301	31.2	383	38.6	94	32.9	92	37.7	
Two	70	7.2	144	14.5	19	6.6	24	9.8	
Three	16	1.7	20	2.0	9	3.1	5	2.0	
Four	3	.3	6	.6	4	1.4	0	-	

<sup>a</sup>Includes spina bifida, contractures, missing extremities, & paralysis; excludes residents with cerebral palsy.

<sup>b</sup>Cannot see a television size image from 8 feet away, but sees enough to walk around without usually bumping into things.

<sup>c</sup>Can hear only a few words said, or loud noises.

<sup>d</sup>Autism, mental illness, alcoholism, or non-prescribed drug dependency.

<sup>e</sup>Of the six handicapping conditions in this table. Includes epilepsy if a seizure was observed during the last year or if resident had a recorded history of seizures & was currently receiving medication for epilepsy.

\*  $p < .01$

\*\*  $p < .0001$

severely impaired vision and 3% were deaf or had a severe hearing loss. The proportion of PRF residents with these handicaps was somewhat larger. Overall, 40.5% of CRF residents had at least one handicap in addition to mental retardation, compared with 55.7% of PRF residents, 44.1% of PRF new admissions, and 49.6% of PRF readmissions.

Resident's locomotor ability and arm-hand use are detailed in Table 10. Care persons were asked how a resident "usually gets around." Approximately 70% of CRF residents and 57.7% of PRF residents were reported to walk well. Nonambulatory residents composed 10.5% of the CRF population and 18.6% of all PRF residents. Most nonambulatory residents used wheelchairs, although some were confined to bed. Arm-hand use was severely impaired for 6.8% of CRF residents and 14.3% of PRF residents. Severely impaired residents required a considerable amount of assistance or adaptive equipment in order to perform motor activities.

#### Chronic Health Conditions and Medical Treatment

Table 11 presents information about residents' chronic health disorders. One-way analysis of variance did not indicate statistically significant differences among resident groups for the prevalence of any category of chronic health disorder. Circulatory system disorders were relatively frequent, as were respiratory and digestive system disorders. Temporary illnesses or infections and physically handicapping conditions such as blindness or deafness were not included among chronic health conditions. Approximately 20% of each resident group had one or more chronic health conditions.

Table 10

## Locomotor Ability and Arm-Hand Use

Characteristic	CRF		PRF		PRF		PRF	
	residents		residents		new admissions		readmissions	
	N	%	N	%	N	%	N	%
Locomotion								
Walks well	679	70.4	575	57.7	171	59.8	182	74.6
Walks, unsteadily	157	16.3	207	20.8	66	23.1	31	12.7
Walks with assistance, cane, walker	26	2.7	29	2.9	6	2.1	3	1.2
Total ambulatory	862	89.4	811	81.4	243	85.0	216	88.5
Propels own wheelchair	23	2.3	48	4.8	8	2.8	3	1.2
Pushed in wheelchair	48	5.0	109	10.9	24	8.4	23	9.4
Crawls, creeps, rolls	11	1.2	7	.7	3	1.0	0	-
Confined to bed	19	2.0	22	2.2	8	2.8	2	.8
Total nonambulatory	101	10.5	186	18.6	43	15.0	28	11.5
Arm-Hand use								
Complete control	742	77.0	658	66.0	202	70.6	197	80.7
Manages most activities independently	157	16.3	196	19.7	46	16.1	27	11.1
Needs much help or adaptive equipment	37	3.8	70	7.0	12	4.2	10	4.1
Little useful control	29	3.0	73	7.3	26	9.1	10	4.1

Table 11

## Chronic Health Disorders of Residents

Health Disorder Category	CRF		PRF		PRF		PRF		F
	<u>residents</u>		<u>residents</u>		<u>new admissions</u>		<u>readmissions</u>		
	N	%	N	%	N	%	N	%	
Infective or parasitic	2	.2	4	.4	0	-	2	.8	.60
Endocrine, nutritional or metabolic (e.g. diabetes, thyroid, hormone imbalances)	17	1.8	35	3.5	5	1.8	5	2.0	2.60
Blood & blood forming organs (e.g. anemia)	3	.3	10	1.0	3	1.1	2	.8	1.46
Nervous system & sense organs (e.g. cataracts, glaucoma, chronic ear infection, Parkinson's disease, muscular dystrophy)	9	.9	8	.8	3	1.1	1	.4	.11
Circulatory system (e.g. heart problems, blood pressure)	69	7.2	75	7.6	10	3.5	7	2.9	2.46
Respiratory system (e.g. asthma, emphysema, chronic respiratory infection)	21	2.2	27	2.7	9	3.2	6	2.5	.74
Digestive system <sup>a</sup> (e.g. ulcers, hernia, chronic constipation, colostomy)	24	2.5	35	3.5	6	2.1	9	3.7	.93
Genitourinary system (e.g. kidney, urinary tract)	6	.6	10	1.0	3	1.1	2	.8	.31
Skin & subcutaneous tissue	14	1.5	11	1.1	2	.7	1	.4	.30
Neoplasms (malignant & nonmalignant)	4	.4	5	.5	4	1.4	2	.8	.31
Teeth & gums	1	.1	7	.7	0	-	0	-	1.64
Other	24	2.5	25	2.5	17	6.0	6	2.5	1.67
Number of health disorders <sup>b</sup>									2.91
None	790	82.5	792	79.9	235	83.3	209	85.7	
One	143	14.9	157	15.8	34	12.1	29	11.9	
Two	21	2.2	32	3.2	11	3.9	4	1.6	
Three	3	.3	9	.9	2	.7	2	.8	
Four	0	-	1	.1	0	-	0	-	

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<sup>a</sup>Included with digestive systems disorders were problems that required tube feeding & chronic emesis that required medical care.

<sup>b</sup>Number of categories exhibited by each resident.

Care persons were asked if the residents had seen a medical doctor within the year prior to the interview and to provide the reasons for this medical service. Table 12 reports that approximately 90% of all residents had received a physical examination within the year prior to the interview. Regarding other reasons for seeing a medical doctor, statistically significant differences were found among groups for the proportion of residents who saw a doctor because of a temporary illness, accident or injury, and chronic illness or disease. Over 45% of PRF readmissions had been treated for a temporary illness during the year, compared with 32.5% of all PRF residents, 29.7% of PRF new admissions, and 24.4% of CRF residents.

Treatment for accident or injury was reported for 19.1% of PRF new admissions, 17.7% of PRF residents in general, 13.8% of PRF readmissions, and 5.6% of CRF residents. A special analysis was done to exclude residents who had been reported to exhibit self-injurious behavior serious enough to require medical attention. With these residents excluded, 14.4% of PRF new admissions, 13.1% of all PRF residents, 9.6% of PRF readmissions, and 5.2% of CRF residents had seen a doctor at least once during the previous year because of accident or injury.

Although, as reported above, the prevalence of chronic health disorders did not differ among resident groups, PRF residents were more likely than CRF residents to have seen a doctor because of a chronic health disorder ( $p < .01$ ). It is possible that chronic conditions were more serious among PRF residents, or that PRF residents received more frequent medical attention for equally serious conditions.

Table 12

## Reasons for Seeing a Medical Doctor during a One-Year Period

Reason	CRF residents		PRF residents		PRF new admissions		PRF readmissions		F
	N	%	N	%	N	%	N	%	
Routine physical exam	855	90.1	870	87.9	255	89.5	216	89.6	.69
Temporary illness	230	24.4	320	32.5	84	29.7	109	45.6	10.29**
Accident or injury	53	5.6	174	17.7	54	19.1	33	13.8	21.17**
Chronic illness, disease	91	9.6	142	14.4	30	10.6	26	10.9	4.82*
Diagnosis, diagnostic procedure	48	5.1	41	4.2	8	2.8	5	2.1	1.46
Regarding medication	30	3.2	17	1.7	8	2.8	8	3.3	1.55
Surgical procedure	28	3.0	23	2.3	5	1.8	2	.8	.58
Regarding prosthetic device	5	.5	4	.4	2	.7	3	1.3	.46
Mental or emotional problem	17	1.8	11	1.1	7	2.5	2	.8	.81
Other	3	.3	1	.1	0	-	0	-	

Note: Time period may be less than one year for PRF new admissions and readmissions who had not resided at the facility for an entire year. Columns do not sum to total because many residents saw doctor for more than one reason.

\*  $p < .01$

\*\*  $p < .0001$

Only small proportions of residents were reported to have seen a doctor specifically because of their medication. It is likely, however, that medications were reviewed through records or during visits primarily for other reasons. At the time of the interview, 54% of all CRF residents were receiving some type of prescribed medication, as were 76% of PRF residents, 71% of PRF new admissions, and 75% of PRF readmissions.

#### Maladaptive Behavior

The term "maladaptive behavior," somewhat more inclusive than "behavior problem," includes behaviors such as stereotyped actions which may not present problems for other people, but depart from social expectations or are in some way counterproductive. Stereotyped behavior such as body rocking usually causes no harm to other people or to the environment, but is often included among maladaptive behaviors because it may interfere with an individual's attention or performance. Stereotyped behaviors were evidenced by approximately one-third of each resident group.

Table 13 reports that there were statistically significant differences among resident groups for the prevalence of every type of maladaptive behavior reported by staff. CRF residents were generally less likely to exhibit maladaptive behavior than were PRF residents. Self-injurious behavior was reported for 11.1% of CRF residents, compared to 21.7% of PRF residents; 16.3% of CRF residents and 30.3% of PRF residents were reported to injure other people; 11.1% of CRF residents and 17.6% of PRF residents damaged property. A fourth major category of maladaptive

Table 13

## Prevalence of Maladaptive Behavior

Type of Behavior	CRF		PRF		PRF		PRF		F
	residents		residents		new admissions		readmissions		
	N	%	N	%	N	%	N	%	
Self-injurious	107	11.1	216	21.7	63	22.0	52	21.3	14.31**
Injures others	157	16.3	302	30.3	120	42.0	94	38.5	32.26**
Damages property	107	11.1	175	17.6	55	19.2	57	23.4	8.56**
Unusual or disruptive behavior	278	28.8	342	34.3	108	37.8	100	41.0	4.86*
Stereotyped behavior	287	29.8	385	38.7	92	32.3	69	28.4	7.73**
Breaks rules, won't follow routine	184	19.1	187	18.8	94	32.4	81	33.2	10.30**
Refuses to go to day program	69	7.2	117	11.7	60	20.9	63	25.8	20.31**
Has spent one of last 30 days at home because of refusal to go	24	2.5	57	5.7	27	9.4	33	13.8	12.72**
Has purposely run away	21	2.2	36	3.6	33	11.5	33	13.5	26.95**
Has run away within the last six months	13	1.3	25	2.5	25	8.7	20	8.2	19.63**
Has broken the law within the last year	15	1.5	5	.5	9	3.1	18	7.4	15.10**
Court or law enforcement personnel involved	7	.7	1	.1	4	1.4	10	4.1	12.22**

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\*  $p < .01$ \*\*  $p < .0001$

behavior that included unusual or disruptive behaviors such as making noise or throwing tantrums was reported for 28.8% of CRF residents and 34.3% of PRF residents.

Public and community facilities had similar proportions of residents who were reported to break house rules or refuse to go along with household routines. These behaviors included general uncooperativeness, refusal to get up or go to bed or eat at reasonable times, or reluctance or refusal to participate in household activities or to comply with reasonable rules such as "no smoking in bed."

Regulations often require that residents attend special daytime programs. Although staff usually prevailed upon residents to attend these programs, they were not always able to succeed, as indicated by the proportion of residents who had actually missed a day of their day program within a month prior to interviews because of refusal to attend.

Although 2.2% of CRF residents were reported to have purposely run away at one time, only 1.3% had actually run away within six months prior to the interview; 2.5% of PRF residents had run away within six months. This item did not include residents who wandered away or got lost unintentionally.

Staff reported that 1.5% of CRF residents had broken the law within the prior year. In almost one-half of these cases the court system or law enforcement personnel had been involved. Among PRF residents, who probably had less access to unstructured or unsupervised settings, only 0.5% had broken the law and in only one instance had law enforcement officers been involved. In other cases, facility staff, parents, or

social workers had intervened. Presumably, staff reported incidents that occurred outside the residential facility or involved people other than staff or other residents. Although many residents were aggressive or destructive, behaviors that occur "in the family" or at home are typically not reported as "against the law."

Except for stereotyped behavior and self-injurious behavior, the incidence of every type of maladaptive behavior reported was much higher among PRF new admissions and readmissions than among PRF residents in general or among CRF residents. Injuring other residents, damaging property, breaking rules, refusing day programs, and running away were 1.5 times to 6 times more prevalent among PRF new admissions and readmissions than among CRF residents. Court or law enforcement personnel had been involved with 4.1% of PRF readmissions during the year; over 8% of PRF new admissions and readmissions had run away within 6 months prior to the survey, over 9% had missed a day of day programs within the previous month, and over 38% had injured other residents.

If a resident exhibited a behavior problem, staff were asked if the behavior problem(s) prevented the resident from getting out into the community more, either alone or with staff members or volunteers. CRF staff reported that 47% of their residents with behavior problems would have been able to get out more if their behavior were better controlled. PRF staff reported that 53% of all residents with behavior problems were limited in community participation by their behavior. CRF staff reported that 8.4% of their residents with behavior problems (3.8%

of all CRF residents) were in danger of being demitted, compared with 2.5% of PRF residents (1.5% of all PRF residents) who were reported to be in danger of demission because of their behavior problems.

Table 14 reports the number of different types of maladaptive behavior exhibited by each resident. Staff reported no behavior problems for 52.7% of CRF residents, 40.3% of PRF residents, 31.5% of PRF new admissions, and 31.6% of PRF readmissions.

Table 14

## Number of Types of Maladaptive Behavior Exhibited by Residents

Number of Types	CRF residents	PRF residents	PRF new admissions	PRF readmissions	F
Number					
None	52.7%	40.3%	31.5%	31.6%	
1	24.4%	24.7%	24.1%	22.5%	
2	10.8%	15.5%	16.4%	14.8%	
3	6.5%	8.1%	8.7%	8.6%	
4	3.2%	7.2%	7.7%	12.3%	
5 or more	2.5%	4.1%	11.5%	10.2%	
Mean	.91	1.31	1.75	1.87	32.83*
SD	1.27	1.48	1.76	1.90	

Note: Eight types of maladaptive behaviors include: self-injurious, injurious to others, damages property, unusual or disruptive behavior, breaks rules, has spent one of last 30 days at home because of refusal to go to day program, has run away during last six months, has broken the law within the year.

\*  $p < .0001$

Approximately 25% of residents in each sample group exhibited only one type of maladaptive behavior. Twenty-three percent of CRF residents and 34.9% of PRF residents displayed two or more types of maladaptive

behavior. Multiple behavior problems were particularly evident among PRF new admissions and PRF readmissions: 11.5% of new admissions and 10.2% of readmissions exhibited five or more types of maladaptive behavior, compared with only 2.5% of CRF residents and 4.1% of all PRF residents.

In order to examine the frequency and staff response to maladaptive behavior, four categories were investigated in greater detail: self-injurious, injurious to others, damages property, and unusual or disruptive behavior.

#### Self-Injurious Behavior

Table 15 reports specific self-injurious behaviors reported by staff. Up to three self-injurious behaviors were coded for each resident. The rank ordering of various types of self-injurious behavior by prevalence was similar among all resident groups. The proportion of PRF residents exhibiting a particular behavior was consistently approximately double the proportion of CRF residents.

Frequency level and level of staff response were reported for the single most prominent self-injurious behavior of each resident. Among self-injurious residents, self-injurious behavior episodes were reported to occur relatively frequently, typically several times a week or more. A one-way analysis of variance, however, indicated that the average frequency level of self-injurious behaviors was not significantly different among resident groups.

The usual staff response to approximately 25% of all residents with self-injurious behavior was to systematically ignore the behavior and

Table 15

## Prevalence of Self-Injurious Behaviors, Frequency, and Staff Response within Residential Facilities

Behavior/Frequency/Response	CRF		PRF		PRF		PRF		F
	residents		residents		new admissions		readmissions		
	N	%	N	%	N	%	N	%	
Behavior <sup>a</sup>									
bites, picks, scratches self	57	5.9	107	10.7	39	13.6	26	10.7	5.60*
bangs head	36	3.7	80	8.0	24	8.4	18	7.3	5.47*
hits, slaps, pinches self	26	2.7	52	5.2	15	5.2	12	4.9	1.81
hits self with, throws self against objects	13	1.3	40	4.0	5	1.7	15	6.1	6.24*
eats non-edible material	10	1.0	44	4.4	6	2.1	3	1.2	9.46**
pokes objects in eyes, ears, etc.	1	.1	3	.3	4	1.4	2	.8	1.70
other	6	.6	10	1.0	3	1.0	5	2.0	
Total	107	11.1	216	21.7	63	22.0	52	21.3	14.31**
Frequency <sup>b</sup>									
(1) less than monthly	10	9.9	24	11.4	7	11.7	7	13.5	1.34
(2) 1-3 per month	17	15.9	40	19.0	12	20.0	13	25.0	
(3) 1-6 per week	35	33.2	63	30.0	16	26.7	19	36.5	
(4) 1-16 per day	34	33.0	72	34.3	18	30.0	9	17.3	
(5) 1 or more per hour	8	8.0	11	5.2	7	11.7	4	7.7	
Staff response <sup>b</sup>									
(1) no response	3	2.8	7	3.3	0	-	3	5.8	1.67
(2) ignore, reinforce other behavior	30	28.5	44	20.5	10	16.1	16	30.8	
(3) verbal response	40	37.4	61	28.4	20	32.3	11	21.2	
(4) physical response	27	25.7	90	41.9	28	45.2	16	30.8	
(5) get help	6	5.6	13	6.0	4	6.5	6	11.5	

<sup>a</sup>Percent of all residents. Columns do not sum to total because some residents exhibited more than one type of self-injurious behavior.

<sup>b</sup>Percent of residents who exhibited self-injurious behavior.

\*  $p < .001$

\*\*  $p < .0001$

reinforce other behaviors that were more desirable. Approximately one-third of self-injurious residents elicited a physical response from staff. The most serious behavior problems were considered to be those that could not be controlled by one staff person. Six percent of self-injurious PRF residents elicited this level of staff response, as did 5.6% of self-injurious CRF residents. Among PRF readmissions, the proportion of self-injurious behaviors that required more than one staff person (11.5%) was considerably higher than among other resident groups. One-way analysis of variance, however, did not indicate statistically significant differences in average level of staff response to self-injurious behaviors among the four sample groups.

#### Behavior Injurious to Other People

Table 16 reports on behavior injurious to other people. Kicking, hitting, or slapping were most common behaviors in this category. Other types of injurious behavior included biting, pinching, and throwing things at people. Some residents caused unintentional injury by pushing or being overly rough. The rank order of the prevalence of various types of behaviors injurious to other people was similar in CRFs and PRFs, although the proportion of PRF residents exhibiting each type of behavior was at least twice that of CRF residents.

There was a wide range in the frequency level at which behaviors injurious to other people occurred. In CRFs, 16.7% of the residents who injured other people did so less than once a month, compared to 12.8% of all injurious PRF residents, 6.8% of injurious PRF new admissions, and 5.6% of PRF readmissions who injured other people. Nearly 30% of

Table 16

Prevalence of Behaviors Injurious to Other People, Frequency, and Staff Response within Residential Facilities

Behavior/Frequency/Response	CRF		PRF		PRF		PRF		F
	residents		residents		new admissions		readmissions		
	N	%	N	%	N	%	N	%	
Behavior <sup>a</sup>									
kicks, slaps, hits	118	12.2	232	23.3	100	35.0	80	32.8	28.59***
scratches, bites	55	5.7	144	14.4	42	14.7	37	15.2	14.54***
pinches, pulls hair	20	2.1	56	5.6	19	6.6	12	4.9	6.43**
hurts by pushing or roughhousing	19	2.0	51	5.1	24	8.4	7	2.9	6.73**
hits with, throws objects at people	25	2.6	38	3.8	16	5.6	12	4.9	2.17
chokes	2	.2	6	.6	3	1.0	6	2.5	5.14*
other	7	.7	13	1.3	5	1.7	6	2.5	
Total	157	16.3	302	30.3	120	42.0	94	38.5	32.26***
Frequency <sup>b</sup>									
(1) less than monthly	26	16.7	38	12.8	8	6.8	5	5.6	2.58
(2) 1-3 per month	43	28.1	78	26.2	25	21.2	38	42.2	
(3) 1-6 per week	60	39.0	111	37.2	50	42.4	29	32.2	
(4) 1-16 per day	21	13.7	67	22.5	33	28.0	16	17.8	
(5) 1 or more per hour	4	2.6	4	1.3	2	1.7	2	2.2	
Staff response <sup>b</sup>									
(1) no response	1	.6	3	1.0	0	-	1	1.1	1.48
(2) ignore, reinforce other behavior	14	8.7	31	10.2	5	4.2	7	7.4	
(3) verbal response	83	52.9	124	40.9	65	54.2	39	41.5	
(4) physical response	50	32.0	107	35.3	34	28.3	28	29.8	
(5) get help	9	5.7	38	12.5	16	13.3	19	20.2	

<sup>a</sup>Percent of all residents. Columns do not sum to total because some residents exhibited more than one type of behavior injurious to other people.

<sup>b</sup>Percent of residents who exhibited behavior injurious to other people.

\*  $p < .01$

\*\*  $p < .001$

\*\*\*  $p < .0001$

PRF new admissions who injured other people did so once a day or more often, compared with 23.8% of all injurious PRF residents and 16.3% of injurious CRF residents. One-way analysis of variance, however, indicated that the difference among groups on average frequency level of behaviors injurious to other people was not statistically significant.

Approximately 50% of behaviors injurious to other people elicited a verbal response from staff, and approximately 30% elicited a physical response. Compared to self-injurious behaviors, relatively few behaviors injurious to other people were systematically ignored. Among PRF readmissions, 20.2% of behaviors injurious to other people required the intervention of more than one staff person, compared with 13.3% of injurious PRF new admissions, 12.5% of all injurious PRF residents, and only 5.7% of CRF residents who injured other people. There was no statistically significant difference, however, in average level of staff response among the four resident groups.

#### Behavior That Damages Property

Property damage by residents is summarized in Table 17. The most common type of property damage consisted of breaking or damaging toys, furniture, or other objects and materials found within the residential facility. The second most common type of property damage involved the actual building structure, with some residents reported to punch holes in walls or doors, break windows or car windshields or damage light fixtures.

Among residents who damaged property, 5.4% in PRFs were reported to do so at least hourly, compared with 2.1% in CRFs. The average

Table 17

## Prevalence of Behaviors That Damage Property, Frequency, and Staff Response within Residential Facilities

Behavior/Frequency/Response	CRF		PRF		PRF		PRF		F
	residents		residents		new admissions		readmissions		
	N	%	N	%	N	%	N	%	
Behavior <sup>a</sup>									
breaks toys, furnishings, contents of building	79	8.2	107	10.7	29	10.1	31	12.7	2.25
breaks windows, doors, structural parts of building, cars	43	4.5	47	4.7	14	4.9	23	9.4	2.53
tears up or destroys clothing	21	2.2	59	5.9	18	6.3	11	4.5	5.77*
throws things, overturns furniture	11	1.1	46	4.6	12	4.2	20	8.2	10.50**
stuffs sinks, toilets with paper, etc.	2	.2	4	.4	4	1.4	1	.4	.93
breaks eyeglasses, hearing aids	2	.2	3	.3	2	.7	2	.8	.26
other	0	-	1	.1	0	-	0	-	
Total	107	11.1	175	17.6	55	19.2	57	23.4	8.56**
Frequency <sup>b</sup>									
(1) less than monthly	23	24.1	24	14.3	8	15.4	11	19.3	3.11
(2) 1-3 per month	34	34.7	44	26.2	17	32.7	23	40.4	
(3) 1-6 per week	22	22.3	58	34.5	13	25.0	12	21.1	
(4) 1-16 per day	16	16.9	33	19.6	14	26.9	10	17.5	
(5) 1 or more per hour	2	2.1	9	5.4	0	-	1	1.8	
Staff response <sup>b</sup>									
(1) no response	2	1.9	4	2.3	1	1.8	0	-	3.40
(2) ignore, reinforce other behavior	13	11.9	22	12.6	6	10.9	3	5.3	
(3) verbal response	62	58.9	71	40.8	24	43.6	28	49.1	
(4) physical response	23	21.7	48	27.6	15	27.3	15	26.3	
(5) get help	6	5.7	29	16.7	9	16.4	11	19.3	

<sup>a</sup>Percent of all residents. Columns do not sum to total because some residents exhibited more than one type of behavior that damages property.

<sup>b</sup>Percent of residents who damaged property.

\*  $p < .001$

\*\*  $p < .0001$

frequency level at which all property damage occurred, however, did not differ statistically among groups.

Relatively few behaviors that damaged property were ignored by staff. Approximately 17% of PRF residents who damaged property required the response of at least two staff members, compared with 5.7% of CRF residents who damaged property. Nevertheless, the average level of staff response did not differ significantly between CRF and PRF groups.

#### Unusual or Disruptive Behavior

Unusual or disruptive behaviors are reported in Table 18. This category included inappropriate verbal behaviors such as swearing, threatening, yelling, or talking too loud, or repeating meaningless phrases over and over. Inappropriate verbal behaviors were more common among CRF residents and among PRF readmissions than among PRF residents in general, no doubt partially because less than half of all PRF residents could talk. PRF residents were more likely to scream, cry, or make non-verbal noises than CRF residents were. Temper tantrums were the third most common type of disruptive behavior. As with other major categories of maladaptive behavior, the rank order by prevalence for various types of disruptive behavior was similar for CRFs and PRFs. Few residents were reported to be disruptive because of a general high activity level, although many were reported to receive medication for overactive behavior (15.7% of CRF residents; 29.9% of PRF residents).

Most disruptive residents engaged in this behavior less frequently than once per day; 22.7% of disruptive CRF residents and 34.4% of disruptive PRF residents were reported to be disruptive daily; and

Table 18

## Prevalence of Unusual or Disruptive Behaviors, Frequency, and Staff Response within Residential Facilities

Behavior/Frequency/Response	CRF		PRF		PRF		PRF		F
	residents		residents		new admissions		readmissions		
	N	%	N	%	N	%	N	%	
Behavior <sup>a</sup>									
inappropriate verbal behavior	100	10.4	81	8.1	30	10.5	42	17.2	4.28*
nonverbal, screams, cries, yells	63	6.5	101	10.1	38	13.3	28	11.5	3.56
temper tantrums	71	7.4	88	8.8	21	7.3	27	11.1	1.40
nuisance behavior: slams doors, flicks lights, water faucets	70	7.3	48	4.8	23	8.0	18	7.4	2.47
inappropriate sexual behavior	41	4.3	34	3.4	8	2.8	11	4.5	.45
throws or overturns things	22	2.3	24	2.4	13	4.5	8	3.3	.79
strange postures, mannerisms	19	2.0	19	1.9	9	3.1	3	1.2	.54
pesters, teases, seeks attention	17	1.8	13	1.3	2	.7	1	.4	.74
inappropriate social interaction	14	1.5	22	2.2	7	2.4	12	4.9	3.73
pushes, rough, aggressive	7	.7	15	1.5	4	1.4	3	1.2	1.28
high activity level	4	.4	13	1.3	8	2.8	3	1.2	1.48
other	30	3.1	57	5.7	17	5.9	14	5.7	
Total	278	28.8	342	34.3	108	37.8	100	41.0	4.86*
Frequency <sup>b</sup>									
(1) less than monthly	28	10.6	19	5.6	4	3.7	1	5.1	6.03**
(2) 1-3 per month	68	25.6	74	21.8	17	15.7	19	19.2	
(3) 1-6 per week	99	37.0	116	34.1	34	31.5	41	41.4	
(4) 1-16 per day	61	22.7	117	34.4	42	38.9	32	32.3	
(5) 1 or more per hour	11	4.1	14	4.1	11	10.2	2	2.0	
Staff response <sup>b</sup>									
(1) no response	6	2.2	7	2.1	5	4.6	1	1.0	1.40
(2) ignore, reinforce other behavior	54	19.7	76	22.6	15	13.9	25	25.0	
(3) verbal response	162	59.1	159	47.2	54	50.0	53	53.0	
(4) physical response	46	16.8	71	21.1	30	27.8	16	16.0	
(5) get help	6	2.3	24	7.1	4	3.7	5	5.0	

<sup>a</sup>Percent of all residents. Columns do not sum to total because some residents exhibited more than one type of unusual or disruptive behavior.

<sup>b</sup>Percent of residents who exhibited unusual or disruptive behavior.

\*  $p < .01$

\*\*  $p < .001$

approximately 4% of each group were reported to be disruptive at least hourly. Overall, the average frequency level of disruptive behaviors was higher for PRF residents and PRF new admissions than for CRF residents ( $p < .001$ ).

Most disruptive behaviors were ignored by staff or responded to verbally. The average level of staff response did not significantly differ among resident groups.

### Summary

Approximately half of all CRF residents were reported to have one or more maladaptive behaviors. The prevalence of most maladaptive behaviors was significantly higher in PRFs where 60% of all residents, including 68% of new admissions and 68% of readmissions, were reported to have behavior problems.

The frequency at which individual residents performed various behaviors and the manner in which staff responded to each type of behavior by each resident were reported for four major categories of maladaptive behavior. Frequency was reported according to five levels that ranged from "less than monthly" to "once or more per hour." On the average, the frequency at which CRF residents performed various maladaptive behaviors was similar to the frequency at which PRF residents with behavior problems performed the same behaviors. The only statistically significant difference in average frequency level was for the category that included unusual or disruptive behaviors: disruptive PRF residents were disruptive more frequently than disruptive CRF residents were.

The manner in which staff responded to acts of maladaptive behavior was reported according to five levels that ranged from "do nothing" to "get the help of an additional staff member." There was wide variation in the manner that staff responded to various behaviors and various residents. However, the average staff response level in CRFs was similar to the average staff response level in PRFs, suggesting that the amount of staff effort expended per maladaptive behavior incident was similar in PRFs and CRFs.

## IV. DISCUSSION

This study has shown that residents of public residential facilities are generally more limited in ability than community facility residents, and are more likely to have additional handicaps and behavior problems. Chronic health problems of PRF residents, however, were reported to be no more prevalent than health problems among CRF residents.

In comparing community residential facilities today with those that existed in 1974 (O'Connor, 1976), it is clear that there are now many more severely retarded individuals living in community facilities, and that their relative proportion is increasing. Since O'Connor's study the proportions of CRF residents with epilepsy, cerebral palsy, visual, or hearing handicaps have also increased dramatically. This change does not appear to result from definitional differences, because definitions were similar in the two studies. Correspondingly, comparing Scheerenberger's data on PRFs in 1974 (Scheerenberger, 1977), the proportion of mildly handicapped individuals in state operated facilities has decreased in recent years.

Most standards for residential services for retarded people are based upon the assumptions that every mentally retarded individual, no matter how severely handicapped, is capable of growth, learning, and development and should be given opportunities to make full use of these capacities. The Joint Commission for the Accreditation of Hospitals

Standards for Residential Facilities for the Mentally Retarded (JCAH, 1974) stated that facilities should make every attempt to move residents from more structured, more dependent to less structured, more independent living, and from larger segregated facilities to smaller, more socially integrated living arrangements.

It is possible to match residents' needs with appropriate levels of care in residential facilities. Budde (1976) proposed a system of classifying residential living environments according to the degree of physical and social integration offered to residents, and Heiny and Stachowiak (1976) suggested a model for matching levels of residents' needs with the characteristics of residential facilities. The Behavioral Characteristics Assessment used in the present study conceptualized residents' needs in terms of levels of independence that have direct implications regarding appropriate level of care.

Results of the study indicate that CRFs, as well as PRFs, are serving residents at all levels of independence, although in considerably different proportions. Fifteen percent of community facility residents, those at or below level 1 of the Behavioral Characteristics Assessment, were dressed, fed, and otherwise directly physically assisted in all daily activities. Forty-one percent of public facility residents required a similar level of care.

In deciding when and where to place residents, emphasis has often been on selecting certain residents who can be expected to fit into one of a limited number of available residential placements. The availability of appropriate community residential facilities, which are

especially in undersupply for severely and profoundly retarded people, often dictates placement in a PRF as the only alternative. It is, perhaps, surprising that deinstitutionalization has progressed as far as it has, given the fact that the development of community residential facilities has relied more upon the spontaneity, good intentions, and entrepreneurial motivations of facility developers than upon organized efforts to establish residential services tailored to match the characteristics of all people who need them. A "buyers market," from the standpoint of CRF operators, served adequately when public institutions housed relatively large numbers of mildly handicapped individuals. This is no longer the case, however. Although approximately 150,000 mentally retarded persons remain in public residential facilities or psychiatric hospitals (Krantz, Bruininks, & Clumpner, 1979), the number of new community residential facilities opening each year may no longer be increasing (Bruininks, Hauber, & Kudla, 1979).

A planning model must be developed to use information about residents' characteristics to estimate the number of community placements needed, and to specify desirable characteristics of residential facilities in terms of residents' needs. To make such planning possible, residents' characteristics must be assessed in a manner that results in information that is useful for planning. With planning in mind, it is of relatively little use to know that most residents are severely retarded per se, or that they have certain standardized test scores for an arbitrarily selected norm group.

The present study assessed residents' behavioral characteristics according to specific levels of independence. For example, Table 4 indicated that 18.8% of public facility residents were below the first level of independence. Applying this proportion to the 151,972 total PRF population in 1977, it could be estimated that approximately 28,000 PRF residents needed residential placements that could provide total care or one-to-one assistance for all activities. CRFs have demonstrated that they are capable of providing care for severely handicapped residents: 7.2% (approximately 4500) of all residents in CRFs in 1977 were nearly totally dependent. Many additional community facilities offering a similar level of care would be needed to serve the equally dependent residents remaining in PRFs. Each of this study's levels of independence offer direct implications for an appropriate level of care, ranging from constant assistance to minimal supervision in semi-independent living arrangements.

Nevertheless, matching resident ability level with the basic level of care offered by a residential facility does not alone assure success in residential placement. PRF readmissions, most of whom had presumably failed to succeed in various community residential facilities, demonstrated basic ability levels that closely matched those of residents remaining in the CRF population. They differed in other respects, however. The prevalence of maladaptive behavior was much higher among PRF readmissions than among CRF residents.

Because of the exploratory nature of this study, no attempt was made to develop a precise psychometric measure of maladaptive behavior.

Data on prevalence, frequency, and staff response to maladaptive behavior are, however, useful in understanding how these behaviors affect residential placement. Generally, results of this study suggest that community residential facilities can successfully manage the same maladaptive behaviors that public facilities can, although at present these problem behaviors are exhibited by a smaller proportion of CRF residents. A great variety of maladaptive behaviors were reported, including many that the general public would consider quite unusual. Yet there was only one single behavior reported among PRF residents that was not also reported among CRF residents (attempts to set fires) and its incidence was so low as to make it difficult to draw conclusions from this sample (0 CRF residents; 0 PRF residents; 0 PRF new admissions; 3 PRF readmissions).

Even though all types of maladaptive behavior occurred in at least some CRFs, it is possible that there may be a qualitative difference in maladaptive behaviors of PRF and CRF residents. It might be argued that CRF residents who injure other people, for example, do not injure them as badly or as frequently as PRF residents do. In an attempt to examine this issue, the study considered specific behaviors--specific types of behavior that injure other people, for example--and investigated the frequency at which various acts were performed. Generally, CRF residents who exhibited a certain behavior performed it just as frequently as PRF residents did; for example, CRF residents who bite other people were reported to bite just as frequently as PRF residents who bite other people were reported to bite.

It might also be argued, however, that PRF residents bite harder than CRF residents bite, a question of severity. There is no commonly accepted way of measuring the severity of maladaptive behavior. The present study gathered information on how staff responded to specific maladaptive acts of each resident. It was hypothesized that from a resident management perspective as it affects staff, residents, and the day-to-day operation of a residential facility, staff response could be a measure of the seriousness of the problem a particular behavior caused.

Five levels of staff response were reported. The data indicate that on the average, CRF staff responded to maladaptive behaviors among CRF residents at the same level that PRF staff responded to maladaptive behaviors among PRF residents. This does not prove that maladaptive behaviors of PRF residents are no more severe than maladaptive behaviors of CRF residents. Staff response might be influenced by a number of other factors. Physically handicapped or non-verbal residents, for example, may be more likely to elicit physical responses, regardless of the severity of the behavior. Nevertheless, from a behavior management standpoint the actual response required of staff may be more important than the cause of the response.

Another limitation of using staff response as a measure of the seriousness of a behavior might be that different staff have different expectations or may tolerate certain behaviors differently. It is possible, for example, that because of the relatively closed environments of most PRFs and because of a high prevalence of maladaptive behavior, PRF staff might be more tolerant, that they might "put up with more,"

and therefore their overall level of response, which was the same as the overall level of CRF staff response, might not reflect that the maladaptive behaviors of PRF residents are more severe than the behaviors of CRF residents.

Several analyses were conducted to examine the possibility that the staff response measure was influenced by factors other than the actual severity of behaviors. A series of one-way analyses of variance indicated that the staff response measure successfully discriminated among different types of maladaptive behavior. A specific behavior such as "bites people" was reported to elicit a statistically significantly higher average level of staff response than a milder behavior such as "pushes people." Although factors other than the maladaptive behavior itself may have influenced staff response, they did not prevent the measure from discriminating among behaviors.

Further analyses indicated that, for specific types of behavior, there were no statistically significant differences between the average level of response of CRF and PRF staff. Although the degree to which various maladaptive behaviors are tolerated may vary among individuals, PRF staff and CRF staff consistently responded to identical types of behavior in a similar manner, i.e., the average level of staff response was the same on a behavior-by-behavior basis.

It seems evident that by maintaining adequate staff to resident ratios and by using adequate behavior management practices, at least some CRFs manage the same maladaptive behaviors that are evidenced by PRF residents. As was the case when considering resident ability, the

problem of too few CRF placements is a problem of availability. It has not been demonstrated that community facilities cannot cope with behavior problems.

Nevertheless, CRFs have more latitude than PRFs in selecting residents whom they choose to admit or demit. Therefore, fewer residents with behavior problems are likely to be admitted to CRFs than to PRFs. In this study behavior problems were cited by staff or in records as contributing factors in placement decisions for 32.8% of PRF residents (54% of those who had been admitted from community facilities). Among CRF residents, however, behavior problems were reported as a contributing factor for only 9.4% of placements. These statistics imply that CRFs are relatively less likely to admit residents with maladaptive behavior, and perhaps more likely to demit them for placement in a publicly operated facility.

Other research studies have reported a generally high prevalence of maladaptive behavior among retarded people (cf. Eyman & Call, 1977). The present study reported similar prevalence figures. It is important, however, to elaborate on these findings. In non-handicapped populations, many maladaptive behaviors are accepted, ignored, or tolerated. In this study, CRF staff reported that 30.1% of their residents exhibited at least one of four major categories of maladaptive behavior. Half of these behaviors, however, never required more than a verbal response from staff and never occurred more than once daily. If these behaviors were excluded, only 18.8% of CRF residents would be considered to have behavior management problems within the four major categories.

Under the same criteria (either more than once per day or more than a verbal response), 36.1% of all PRF residents, 42.2% of PRF new admissions, and 44.5% of PRF readmissions would be considered to exhibit behavior management problems.

Similarly, for less than half the CRF residents who were reported to have behavior problems did staff feel that the problem affected the resident's ability or opportunity for more community interaction; less than half of those who were reported to refuse to go to day programs had actually stayed at home during the last month; only 62% of those reported to have run away had actually done so in the past six months; and for only 50% of those reported to damage property did the staff report that there had been any repair cost during the last month.

There appears to be a wide range in the degree to which CRFs are prepared to cope with behavior problems. In many of the community facilities included in this study, residents with a multitude of severe behavior problems were accommodated and extensive efforts were made to modify maladaptive behavior. In other facilities, residents whose only maladaptive behavior was being "generally uncooperative" or screaming "once a week or so" were reported to be in danger of demission. In this respect, residents' prospects for successfully remaining in a community facility depended to a large extent upon the characteristics of the community facility that they were living in.

Residential facility characteristics and support services are also important as they relate to residents' health care needs. It is difficult to make generalizations about health care in residential

facilities. Nelson and Crocker (1978) suggested that the dissolution of medical authority in response to an inter-disciplinary model, marginal medical staffing, diversity of judgments about what constitutes appropriate medical intervention, and the fact that most PRF hospital or infirmary units lack much of the diagnostic and support equipment available in community general hospital settings are among the many considerations which suggest that public residential facilities are not necessarily best able to deal with health care needs.

Although the present study found little or no difference between PRF and CRF residents with regard to the prevalence of chronic health problems or health maintenance that required medical care, health problems have frequently been cited as reasons for institutionalization. This study is not the first to question the factual basis of this claim. Pagel and Whitling (1978) found that the greatest number of health problems resulting in readmissions to the institutions they studied occurred among profoundly retarded people from community facilities called convalescent hospitals. The convalescent hospitals, which by law provided 24-hour skilled nursing care, were better equipped than other community facilities to handle health-related problems. They stated that:

. . . few of the health problems leading to readmission were of a life-threatening nature and most could have been treated by a physician in the community in conjunction with the nursing care available at the convalescent hospital. . . . Conceivably, when a resident's behavior or health requires more than the normal amount of supervision and care the placements return their client to the institution and substitute him or her with a more "healthy" or "well-behaved" individual. This practice--if real--is economically productive since the same reimbursement policies apply to residents, whether or not they become more difficult. (p. 166)

Quality health care should be an integral component of all types of residential facilities. However, the presence of medical and nursing staff must be differentiated from residents' actual need for health care. It cannot be assumed that residents have health problems or need intense medical care just because a facility has medical staff, nor can it be assumed that the presence of medical staff assures the most satisfactory residential placement for a resident.

According to staff reports, residents were more likely to see a doctor because of temporary illnesses and injuries than because of chronic illnesses. Nearly half of PRF readmissions (45.8%) had seen a doctor within a year (or since readmission if less than one year) because of a temporary illness, compared to 32.5% and all PRF residents and 24.4% of CRF residents. Past studies of the relocation of residents who are transferred from one facility to another (e.g., Cochran, Sran, & Varano, 1977) have suggested that health problems may develop from stress associated with transfer. The relative frequency of illnesses among all resident groups may suggest the desirability of future research on the prevention of temporary illnesses in residential facilities. Prevention might also reduce the frequency of accidents and injuries requiring a doctor's care, which were three times as frequent in PRFs (17.7% of residents in one year) as in CRFs (5.6% of residents). Pierce (1977) also reported a high rate of injuries in a Canadian institution. The pain and possible permanent harm caused to residents as well as the costs associated with medical care or even hospitalization of injured residents must be considerable.

The present study reported that although many CRF residents have handicaps in addition to mental retardation, PRFs continue to serve larger proportions of residents with epilepsy, vision or hearing problems, and physical handicaps. Approximately 20% of PRF residents were nonambulatory, compared with approximately 10% of CRF residents. Since O'Connor's national study of community facilities in 1974 (O'Connor, 1976), however, the proportions of CRF residents with cerebral palsy, epilepsy, hearing, and visual handicaps have approximately doubled.

Many quality residential alternatives have been created during recent years. Community facilities, when properly managed, have demonstrated that they can meet the needs of handicapped individuals for whom institutionalization was previously the only alternative. The data indicate that there are community residential facilities for some very severely handicapped individuals with multiple physical and behavioral disabilities, as well as for less disabled residents who are approaching independence. Yet there are presently far from enough community facilities to serve the residents remaining in public facilities, most of whom require high levels of care, and many who have additional handicaps or maladaptive behavior.

Information about mentally retarded people who need residential care must be put to use and incentives must be developed to encourage the provision of additional community residential services. There are gross discrepancies between the financial and technical resources available to community and public facilities. Too often, residential care providers are expected to operate with insufficient funds (Wieck &

Bruininks, 1980) and insufficient staff (Lakin, 1981). Yet providers are sometimes viewed with suspicion, criticized for profits, perhaps expected to "bite off more than they can chew," and to do so eagerly with few incentives, few rewards, and little sense of direction. Support is needed to solve problems that relate to attaining adequate staff ratios, staff training, acquiring appropriate buildings, and to characteristics of cooperating community agencies and generic services, which all influence a residential facility's ability to constructively deal with its residents' behavioral and physical characteristics, health care needs, and maladaptive behaviors.

Nonambulatory residents, for example, require accessible buildings. Many CRFs have been established in existing homes or buildings that are not accessible and cannot be easily modified. New construction requires financing that is not easily obtained, and PRFs are often required to compete for the same funds in order to be remodeled to comply with federal standards.

Attention should also be directed toward residential facility staff. The availability of an adequate number of staff who are skilled in behavior modification techniques could ameliorate many residents' maladaptive behaviors. Community facilities need the resources to interact constructively with residents on a day-to-day basis. Periodic consultation is not enough to help a group home that can afford to employ only one or two counselors to cope with 10 residents, 4 who are not toilet trained, 5 who cannot talk, 2 who cannot walk, 6 who have an additional handicap, 2 who have a chronic health problem, and 6 who have

at least one maladaptive behavior (averages for residents now in PRFs).

Organized planning based upon factual information about the characteristics of residents could be used to plan and develop residential living alternatives, to estimate types and number of community facilities needed, appropriate staff ratios, and the kinds of services necessary to provide quality programs. The continued depopulation of institutions will depend on greater numbers of specialized facilities and greater numbers of persons willing and able to work in them. This report represents a first step--it provides information which could be used for planning and for promoting incentives that would encourage the development of adequate numbers of appropriate facilities.

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Facility ID \_\_\_\_\_

Resident ID \_\_\_\_\_

Care Person ID \_\_\_\_\_

RESIDENTIAL FACILITIES FOR  
MENTALLY RETARDED PEOPLE

# PERSONAL RECORD SHEET

Please provide the following information for the above named resident from his or her records:

1. Sex:  1. MALE  2. FEMALE

2. Date of Birth: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
MONTH DAY YEAR

3. Weight: \_\_\_\_\_ LBS. 4. Height: \_\_\_\_\_ FT. \_\_\_\_\_ INS.

5. Degree of retardation from most recent evaluation:

- |   |  |
|---|--|
| <input type="checkbox"/> 1. Borderline (IQ 69-84) | <input type="checkbox"/> 4. Severe (IQ 20-35)          |
| <input type="checkbox"/> 2. Mild (IQ 52-68)       | <input type="checkbox"/> 5. Profound (IQ 19 and below) |
| <input type="checkbox"/> 3. Moderate (IQ 36-51)   | <input type="checkbox"/> 6. Unknown                    |

6. What is his or her race or ethnic background?

- |   |   |
|---|---|
| <input type="checkbox"/> 1. White                     | <input type="checkbox"/> 4. American Indian or Alaskan Native |
| <input type="checkbox"/> 2. Black                     | <input type="checkbox"/> 5. Hispanic                          |
| <input type="checkbox"/> 3. Asian or Pacific Islander | <input type="checkbox"/> 6. Unknown                           |

7. Date of current admission to this facility: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
MONTH DAY YEAR

8. Is there any reason stated in the records why he or she was admitted to this particular facility? If yes, what is it?

---



---



---

9. Has he or she ever lived in this facility prior to the current admission date? (Exclude trial visits, and respite care arrangements.)

1. YES  5. NO

10. What type of home or facility did he/she live in immediately before coming here?

01. Foster or family care home
  07. Boarding home  
 02. Group home or community residential facility with 1-15 residents
  08. Nursing home  
 03. Community residential facility with 16 or more residents
  09. Public institution  
 04. Semi-independent living (e.g., supervised apartments)
  77. Other (Please Specify): \_\_\_\_\_  
 05. Natural/adoptive home  
 06. Independent living
  88. No information in records

10a. Has resident ever lived in a residential facility prior to his/her current placement here?

1. YES
  5. NO
  8. DON'T KNOW

11. How long did he or she live in residence/home mentioned in question 10? \_\_\_\_\_ YEAR

12. Is there any reason given in the records why he or she left the (facility/home) mentioned in question 10? If yes, what is it?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

13. Do his or her records show a history of seizures at any time during his or her life?

1. YES
  5. NO

13a. What type of seizures?

1. Petit Mal
  2. Grand Mal
  3. Other (please specify) \_\_\_\_\_
  4. Records do not specify type

14. In addition to evidence of his or her mental retardation, do the records show autism or mental illness of any kind?

1. Yes, autism
  3. Yes, mental illness
  5. No, neither

15. Is the resident legally adjudicated incompetent?

1. YES
  5. NO
  8. Don't Know

APPENDIX B

Behavioral Characteristics Assessment

	Page
Behavior Description Booklet . . . . .	83
Instructions to Interviewer . . . . .	91
Interviewer's Instructions to Care Person (Respondent).	92

Facility ID# \_\_\_\_\_

Care Person ID# \_\_\_\_\_

Resident ID# \_\_\_\_\_

# RESIDENTIAL FACILITIES FOR MENTALLY RETARDED PEOPLE BEHAVIOR DESCRIPTION BOOKLET

## INSTRUCTIONS

Each of the questions you are about to answer is preceded by four possible answers, for example:

<u>YES</u> Does it well with no reminder, or functions beyond this level.	<u>NO, DOES NOT</u> too hard	<u>NO, DOES NOT</u> needs to be coaxed or reminded	<u>NO, DOES NOT</u> would do it well but has no opportunity	
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Eats a family style meal using all normal utensils with no spilling.

You are to put an "X" in the appropriate circle for each item. Mark *one* circle for *every* item.

YES

Does it well with  
no reminder, or  
functions beyond  
this level.



The resident has completely mastered this skill and always does it well by himself without help and without having to be reminded or coaxed, OR the item is too easy, something that is no longer appropriate.

NO, DOES NOT

too  
hard



The resident does not do this activity well without help because it is too hard, he hasn't learned it, OR because of a physical handicap.

NO, DOES NOT

needs to be  
coaxed or  
reminded



The resident has done this activity well without any help when he has had to, but he doesn't do it without being told, coaxed, or repeatedly reminded.

NO, DOES NOT

would do it  
well but has  
no opportunity



You are positive that the resident can do this activity well, without help; but he is not allowed to do it for some reason. He may not have the opportunity to do the activity or it may be against the rules.

**YES**  
Does it well with  
no reminder, or  
functions beyond  
this level.

**NO, DOES NOT**  
too  
hard      needs to be  
coaxed or  
reminded      would do it  
well but has  
no opportunity

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### A. Eating and Meal Preparation

1. Feeds self with fingers.
2. Eats a complete meal with a knife, fork, and spoon with little spilling.
3. Prepares a snack that doesn't require cooking (such as a sandwich or bowl of cereal) without supervision.
4. Mixes and cooks simple foods such as scrambled eggs or hamburgers on a range without direct supervision.
5. Cooks a complete hot meal with help only in planning.
6. Independently plans, shops for groceries, and cooks complete hot meals.

**YES**  
Does it well with  
no reminder, or  
functions beyond  
this level.

**NO, DOES NOT**  
too  
hard      needs to be  
coaxed or  
reminded      would do it  
well but has  
no opportunity

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### B. Dressing

1. Cooperates by holding out arms and legs while being dressed.
2. Dresses self completely and correctly except for some fastenings such as zippers or shoelaces.
3. Dresses self completely and correctly including buttons and belts and shoelaces.
4. Independently selects appropriate clothing for various situations and weather conditions.
5. Independently selects and buys correct size and style of clothing and accessories in a store.
6. Independently sews back on buttons that have fallen off clothing.

**YES**  
Does it well with  
no reminder, or  
functions beyond  
this level.

**NO, DOES NOT**  
too  
hard      needs to be  
coaxed or  
reminded      would do it  
well but has  
no opportunity

### C. Toileting

- |                       |                       |                       |                       |   |
|-----------------------|-----------------------|-----------------------|-----------------------|---|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 1. When taken to the bathroom at appropriate times, uses the toilet, but may still have frequent accidents unless reminded.             |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 2. Uses the toilet independently with few reminders (including removing and replacing clothing), with less than one accident per month. |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 3. In new surroundings, finds or asks where the bathroom is.  |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 4. Always closes the bathroom door when bathing, using the toilet, or in need or privacy.   |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 5. Locates and properly uses the correct men's or women's rest-room in a restaurant or public building.                                 |

**YES**  
Does it well with  
no reminder, or  
functions beyond  
this level.

**NO, DOES NOT**  
too  
hard      needs to be  
coaxed or  
reminded      would do it  
well but has  
no opportunity

### D. Personal Self Care

- |                       |                       |                       |                       |   |
|-----------------------|-----------------------|-----------------------|-----------------------|---|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 1. Holds hands under running water for washing.   |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 2. When asked, applies toothpaste, brushes teeth and rinses mouth and toothbrush.   |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 3. Adjusts water faucets for proper temperature in sink or bathtub.   |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 4. Prepares and completes bathing, including washing and drying hair, at regular intervals or as needed without reminder. |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 5. Without reminders, keeps self clean and well groomed overall (hair cuts, make-up, filing nails, etc.).                 |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 6. Independently goes to doctor, dentist, clinic as needed for routine health care or illness.                            |

**YES**

Does it well with  
no reminder, or  
functions beyond  
this level.

**NO, DOES NOT**

too  
hard

needs to be  
coaxed or  
reminded

would do it  
well but has  
no opportunity

**E. Language Comprehension**

1. Responds appropriately to simple words and gestures such as "sit down" or "come here".
2. Follows simple one part directions which include a preposition such as "Put your coat in the closet".
3. Follows two part directions in order. For example: "First hang up your coat and then find the book".
4. Follows verbal directions about how to put things together or take them apart, how to operate appliances, and so on.
5. Could summarize a story or what happened in a movie or TV program.
6. Understands and remembers information presented by a speaker to a group of about 20 people such as in a classroom or club meeting.

**YES**

Does it well with  
no reminder, or  
functions beyond  
this level.

**NO, DOES NOT**

too  
hard

needs to be  
coaxed or  
reminded

would do it  
well but has  
no opportunity

**F. Language Expression**

1. Shakes head or otherwise indicates yes or no in response to a simple question like "Do you want some milk?"
2. Says at least ten words that can be understood by someone who knows him/her.
3. Speaks (or signs) in short sentences.
4. Uses complex sentences containing "and," "because," etc. For example: "I'm not going outside today because it's raining".
5. Carries on a meaningful ten minute social conversation with someone he/she knows casually.
6. Calls the landlord or a repairman if something major around the house breaks down.

YES  
Does it well with  
no reminder, or  
functions beyond  
this level.

NO, DOES NOT  
too  
hard      needs to be  
coaxed or  
reminded      would do it  
well but has  
no opportunity

### G. Social Interaction

- |                       |                       |                       |                       |   |
|-----------------------|-----------------------|-----------------------|-----------------------|---|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 1. Responds to the presence of another person by smiling or turning head.   |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 2. Plays catch or another simple game with another person.  |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 3. Takes part in simple group games and social activities such as parties.  |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 4. Acts appropriately (does not draw people's attention) when alone in a routine public situation, such as in a store.        |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 5. Uses a telephone independently, including finding the number and placing the call, to get information and talk to friends. |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 6. Plans and entertains others in own residence — provides food, beverage and appropriate activity.                           |

YES  
Does it well with  
no reminder, or  
functions beyond  
this level.

NO, DOES NOT  
too  
hard      needs to be  
coaxed or  
reminded      would do it  
well but has  
no opportunity

### H. Domestic Activities

- |                       |                       |                       |                       |  |
|-----------------------|-----------------------|-----------------------|-----------------------|--|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 1. If handed an empty dish, will set it down on a table or sink in appropriate circumstances.  |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 2. When given a damp cloth, wipes a counter or table in appropriate circumstances.   |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 3. Finds something to do or asks if there is something to do when he/she is unoccupied for more than 15 minutes.                           |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 4. Demonstrates the physical and mental ability to get out of the house safely alone in case of a fire.                                    |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 5. Independently determines by looking at a clock when it is time to go to school or work, eat, or to be home.                             |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 6. Independently loads and operates an automatic clothes washer and dryer, including correct settings and appropriate amount of detergent. |

YES  
Does it well with no reminder, or functions beyond this level.

NO, DOES NOT  
too hard      needs to be coaxed or reminded      would do it well but has no opportunity

**I. Community Orientation**

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

1. Finds favorite toys or objects that are always kept in the same place.
2. If asked to go to a certain room at home or in a familiar building, finds own way correctly.
3. Goes outside unsupervised in an unfenced yard for ten minutes without wandering away or getting lost.
4. Goes four blocks from home, school, or work alone or with peers without getting lost.
5. If lost, asks directions, telephones for help, or otherwise regains sense of direction and finds planned destination.
6. Locates or follows directions to a specific street address several miles away.

YES  
Does it well with no reminder, or functions beyond this level.

NO, DOES NOT  
too hard      needs to be coaxed or reminded      would do it well but has no opportunity

**J. Value and Money**

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

1. When given a choice between two objects or toys, usually points at or otherwise indicates which of the two he/she prefers.
2. Persistently points at or names things that he/she sees or wants.
3. Shows that he/she knows money or tokens have value because will trade something for them or do something to earn them.
4. Without supervision, uses money to make minor purchases at local stores or fast food restaurants (but need not count change correctly).
5. Budgets transportation and/or recreation money to last an entire week.
6. Counts out exact amount of change for a purchase of \$5.00 or less.

**YES**  
Does it well with  
no reminder, or  
functions beyond  
this level.

**NO, DOES NOT**  
too  
hard      needs to be  
coaxed or  
reminded      would do it  
well but has  
no opportunity

### K. Reading and Writing

- |                       |                       |                       |                       |   |
|-----------------------|-----------------------|-----------------------|-----------------------|---|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 1. Looks at pictures in a book or at a TV program for at least a few minutes at a time.   |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 2. Identifies a printed example of his/her first name from a group of names; for example on lockers or over coat hooks.                 |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 3. Prints own first name with an example to look at.  |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 4. Prints or writes first and last name with no example to look at.   |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 5. Reads and understands written sentences and simple instructions well enough to follow directions; for example, on a box of cake mix. |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | 6. Completes short application forms.   |

Please check your booklet to see that you have marked *one* circle for *every* item.

Thank you.

Instructions to Interviewer

Read the instructions first, then allow respondent to study each of the four responses criteria before asking if he/she has any questions.

If you sense that he is at all unclear about what he is to do, go over the first section with him, helping with each answer so that he understands he is to mark one of the four circles for every item.

Be sure that respondent understands that in order to pass an item (get a Yes), the resident must be able to do an activity well, without help, and he/she must do it whenever it needs to be done without having to be told, coaxed, or repeatedly reminded unless the item specifically states that a reminder is acceptable as in "When asked, resident . . ."). He would also be rated yes, of course, if the resident is beyond that behavior as in the case of A1 "Feeds self with fingers" for those residents who eat with a knife and fork.

Use as a standard for what constitutes "repeatedly reminded" the same standard as you would use for yourself. In other words, a resident gets a "Yes" for an item if he/she does it well and does it on his/her own. Items within each area are arranged roughly in order of difficulty. If the first few items are so easy that they were learned long ago and are no longer appropriate (e.g., "Holds hands under running water for washing") score them "Yes" so resident gets credit for these easy items.

"No, does not, needs to be coaxed or reminded" means that a resident knows how to do a skill well, without help, but does not do it when it needs to be done--for example, a resident who knows perfectly well how to blow his/her nose, but who often has a running nose unless someone tells him/her to blow it. Be sure the respondent understands that this alternative gets at the need to be reminded or coaxed, not that he/she needs help or that he only performs an activity half well or well half of the time. Resident does skill well, but not on his/her own.

"No, does not, too hard" should be marked if resident needs any kind of help to perform an activity or if he/she does the activity in a sloppy manner or in a way that later needs to be redone. If the resident has a PHYSICAL HANDICAP that prevents him/her from performing an item, also score it "No, does not, too hard." Remind respondent, if he/she asks about the physical handicap, that we will take the physical handicap into consideration in the "Physical Characteristics" section of the questionnaire. Any item which isn't done well, or isn't done without help, should be scored "No, does not, too hard."

"Would do it well, but has no opportunity" is the alternative which may be used in the case where a resident would ordinarily receive a "Yes," -- that is, he/she would do the activity well on his/her own and without reminding, but he/she is not permitted to, either because it is against the rules (e.g., against the rules to go into the kitchen) or because the opportunity isn't available (e.g., the kitchen is in another building) so resident can't make sandwiches, for example, even though he already knows how to do it well and actually would to it right now if given the chance.

If respondent comments that the items in the booklet either cover too wide a range of ability or that they don't cover enough skills, or that residents who are very retarded don't pass any items at all, tell him/her that we are aware of this concern, but for the purposes of this survey, we don't need that same detail that would be needed for developing habilitation plans. This evaluation will provide enough detail to enable us to get a good idea about how independent a resident is, which is all we need to know.

Interviewer's Instructions to Respondent

"And now, finally, I'd like you to fill out this Behavior Description Booklet for (RESIDENT)." (HAND RESPONDENT BEHAVIOR DESCRIPTION BOOKLET.)

INTERVIEWER: READ ALL INSTRUCTIONS IN BOX BELOW IF RESPONDENT IS FILLING OUT BOOKLET FOR THE FIRST TIME.

"This booklet describes a series of behaviors in different categories. I'd like you to score each behavior description with regard to (RESIDENT). There are four ways to score each one. Please take a few minutes to read the instructions." (ALLOW PLENTY OF TIME.)

"You may ask any questions as you go along. Mark one answer for every item -- even those that are too easy or too hard. Some items, such as "eats with fingers" may describe skills which were mastered long ago and do not describe the resident's present behavior. Score these items in the first circle along with "Yes, does it well or functions beyond this level." Some residents may not be able to perform any of these skills. Score each item "No, too hard" for such residents."

IF RESIDENT USES SIGN LANGUAGE:

"Any item that calls for language can be interpreted to mean sign language. 'When asked' can be interpreted to mean 'When asked in signs.'"

IF RESIDENT HAS A PHYSICAL HANDICAP:

"If (RESIDENT) can't do something because of (his/her) physical handicap, score it 'No, too hard' and we'll know what it means because we asked about physical handicaps earlier in the questionnaire."

ASK EVERYBODY: "Do you have any questions?"

IF RESPONDENT IS AT ALL UNCLEAR, GO THROUGH FIRST SECTION WITH (HIM/HER).

"Let's go through the first area of behavior together."

1. Feeds self with fingers. "How would you score this?"

READ ALL SIX ITEMS IN EATING SECTION AND MAKE SURE RESPONDENT UNDERSTANDS THE SCORING INSTRUCTIONS AND THAT HE/SHE COMPLETES EVERY ITEM.

2. Eats a complete meal with knife, fork, and spoon with little spilling.

3. Prepares a snack that doesn't require cooking, such as a sandwich or bowl of cereal, without supervision.

4. Mixes and cooks simple foods such as scrambled eggs or hamburgers on a range without direct supervision.

5. Cooks a complete hot meal with help only in planning.

6. Independently plans, shops for groceries, and cooks complete hot meals.

BE SURE TO CHECK BOOKLET TO SEE THAT ALL ITEMS ARE MARKED WITH ONE ALTERNATIVE.

APPENDIX C

Care Personnel Questionnaire:  
Health and Physical Characteristics

	Page
Section A: Physical Characteristics . . . . .	96
Section G: Utilization of Services . . . . .	102

for office use only

RESIDENTIAL FACILITIES FOR  
MENTALLY RETARDED PEOPLEProject 12  
Fall, 1978
**SURVEY RESEARCH CENTER**  
 INSTITUTE FOR SOCIAL RESEARCH  
 THE UNIVERSITY OF MICHIGAN

1. Interviewer's Label

2. Facility ID: \_\_\_\_\_
3. Resident ID: \_\_\_\_\_
4. Care Person ID: \_\_\_\_\_
5. Your Interview Number: \_\_\_\_\_
6. Date of Interview: \_\_\_\_\_
7. Length of Interview \_\_\_\_\_  
(minutes)
8. Additional time for Forms: + \_\_\_\_\_  
(mins)
9. Total Time: \_\_\_\_\_  
(minutes)
10. Length of Edit \_\_\_\_\_  
(minutes)

# CARE PERSONNEL QUESTIONNAIRE

 THE FOLLOWING STATEMENT MUST BE READ

Your participation in this research is completely voluntary.  
 If we should come to any question you feel you can't answer  
 just let me know and we'll go on to the next question.

INTERVIEWER: YOU MUST HAVE THE COMPLETED PERSONAL RECORD SHEET  
 FOR THIS RESIDENT BEFORE TAKING THIS INTERVIEW.

EXACT TIME NOW: \_\_\_\_\_

## SECTION A: PHYSICAL CHARACTERISTICS

INTERVIEWER: CHECK PERSONAL RECORD SHEET AND ASK CARE PERSON ABOUT ANY MISSING INFORMATION.

First of all we need to get an idea of (RESIDENT'S) physical condition and capabilities.

A1. Besides being mentally retarded, does (RESIDENT) have any of these other disabilities:

	YES (1)	NO (5)
a. Deaf or hearing impaired?		
b. Blind or visually impaired?		
c. Cerebral palsy?		
d. Other physical handicap? (What kind?) _____		
e. Anything else? (What?) _____ _____		

A2. Does (RESIDENT) have a hearing aid?

1. YES

5. NO

A2a. To your knowledge, does (he/she) wear it at least half the time?

1. YES      5. NO

A2b. (RESPONDENT BOOKLET, P. 1) Which of these best describes how well (he/she) hears with the hearing aid?

1. NO DIFFICULTY WITH HEARING

SOME DIFFICULTY, CAN HEAR  
2. MOST OF THE THINGS A PERSON SAYS

GREAT DIFFICULTY, CAN HEAR  
3. ONLY A FEW WORDS SAID OR LOUD NOISES

4. DEAF OR NO USEABLE HEARING

8. DON'T KNOW

TURN TO P. 3, A3

A2c. (RESPONDENT BOOKLET, P. 1) Which of these best describes how well (he/she) hears (without it)?

1. NO DIFFICULTY WITH HEARING

SOME DIFFICULTY, CAN HEAR  
2. MOST OF THE THINGS A PERSON SAYS

GREAT DIFFICULTY, CAN HEAR  
3. ONLY A FEW WORDS SAID OR LOUD NOISES

4. DEAF OR NO USEABLE HEARING

8. DON'T KNOW

TURN TO P. 3, A3

A3. Does (he/she) have glasses?

<div style="border: 1px solid black; padding: 5px; margin-bottom: 10px; width: fit-content; margin: 0 auto;">1. YES</div> <p style="text-align: center;">↓</p> <div style="border: 1px solid black; padding: 10px;"> <p>A3a. Is (he/she) supposed to wear them all the time?</p> <div style="margin-top: 10px;"> <div style="border: 1px solid black; padding: 2px; margin-bottom: 5px; width: fit-content;">1. YES, ALL THE TIME</div> <div style="border: 1px solid black; padding: 2px; margin-bottom: 5px; width: fit-content;">5. NO, ONLY OCCASIONALLY</div> <div style="border: 1px solid black; padding: 2px; margin-bottom: 5px; width: fit-content;">8. DON'T KNOW</div> </div> <p style="margin-top: 10px;">A3b. To your knowledge, <u>does</u> (he/she) wear them at least half the time?</p> <div style="margin-top: 10px; display: flex; justify-content: space-around;"> <div style="border: 1px solid black; padding: 2px; width: 40px; text-align: center;">1. YES</div> <div style="border: 1px solid black; padding: 2px; width: 40px; text-align: center;">5. NO</div> </div> <p style="margin-top: 10px;">A3c. (RESPONDENT BOOKLET, P. 2) Which of these best describes how well (he/she) sees with (his/her) glasses?</p> <div style="margin-top: 10px;"> <input type="checkbox"/> 1. NO DIFFICULTY SEEING  <input type="checkbox"/> 2. SOME DIFFICULTY IN SEEING BUT CAN SEE TELEVISION SIZE IMAGES FROM 8 TO 10 FEET AWAY  <input type="checkbox"/> 3. GREAT DIFFICULTY IN SEEING BUT SEES ENOUGH TO WALK AROUND WITHOUT USUALLY BUMPING INTO THINGS  <input type="checkbox"/> 4. BLIND OR NO USEABLE VISION  <input type="checkbox"/> 8. DON'T KNOW         </div> </div>	<div style="border: 1px solid black; padding: 5px; margin-bottom: 10px; width: fit-content; margin: 0 auto;">5. NO</div> <p style="text-align: center;">↓</p> <div style="border: 1px solid black; padding: 10px;"> <p>A3d. (RESPONDENT BOOKLET, P. 2) Which of these best describes how well (he/she) sees (without [his/her] glasses)?</p> <div style="margin-top: 10px;"> <input type="checkbox"/> 1. NO DIFFICULTY SEEING  <input type="checkbox"/> 2. SOME DIFFICULTY IN SEEING, BUT CAN SEE TELEVISION SIZE IMAGES FROM 8 TO 10 FEET AWAY  <input type="checkbox"/> 3. GREAT DIFFICULTY IN SEEING BUT SEES ENOUGH TO WALK AROUND WITHOUT USUALLY BUMPING INTO THINGS  <input type="checkbox"/> 4. BLIND OR NO USEABLE VISION  <input type="checkbox"/> 8. DON'T KNOW         </div> <p style="text-align: center; margin-top: 10px;">TURN TO P. 4, A4</p> </div>
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TURN TO P. 4, A4

A4. (RESPONDENT BOOKLET, P. 3) How would you describe how (he/she) usually gets around at (FACILITY)?

(CHECK ONE)

01. WALKS WITH NO PROBLEM
02. WALKS UNSTEADILY OR AWKWARDLY WITHOUT ASSISTANCE
03. WALKS WITH ASSISTANCE OF CANE, CRUTCHES, WALKER OR ANOTHER PERSON
04. PROPELS SELF IN WHEELCHAIR OR OPERATES OWN MOTORIZED WHEELCHAIR
05. MUST BE PUSHED IN WHEELCHAIR
06. CRAWLS OR CREEPS
07. CONFINED TO BED, CRIB, OR MAT
- OTHER (DESCRIBE): \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

A5. (RESPONDENT BOOKLET, P. 4) How would you describe (RESIDENT'S) hand and arm use?

1. HAS COMPLETE CONTROL IN USING HANDS AND ARMS FOR ACTIVITIES APPROPRIATE TO HIS/HER AGE
2. HAS SOME INABILITY TO USE HANDS OR ARMS, BUT CAN MANAGE MOST ACTIVITIES INDEPENDENTLY
3. NEEDS A GOOD DEAL OF HELP AND/OR USE OF ADAPTIVE EQUIPMENT TO USE HANDS AND ARMS
4. HAS LITTLE OR NO USEFUL HAND OR ARM CONTROL

A6. (RESPONDENT BOOKLET, P. 5) Which of these best describes the way (RESIDENT) usually communicates with other people? (MOST USUAL METHOD ONLY)

(CHECK ONE)

- 1. TALKS
- 2. USES SIGN LANGUAGE (FORMAL SIGNS SUCH AS THOSE USED BY DEAF PEOPLE)
- 3. PRINTS, TYPES OR WRITES INSTEAD OF TALKING → GO TO A7
- 4. USES A SYMBOL SYSTEM (POINTS TO PICTURES OR SYMBOLS SUCH AS BLISS SYMBOLS ON A SYMBOL BOARD) → GO TO A7
- 5. POINTS OR USES GESTURES → GO TO A7
- 6. MAY CRY OR SMILE, BUT OTHERWISE UNABLE TO COMMUNICATE → GO TO A7
- 7. OTHER (SPECIFY): \_\_\_\_\_ → GO TO A7

A6a. (RESPONDENT BOOKLET, P. 6) How easily can the (words/signs) be understood by the average person (who knows sign language)? (CHECK ONE)

- 1. EASILY UNDERSTOOD
- 2. SOMEWHAT DIFFICULT TO UNDERSTAND (CAN USUALLY BE UNDERSTOOD, BUT HAS DIFFICULTY WITH SOME WORDS OR SIGNS)
- 3. HARD TO UNDERSTAND (CAN BE UNDERSTOOD ONLY WITH DIFFICULTY, USUALLY CANNOT BE UNDERSTOOD WELL BY A STRANGER)

A7. Has (RESIDENT) had an epileptic seizure that you know of within the last year?

1. YES

5. NO

→ TURN TO P. 6, A8

A7a. How frequently do seizures occur--once a day or more often, about once a week or more often, about once a month, several times a year, or about once a year or less often?

- |                                   |  |                             |                               |  |
|-----------------------------------|--|-----------------------------|-------------------------------|--|
| ONCE A DAY<br>1. OR MORE<br>OFTEN | ABOUT ONCE<br>2. A WEEK OR<br>MORE OFTEN | ABOUT<br>3. ONCE A<br>MONTH | SEVERAL<br>4. TIMES A<br>YEAR | ABOUT ONCE<br>5. A YEAR OR<br>LESS OFTEN |
|-----------------------------------|--|-----------------------------|-------------------------------|--|

A8. Does (RESIDENT) have any long term health problems such as heart trouble, diabetes, and so on?

1. YES

5. NO

→ GO TO A9

A8a. What are they? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

A9. (RESPONDENT BOOKLET, P. 7) Is (he/she) receiving any prescribed medication now, for any of these reasons? (CHECK ALL THAT APPLY.)

A. SEIZURES

B. SLEEPING PROBLEMS

C. A CHRONIC MEDICAL CONDITION SUCH AS DIABETES, OR ALLERGIES

D. OVERACTIVE BEHAVIOR

→ (What is the name of the drug? \_\_\_\_\_)

E. A PSYCHIATRIC CONDITION

F. TO REDUCE TREMORS OR SHAKING

G. BIRTH CONTROL

H. FOR ANYTHING ELSE OTHER THAN A TEMPORARY ILLNESS (SPECIFY REASON(S) FOR USE, OR NAME OF DRUG):

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

J. NONE

SECTION G: UTILIZATION OF SERVICES

G1. Now I want to ask you about different services which residents sometimes use. First, how about dental care? Has (RESIDENT) had any dental care (in the past year/since coming here)? (USE "SINCE COMING HERE" FOR RESIDENTS ADMITTED LESS THAN ONE YEAR AGO.)

1. YES

5. NO

8. DON'T KNOW

G2. Has (RESIDENT) seen a doctor (in the past year/since coming here)?

1. YES

5. NO

8. DON'T KNOW

TURN TO P. 31, G3

G2a. Was this for a routine physical examination, or treatment of an illness or injury?

1. ROUTINE PHYSICAL  
GO TO G2c

2. TREATMENT

3. BOTH

G2b. Why did (he/she) see the doctor for treatment? What was the problem?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

G2c. (RESPONDENT BOOKLET, P. 20) How often does (he/she) see a doctor for a physical examination--more than twice a year, twice a year, once a year, or less than once a year?

1. MORE THAN TWICE A YEAR

2. TWICE A YEAR

3. ONCE A YEAR

4. LESS THAN ONCE A YEAR

8. DON'T KNOW

for office use only



**SURVEY RESEARCH CENTER**  
INSTITUTE FOR SOCIAL RESEARCH  
THE UNIVERSITY OF MICHIGAN

1. Interviewer's Label

2. Facility ID: \_\_\_\_\_

3. Resident ID: \_\_\_\_\_

4. Care Person ID: \_\_\_\_\_

5. Your Interview Number: \_\_\_\_\_

6. Date of Interview: \_\_\_\_\_

7. Length of Interview \_\_\_\_\_  
(minutes)

8. Additional time for Forms: + \_\_\_\_\_  
(mins)

9. Total Time: \_\_\_\_\_  
(minutes)

10. Length of Edit \_\_\_\_\_  
(minutes)

# CARE PERSONNEL QUESTIONNAIRE

THE FOLLOWING STATEMENT MUST BE READ

Your participation in this research is completely voluntary.  
If we should come to any question you feel you can't answer  
just let me know and we'll go on to the next question.

INTERVIEWER: YOU MUST HAVE THE COMPLETED PERSONAL RECORD SHEET  
FOR THIS RESIDENT BEFORE TAKING THIS INTERVIEW.

## SECTION F: BEHAVIOR PROBLEMS

We need to know about any behavior problems (RESIDENT) has now, such as hurting (himself/herself), hurting other people, destroying property, or doing things that are disturbing or cause problems to you or other people. If (RESIDENT) has any behavior problems I'd like to go into a little more detail with you.

F1. (RESPONDENT BOOKLET, P1 17) Does (RESIDENT) have any of these behavior problems? (CHECK ALL THAT APPLY AND FOLLOW INSTRUCTIONS FOR FIRST (TOP) MARKED BEHAVIOR.)

- A. SELF-INJURIOUS BEHAVIOR, SUCH AS BANGING HIS OR HER HEAD OR PURPOSELY EATING NONEDIBLES THAT COULD HARM HIM OR HER → TURN TO P. 22, F2
- B. HURTS OTHER PEOPLE BY KICKING, HITTING, BITING OR OTHERWISE PHYSICALLY INJURING THEM → TURN TO P. 23, F4
- C. PURPOSELY BREAKS OR DAMAGES WINDOWS, CLOTHING, FURNITURE, TOYS OR OTHER PROPERTY OR OBJECTS → TURN TO P. 24, F6
- D. UNUSUAL OR DISRUPTIVE BEHAVIOR THAT CANNOT BE IGNORED, SUCH AS THROWING TANTRUMS, BANGING DOORS, MAKING UNUSUAL NOISES OR SEXUAL MISCONDUCT → TURN TO P. 26, F8
- E. BREAKS HOUSE RULES OR REFUSES TO GO ALONG WITH HOUSEHOLD ROUTINE → TURN TO P. 27, F10
- F. REFUSES TO GO TO SCHOOL, WORK, OR DAY PLACEMENT → TURN TO P. 27, F12
- G. HAS PURPOSELY RUN AWAY FROM HOME → TURN TO P. 28, F14
- H. HAS BROKEN THE LAW → TURN TO P. 28, F16
- NO PROBLEMS → TURN TO P. 29, F19

F2. Tell me about (his/her) self-injurious behavior. What types of things does (he/she) do?

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F2a. (RESPONDENT BOOKLET, P. 18) Which of these best describes what you usually do when this behavior occurs? Just give me one number--what you do most often. (IF THERE ARE SEVERAL BEHAVIORS, ASK ABOUT THE BEHAVIOR OR GROUP OF BEHAVIORS THAT CAUSE THE BIGGEST PROBLEM.)

1. DO NOTHING
2. SYSTEMATICALLY IGNORE IT OR REINFORCE OTHER BEHAVIORS
3. ASK THE RESIDENT TO STOP, OR THREATEN TO TAKE AWAY
4. ASK THE RESIDENT TO LEAVE THE ROOM OR GO TO TIME-OUT
5. TOUCH OR TAKE HOLD OF RESIDENT, TAKE HIM/HER FROM THE ROOM, OR PHYSICALLY TOUCH OR RESTRAIN HIM/HER IN SOME WAY
6. HAVE TO GET HELP FROM OTHER STAFF. IT TAKES AT LEAST TWO PEOPLE TO GET THE SITUATION UNDER CONTROL.
7. OTHER (SPECIFY) (IF NECESSARY: Do you just ask (him/her) or must you physically take hold of (him/her)?)

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F2b. How often (does this/do these) behavior(s) occur on the average?

\_\_\_\_\_ TIMES PER \_\_\_\_\_

F2c. Does (he/she) ever injure (himself/herself) so seriously that (he/she) needs medical attention?

1. YES

5. NO

## F3. INTERVIEWER CHECKPOINT (SEE F1)

<input type="checkbox"/>	1. RESIDENT ALSO HURTS OTHER PEOPLE
<input type="checkbox"/>	2. RESIDENT DOES <u>NOT</u> HURT OTHER PEOPLE → TURN TO P. 24, F5

F4. Tell me about (his/her) hurting other people. What types of things does (he/she) do?

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F4a. (RESPONDENT BOOKLET, P. 18) Which of these best describes what you usually do when this behavior occurs? Just give me one number--what you do most often. (IF THERE ARE SEVERAL BEHAVIORS, ASK ABOUT THE BEHAVIOR OR GROUP OF BEHAVIORS THAT CAUSE THE BIGGEST PROBLEM.)

1. DO NOTHING
2. SYSTEMATICALLY IGNORE IT OR REINFORCE OTHER BEHAVIORS
3. ASK THE RESIDENT TO STOP, OR THREATEN TO TAKE AWAY PRIVILEGES
4. ASK THE RESIDENT TO LEAVE THE ROOM OR GO TO TIME-OUT
5. TOUCH OR TAKE HOLD OF RESIDENT, TAKE HIM/HER FROM THE ROOM, OR PHYSICALLY TOUCH OR RESTRAIN HIM/HER IN SOME WAY
6. HAVE TO GET HELP FROM OTHER STAFF. IT TAKES AT LEAST TWO PEOPLE TO GET THE SITUATION UNDER CONTROL.
7. OTHER (SPECIFY) (IF NECESSARY: Do you just ask (him/her) or must you physically take hold of (him/her)?

F4b. How often (does this/do these) behavior(s) occur on the average?

\_\_\_\_\_ TIMES PER \_\_\_\_\_

F5. INTERVIEWER CHECKPOINT (SEE F1)

<input type="checkbox"/>	1. RESIDENT ALSO DAMAGES THINGS
↓	
<input type="checkbox"/>	2. RESIDENT DOES <u>NOT</u> DAMAGE THINGS → TURN TO P. 26, F7

F6. Tell me about (his/her) damaging or breaking things. What types of things does (he/she) do?

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F6a. (RESPONDENT BOOKLET, P. 18) Which of these best describes what you usually do when this behavior occurs? Just give me one number--what you do most often. (IF THERE ARE SEVERAL BEHAVIORS, ASK ABOUT THE BEHAVIOR OR GROUP OF BEHAVIORS THAT CAUSE THE BIGGEST PROBLEM.)

- 1. DO NOTHING
- 2. SYSTEMATICALLY IGNORE IT OR REINFORCE OTHER BEHAVIORS
- 3. ASK THE RESIDENT TO STOP, OR THREATEN TO TAKE AWAY PRIVILEGES
- 4. ASK THE RESIDENT TO LEAVE THE ROOM OR GO TO TIME-OUT
- 5. TOUCH OR TAKE HOLD OF RESIDENT, TAKE HIM/HER FROM THE ROOM, OR PHYSICALLY TOUCH OR RESTRAIN HIM/HER IN SOME WAY
- 6. HAVE TO GET HELP FROM OTHER STAFF. IT TAKES AT LEAST TWO PEOPLE TO GET THE SITUATION UNDER CONTROL.
- 7. OTHER (SPECIFY) (IF NECESSARY: Do you just ask (him/her) or must you physically take hold of (him/her)?

---

F6b. How often (does this/do these) behavior(s) occur on the average?

\_\_\_\_\_ TIMES PER \_\_\_\_\_

F6c. Is there ever any cost involved in having the damage repaired?

1. YES

5. NO

→ TURN TO P. 26, F7



F6d. (RESPONDENT BOOKLET, P. 19) During the last 30 days, how much has it cost to repair the damage (RESIDENT) has done?

\$6  
1. OR  
LESS

\$6.01  
2. TO  
\$26

\$26.01  
3. TO  
\$100

MORE  
4. THAN  
\$100

HAS NOT  
7. OCCURRED  
IN LAST  
30 DAYS

8. DON'T  
KNOW

## F7. INTERVIEWER CHECKPOINT (SEE F1)

1. RESIDENT ALSO HAS DISRUPTIVE BEHAVIOR
2. RESIDENT DOES NOT HAVE DISRUPTIVE BEHAVIOR → TURN TO P. 27, F9

F8. Tell me about this unusual or disruptive behavior. What types of things does (he/she) do?

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F8a. (RESPONDENT BOOKLET, P. 18) Which of these best describes what you usually do when this behavior occurs? Just give me one number--what you do most often. (IF THERE ARE SEVERAL BEHAVIORS, ASK ABOUT THE BEHAVIOR OR GROUP OF BEHAVIORS THAT CAUSE THE BIGGEST PROBLEM.)

1. DO NOTHING
2. SYSTEMATICALLY IGNORE IT OR REINFORCE OTHER BEHAVIORS
3. ASK THE RESIDENT TO STOP, OR THREATEN TO TAKE AWAY PRIVILEGES
4. ASK THE RESIDENT TO LEAVE THE ROOM OR GO TO TIME-OUT
5. TOUCH OR TAKE HOLD OF RESIDENT, TAKE HIM/HER FROM THE ROOM, OR PHYSICALLY TOUCH OR RESTRAIN HIM/HER IN SOME WAY
6. HAVE TO GET HELP FROM OTHER STAFF. IT TAKES AT LEAST TWO PEOPLE TO GET THE SITUATION UNDER CONTROL.
7. OTHER (SPECIFY) (IF NECESSARY: Do you just ask (him/her) or must you physically take hold of (him/her)?

F8b. How often (does this/do these) behavior(s) occur on the average?

\_\_\_\_\_ TIMES PER \_\_\_\_\_

## F9. INTERVIEWER CHECKPOINT (SEE F1)

<input type="checkbox"/>	1. RESIDENT ALSO BREAKS RULES
<input type="checkbox"/>	2. RESIDENT DOES <u>NOT</u> BREAK RULES → GO TO F11

F10. Tell me about (his/her) breaking rules or refusing to go along with the household routine. What does (he/she) do and what type of problem does it cause?

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## F11. INTERVIEWER CHECKPOINT (SEE F1)

<input type="checkbox"/>	1. RESIDENT ALSO REFUSES TO GO TO WORK, SCHOOL, OR DAY PLACEMENT
<input type="checkbox"/>	2. RESIDENT DOES NOT REFUSE TO GO → TURN TO P. 28, F13

F12. Within the last 30 days, has (he/she) spent a day at (HOME/FACILITY) because (he/she) refused to go to (his/her) day program?

1. YES

5. NO

8. DON'T KNOW

F13. INTERVIEWER CHECKPOINT (SEE F1)

<input type="checkbox"/> ↓	1. RESIDENT ALSO RUNS AWAY FROM HOME  <input type="checkbox"/> 2. RESIDENT DOES <u>NOT</u> RUN AWAY FROM HOME → GO TO F15
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F14. Within the last six months has (RESIDENT) purposely run away from (HOME/FACILITY)?

1. YES

5. NO

F15. INTERVIEWER CHECKPOINT (SEE F1)

<input type="checkbox"/> ↓	1. RESIDENT ALSO HAS BROKEN THE LAW  <input type="checkbox"/> 2. RESIDENT HAS <u>NOT</u> BROKEN THE LAW → TURN TO P. 29, F17
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F16. During the last year what did (he/she) do that was against the law?

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DID NOT BREAK LAW DURING THE LAST YEAR

→ TURN TO P. 29, F17

F16a. Who got involved? Was it only the staff here (or at the day program), a storekeeper, the police, or someone else?

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F17. Do you think (RESIDENT) would be able to get out into the community more, either alone or with a staff member or volunteers, if (he/she) didn't have the problem behavior(s) we have just been talking about?

1. YES

5. NO

8. DON'T KNOW

F18. (Is the/Are any of these) behavior problem(s) so severe that (it is/they are) endangering (RESIDENT'S) continued placement here?

1. YES

5. NO

8. DON'T KNOW

F19. Does (RESIDENT) have any stereotyped behaviors such as body-rocking or arm waving, that affects (him/her) but not usually the people around (him/her)?

1. YES

5. NO

8. DON'T KNOW