DEVELOPMENTAL DISABILITIES QUALITY ASSURANCE: A STUDY OF DEINSTITUTIONALIZATION IN OKLAHOMA

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In January of 1990 a team of researchers undertook the quality assurance monitoring of the developmentally disabled in the state of Oklahoma. This longitudinal data gathering effort allowed me as an interviewer to observe the lives of many individuals with developmental disabilities from an outsider perspective. Being part of this team for two years, I was able to observe daily routines, environmental conditions, and interactions of individuals with developmental disabilities and to hear the opinions of others concerning this group. This study has given me a greater understanding of societal attitudes and perceptions of those with developmental disabilities.

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CHAPTER I

INTRODUCTION

Statement of the Problem

On July 24, 1987, a class action law suit was filed against Hissom Memorial Center by the families of individuals with developmental disabilities, accusing the institution of not providing adequate services for their developmentally disabled relatives. The resulting court order called for the eventual closure of Hissom, and also called for the Developmental Disabilities Services Division to contract with a national expert to review annually plans in the implementation of the quality assurance. The court order also stipulated that an automated data base be developed to analyze, on an annual basis, changes in class members' independence (adaptive development, behavior development, adaptive behavior), satisfaction with services, and quality of life based upon standardized measures. Finally, a suggestion was that all class members be provided, at least annually, an opportunity to evaluate services they have received. Consequently, the Developmental Disability Services Divisions began to implement a program to develop this data base with standardized measures (Baysinger,

Gordon, Pumphrey, Bean, and Rowe, 1988, p. 84). The mission statement for the quality assurance project stated by Baysinger et al. (1988);

> "The Advocacy, Safeguards and Quality Assurance subcommittee seeks to develop systems which promote independence, choice and rights for people served. Rights protection and advocacy will be primary considerations in developing DHS Regulations, Accreditation, Systematic Communications, Procedural Protections and Transitional Safeguards.
>
> Quality Assurance activities shall assure that services contracted for or rendered by DHS are responsive to the needs of class members, comply with ethical standards of practice, produce outcomes prescribed in each class member's Individual Habilitation Plan, are modified to meet the changing needs of class members and comply with standards of public and physical accountability" (pg. 1).

A research grant was written in conjunction with Oklahoma State University's Sociology Department to conduct the monitoring of the quality of services provided. In 1989 the grant was awarded. Researchers from Temple University (Conroy and Feinstein and Associates) were contacted as national experts to assist in the development of a monitoring instrument and the subsequent training of surveyors at OSU. Several instruments were selected, based upon a model from Temple University, which represented a similar court-ordered monitoring of the developmentally disabled. The instruments were built upon the Temple survey and subsequent monitoring activities. The final version of the instrument used in Oklahoma was designed to gather data

on demographics, residential history, family and advocate contact, adaptive equipment needs, adaptive development, abilities to control the frequency and severity of challenging behavior, need for medical services, drug usage, weekly contact information, civil involvement, citizenship activities, service planning, consumer perceptions of their living situation and interviewer perceptions of the site's physical quality.

Training started in December of 1989 to prepare the team of researchers which would collect data on the quality of care given to the developmentally disabled not only in Hissom Memorial Center, but also in the other institutions and community settings across the state. Interviewing began in January of 1990. Three years of data have been collected since the project began, and a fourth is underway. Past studies have not focused on an entire state population of developmentally disabled but only those in institutions or those in one community center for the developmentally disabled. The current study uses the data base which represents the developmentally disabled population receiving funds from the Developmental Disabilities Service Division of the State's Department of Human Services, hereafter referred to as DDS.

The research proposed here will use part of the data base described above and will seek to determine differences between three categories of individuals, those who were moved out of Hissom (Movers) from 1991 to 1992, those in

Hissom (Stayers) and those who were residing in community settings (Community Residents) during the same period (see pg. 24 for more elaboration). Past research has not considered categories of Movers, Stayers and Community Residents across an entire state's population while those individuals with developmental disabilities are in the process of deinstitutionalization.

Lakin, Krantz, Bruininks, Clumpner, and Hill (1982) called for a comprehensive data base of information necessary for effective planning, resource development, consumer tracking and monitoring procedures for public residential facilities for individuals with developmental disabilities. Griffith (1985) asserted:

> "Professionals will decide who is served there and who remains in, or moves to, the community... the professionals charged with the operations of the programs and services for the developmentally disabled who have the major say as to who gets what, where. . . rights of citizens who are mentally retarded have been clarified in the courts and . . . continue to be inalienable, they are also more minimal (pg. 196)."

Cullari (1984) concluded that the role of the institution is not simply to provide custodial care but to make a real commitment to training and increasing staff/consumer interactions; Cullari also concluded that, now is the time to focus on quality in the care of the developmentally disabled. The current study shall utilize the data gathered by the Quality Assurance Team from Oklahoma State University during 1991 and 1992 on several quality of life indicators.

Objectives

The primary objective of this study is to focus on the impact of the process of moving individuals with developmental disabilities from institutions to community settings. Related to the primary objective is the focus on the changes which occur in relation to the individuals' quality of life once moved into the community. Categories of consumers will be selected to monitor changes over a one year period.

The quality of life data characteristics will be examined in both 1991 and 1992 for Movers, Stayers, and Community Residents (shall be referred to as categories) on ten dependent variables; 1) adaptive development, 2) ability to control the frequency of challenging behavior 3) ability to control the severity of challenging behavior 4) medical services, 5) civic involvement, 6) social contacts, 7) consumer satisfaction 8) number of work skills goals, 9) number of self care goals and 1Ø) number of interaction goals. Changes between 1991 and 1992 in the mean scores for these categories on the dependent variables will be evaluated. Differences by types of consumer (based on grouping by race, sex, and level of retardation) on the dependent variables will also be evaluated. Finally, the interaction of type of consumer by year differences will be evaluated for these variables.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

"The people who have moved from institutions to community placements have benefited immensely in almost every way we know how to measure" (Conroy, Feinstein, & Lemanowicz, 1988). The quote articulates a direction for the current review of literature. This chapter presents a review of literature which addresses research on the quality of life of individuals as the process of deinstitution-alization takes place. The review of the literature is presented as it relates to several quality of life measures for individuals with developmental disabilities and their movement into community based residential settings. Also, the quality of life changes which result will be viewed as an important component in this literature review. The literature is presented according to studies related to: (1) definitions and perceptions of developmental disabilities, (2) residential settings for the developmental disabled, (3) deinstitutionalization, (4) adaptive development, (5) challenging behaviors, (6) consumers' medical needs, (7) civic involvements and social contacts, (8) goals related behaviors, and (9) consumer satisfaction.

Definitions and Perceptions of Developmental Disabilities

The use of terminology such as moron, feebleminded, simple, imbecile, dimwitted, or slow was historically used to refer to individuals with developmental disabilities. Public perceptions of individuals with developmental disabilities have become increasingly important as deinstitutionalization and other normalization efforts have become more popular across the United States. Caruso and Hodapp (1988), in a study of college students, found students' perceptions of individuals with developmental disabilities to be similar to those with mental illnesses. Further, they found that undergraduates perceived developmental disabilities to be caused by heredity or brain damage and not by environmental deprivation. In addition, they found that the idea of psychosocial deprivation was unfamiliar to the students.

The definition of developmental disabilities is contained in Public Law 100-146 of the Developmental Disabilities Assistance and Bill of Rights Acts: the term "developmental disability" refers to a severe, chronic disability of a person which:

1) is attributable to a mental or physical impairment or combination of mental and physical impairments;
2) is manifested before the person attains age 22;
3) is likely to continue indefinitely;

4) results in substantial functional limitations in three or more of the following areas of major life activity;

   a) self-care,
   b) receptive and expressive language,
   c) learning,
   d) mobility,
   e) self-direction
   f) capacity for independent living, and
   g) economic self-sufficiency;

5) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated (Public Law 98-527; p. 2664).

The classification of individuals with developmental disabilities is based upon IQ scores (derived from the Stanford-Binet or Wechsler IQ inventories) and an adaptive development scale. Five classifications of individuals with developmental disabilities are identified: (1) Profoundly developmentally disabled refers to individuals with IQ levels below 16, (2) Severely developmentally disabled refers to individuals with IQ levels between 16 and 32, (3) Moderately developmentally disabled refers to individuals with IQ levels between 33 and 49, (4) Mildly developmentally disabled refers to individuals with IQ levels of 5Ø to 66, and (5) Borderline developmentally disabled refers to individuals who score 67 to 83 on IQ inventories.

Studies of Residential Settings for Individuals with Developmental Disabilities

This study will employ the data gathered in the monitoring of Oklahoma's developmentally disabled population and includes all known individuals receiving funds through the Developmental Disabilities Services Division of the Department of Human Services. Individual subjects live in large state institutions, intensive care facilities (ICF), intensive care facilities for the developmental disabled (ICF/MR), group homes, supported living, private homes, foster care, and semi-independent living. The large state institutions, ICF, and ICF/MR facilities function as "total institutions" for individuals with developmental disabilities. Goffman (1958) suggested four features of "total institution;"

> "First, all aspects of life are conducted in the same place and under the same single authority. Second, each phase of the member's daily activity will be carried out in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing together. Third, all phases of the day's activities are tightly scheduled, with one activity leading at a prearranged time into the next, . . . Finally, the contents of the various enforced activities are brought together as parts of a single overall rational plan purportedly designed to fulfill the official aims of the institution (p. 295-296).

Institutions for the developmentally disabled across the nation still have similar features to those observed by Goffman (1958) more than 35 years ago. Hissom Memorial Center, being the focal point of the monitoring of

Oklahoma's institutions for the developmental disabled, is similar to what Goffman (1958) described as the "total institution." Culari (1984) and Ferguson (1987) both described the daily life of residents of facilities for the developmentally disabled with similar characteristics to what Goffman (1958) described. Zirpoli and Wieck (1989) reported that nearly 100,000 persons with developmental disabilities reside in large state-run institutions throughout the United States.

Several of the features of the institution can lead to restrictive environments. These factors can produce environments where living, learning, working and leisure are inhibited. The least restrictive environment is closely tied to deinstitutionalization and normalization. Tjosvold and Tjosvold (1983) suggested two types of administration in institutional settings for the developmental disabled. The first, a management style, which emphasizes unilateral control over subordinates, centralized decision making, and an environment where feelings, personal relations and individual differences are not to interfere with task or role performance. The second, a collaborative style, reflects a respect for individuals, shared decision making, and focus on interpersonal skill development. While the collaborative style leads to a less restrictive environment, provides opportunities for self-expression, cooperation, recognition, social competence, and self development, the control style tends to be more restrictive in allowing for

consumer growth. MacEachron (1983), in studying normalization in a large state school for the developmentally disabled, found that both physical and social, but especially the social aspects of a normalized setting are associated positively with the development of the developmentally disabled.

Researchers have proposed that smaller residential settings are more beneficial to individuals with developmental disabilities in terms of improvement in quality of life (Conroy; 1992, Murray; 1992, Wilson and Kouzi; 199Ø, Conroy, Lemanowicz, Feinstein; 1987, Conroy and Bradley; 1985). Conroy and Bradley (1985) found that the amount of staff time directly allocated to consumers was higher in small community settings than in large institutions. Conroy (1992) put forth the assertion that large groups are not as beneficial for individual interactions. He suggested that individuals interact more in small groups, and higher levels of development are achieved later in the process. Conroy (1992) reported that institutions are not as beneficial for the developmentally disabled's quality of life, adaptive development, normalization, or daily interactions as smaller community settings. Rotegard, Hill, and Bruininks (1983) found that large institutional settings are judged less homelike as their resident populations increase in number. By controlling for size of facility, individual, and staff characteristics, the researchers discovered that the size of the facility remained an important predictor of the physical

characteristics of the environment. Willer and Intagliata (1982) reported that individuals placed in group homes are more likely to improve in community living skills; those placed in family homes are more likely to improve in challenging behaviors; and both groups are equally likely to have friends and make use of community resources. Thus, the research literature indicates that increases in several quality of life measures may be obtained within smaller residential community placements.

Studies Related to Deinstitutionalization

Deinstitutionalization is a process of transferring consumers from large institutional settings to smaller community based locations. This movement of individuals with developmental disabilities is based on the idea that environmental changes are beneficial to individual quality of life. Lakin, Hill and Bruininks (1986) defined deinstitutionalization as:

> "a term used to describe the social, bureaucratic, and fiscal processes involved in transferring developmentally disabled residents and the resources needed to serve them to "noninstitutional," . . . less custodial, less regimented, less segregated, and . . . less differential from normal environments. . . (p. 54)"

Zirpoli and Wieck (1989) reported a growing trend in the nation toward deinstitutionalization. From their 43 state survey Zirpoli and Wieck (1989) found that 27 states reported closure of entire institutions. Grimes and Vitello

(1990) pointed out the concerns of parents with this trend in deinstitutionalization. These concerns focused on the potential instability of community programs and the absence of supportive services particularly for those clients with medical and behavioral problems. It is stated in Rehab Brief (1980):

> ". . .that a simple transfer from an institution for the mentally retarded to a hospital or a convalescent home cannot be considered real "deinstitutionalization." To be truly deinstitutionalized, the consumer must be moving to smaller, less restrictive living situation such as a group home, family, foster home, or host (p. 2).

A primary assumption of deinstitutionalization is that as consumers are moved from the large state operated institutions, that the quality of life will improve. Kleinberg and Galligan (1983) reported that:

> "Deinstitutionalization is a highly complex social policy with an intricate pattern of reasons underlying its implementation. Two assumptions are primary for most deinstitutionalization rationales: (a) institutions do not engender consumer growth, and (b) community residences are more 'normalizing' environments than are institutions" (p. 21).

Normalization is closely associated with the idea of deinstitutionalization. Further, deinstitutionalization allows individuals with developmental disabilities an opportunity to engage in age-appropriate activities. Devlin (1989) described normalization as "an ideology, complete with a moral system of thought, and a self contained value

system" (p. 1). Wolfensberger (1972) further described normalization as the:

> "utilization of means which are culturally normative as possible in order to establish and or maintain personal behaviors and characteristics which are as culturally normative as possible" (p. 28).

This statement suggests that for an environment to be normalized it should be one that reflects similar characteristics to the community in which the individual belongs.

The enviornment in which an individual with developmental disibilities resides is the topic of much research. Lakin, Hill and Bruininks (1986) reported that changes in the adaptive development of developmentally disabled persons who moved from large to small facilities has been the subject of only a modest amount of research. Silverstein, Wothke and Slabaugh (1988) compared consumers that lived in community facilities to those in large state-operated facilities. They found that community living facilities were less-restrictive than larger state-run institutional settings. Silverstein et al. (1988) described community living facilities as typically requiring residents to have higher adaptive development scores than residents of state-operated institutions. Conroy, Efthimiou, and Lemanowicz (1982) found that those who moved showed gains in adaptive development while those individuals who stayed only showed slight increases in adaptive development.

The focus of much literature has been upon the level of retardation and the individual's developmental abilities. These behaviors indicate the level of independence of the developmentally disabled. Adaptive behavior (development) as a measure of independence is used along with other criteria such as IQ to make placement decisions for those being moved. Silverman, Johnson, Sersen, Lubin, and Schwartz (1986) reported improvements in adaptive development among a sample of people living in community programs with severe and profound disabilities. The consumers displayed more fully developed ambulation and eating skills and exhibited more ability to understand language as a result of their living arrangement. Silverman et al. (1986) noted that the majority of the community-based residents were unable to produce speech or use signs to express their desires.

The characteristics of environments for the aging and those for individuals with developmental disabilities shared several similarities. These similarities were reflected in the activities offered, restrictiveness, and the effects of movements from one residence to another. Studies of the environments for the elderly may be been useful in understanding some of the characteristics of environments for individuals with developmental disabilities. Lawton and Nahemows' (1973), for example, presented an Ecological Model which described individual autonomy and security increasing along with individual competence level. Therefore,

decreases in the individual's ability to manage the affairs of their daily lives indicates decreases in their level of competence.

Studies Related to Quality of Life Measures

Quality of life is related to several variables which are explored in the following literature. As individuals are moved from large state-run institutions to smaller residential community settings, planners expect quality of life to improve (Balla, 1976; Hemming, Lavender, and Pill, 1981; Hemming, 1986; McEvoy, 1991). These improvements include changes in adaptive development, challenging behaviors, services received, civic and social involvements, goals related behaviors, and consumer satisfaction. This view of quality of life is based upon social and psychological indicators and are discussed in the following review.

Studies Related to Adaptive Development

Adaptive development (also referred to as adaptive behavior or behavior development is dependent upon the researcher and the particular scales used) is a major developmental criteria used to evaluate individuals with developmental disablities ability to meet social and cultural standards for independence and responsibility. Adaptive development is primarily a measure of individual independence. Several perspectives are found in the literature on the nature of adaptive development.

> ". . .the reversible aspect of mental retardation, and it reflects primarily those behaviors which are most likely to be modified through appropriate treatment or training methods" (Leland, 1978, p. 28).

> ". . .is a construct influenced by considerations of place and time. A person judged as "adaptive" in one setting may not necessarily be evaluated similarly in another place; adaptive behaviors at one developmental level are qualitatively different from another level. In short, adaptive behavior is relative and dynamic, rather than absolute and static" (Horn and Fuchs, 1987, p. 11).

Gresham and Elliott (1987) suggested that individual social competence consists of two parts: adaptive development and social skills. An individual's social skills are related to their ability conform to social norms. Vitello, Atthowe and Cadwell (1983) reported that institutionalized developmentally disabled are generally not recommended for community placements until they attain higher levels of adaptive development. Adaptive development has thus become a primary consideration in the decision to place consumers in community settings.

Adaptive development and level of retardation are two factors which have been the focus of several studies on the developmentally disabled. Harrison (1987) reported moderate relationships between adaptive development and intelligence. Schlottmann and Anderson (1982) revealed in their study of 200 institutionalized developmentally disabled children that differences in measured intelligence are associated with differences in various types of developmental behaviors. Adaptive development may increase with placements in setting

which focus on individuality and less on institutionality.

Age and level of retardation are important factors in determining if consumers' behavior development will improve when placed in a smaller community setting. Hodapp and Zigler (1985) found, for example, that once placed in a less restrictive environment younger children, who are severely mentally retarded, did not show any greater improvements in behavior development than did older children in institutional settings.

Hemming, Lavender, and Pill (1981) used the Adaptive Behavior Scale to assess improvements in adaptive behavior (referred to in this research as adaptive development) as a final criterion to assess improved quality of life in their study of the developmentally disabled after transfer from large institutions into smaller community settings. Lakin et al. (1986) found significantly greater adaptive development scores among community residents at nine months after transfer, but, not one to two years later. Silverman et al. (1986) studied moderately sized facilities (IFC/MR) over a one-year period and found that profoundly disabled individuals were capable of skill acquisition within this type of environment.

Studies of the movement of individuals with developmental disabilities into community settings has included varied results, based on level of retardation. Hemming, Lavender, and Pill (1981) reported that for those individuals with higher levels of functioning (mild to

moderate levels), improved least upon movement from the institution. Further, Silverman et al. (1986) surmised that individuals with profound developmental disabilities when moved to community settings resulted in a decline in adaptive development. Kleinberg and Galligan (1983) suggested that individuals with higher levels of retardation displayed decreases in their levels of adaptive development in the first few months after movement into the community. However, Conroy, Efthimiou and Lemanowicz (1982) found that movers at all levels (profound to mild retardation) gained in adaptive development. This is supported by Hemming (1986) who found that individual's quality of life improved one year after transfer in several areas (independent functioning, language development, physical development, and domestic activities). McEvoy (1991) studied individuals who stayed in institutional settings and those who were transfered to residential settings on adaptive behavior and found that individuals who stayed showed less improvements than those who moved on levels of adaptive development. These results indicate that the observed improvements in adaptive behavior between staying at an institutional setting and moving to the community are contingent upon the reported level of retardation.

Studies Related to Challenging Behavior

Hill and Bruininks (1984) referred to behaviors which are self-injurious, harm others, damage property, or disrupt

others as challenging behaviors. In the current study challenging behavior is similar to the term maladaptive behavior which is used in other studies. Fine et al. (1990) reported deinstitutionalization may be related to at least short term increases in maladaptive behaviors. Hill and Bruininks (1984) suggested that most types of maladaptive behaviors are more common among public facility residents than among community residents. Kleinberg and Galligan (1983) indicated that during the first few months after moving to residential settings, lower functioning consumers showed increases in antisocial behaviors, while higher functioning consumers decreased their antisocial behaviors. Increases in interactions with staff members and other residents may increase the opportunity to exhibit maladaptive behaviors. This possibly would influence the rate of reporting on these behaviors by staff members. Willer and Intagliata (1982) suggested that individuals placed in family-care are more likely to improve their maladaptive behaviors but self-care skills do not improve dramatically. Hemming, Lavender, and Pill (1981) found that maladaptive behaviors (challenging behaviors in the current study) increased between transfer, four months after transfer, and most of the increase were in those residents with lower abilities.

The demographic factors of age and sex were shown to be related to the movements of individuals with developmental disabilities into community residences. Salgaras and

Nettelbeck (1983) reported that age factors produce significant main effects in eight domains: violent and destructive behaviors, antisocial behaviors, untrustworthy behavior, withdrawal, inappropriate interpersonal manners, unacceptable or eccentric habits, hyperactive tendencies, and psychological disturbances. Salgaras and Nettelbeck (1983) also suggested that sex differences were found in antisocial behavior, self-abusive behavior, and hyperactive tendencies with males exhibiting more antisocial and hyperactive behaviors, while females exhibited more self-destructive behaviors. Schlottmann and Anderson (1982) found in a study of developmental records from 2ØØ Hissom Memorial Center residents that differences in measured intelligence were associated with differences in developmental behaviors. Further, they found that when individuals were separated into groups by sex rather than levels of retardation the differences were minimal. Alexander, Huganir, and Zigler (1985) reported that females had higher subjective and objective preinstitutional social deprivation scores than did males. They suggested that this might be due to the sexist stereotype that females need more social and emotional protection than males.

Conroy et al. (1982) found maladaptive behavior increases for those who stayed in institutional settings while those who moved showed no increases in maladaptive behaviors. This finding is contradicted by McEvoy (1991) who reported that levels of maladaptive behavior for an

institutional group decreased over a period of three months while a community group increased in these behaviors for the same time period.

Studies Related to Routine Services

Medical Needs. The medical needs of consumers with developmental disabilities play an important role in decisions to place individuals in a community setting. Conroy, Efthimiou, and Lemanowicz (1982) explored medical needs, ambulation, vision, hearing, and seizure history after matching groups of movers and stayers. They found that movers had more impairments, ambulation, vision and hearing. However, there was no difference between movers and stayers on medical needs. McDonald (1985) reported on the needs of those individuals with severe disablities who were being returned to community settings. He suggested that proper implementation of the ICF/MR (Intermediate Care Facilities for Mentally Retarded) model, which was designed to meet the service needs of severely disabled individuals returning to community settings, would have the most benefit for consumers. The model calls for 24 hour, on-site nursing care and employment of a nurse as the health care coordinator in the homes. This would allow for many potentially serious medical problems to be attended to at their earliest signs and thus lower the need for emergency visits to hospitals or visits by physicians. McDonald (1985) gathered data from subject's records to determine

major handicapping conditions, diagnoses, and functioning levels in activities necessary for daily living. McDonald (1985) challenged the high-risk assumptions for severely developmentally disabled in community settings, since 57 acute care visits had been reduced to an average of two per resident per year once moved to community settings.

Civic Involvement and Social Contacts. Luck and Heiss (1972) suggested that environment and personality may be viewed as a two-way street--environment and that events shape people but also play an important part in selecting and shaping their own experiences. Increases in social contacts and involvements of citizens with developmental disabilities in activities with non-handicapped individuals would indicate movements toward a more normalized environment and a higher quality of life. Conroy, Efthimiou and Lemanowicz (1982) found that individuals with developmental disabilities that resided in the more deprived institutional settings (less normalized, less individualized, and less physically pleasant) gained more upon transfer to community settings.

The reviewed literature on deinstitutionalization supports the assertion that increased community activities would promote a more normalized quality of life for individuals with developmental disabilities.

Number of Weekly Goals. Emerson (1985) defined quality of life as the satisfaction of individual values, goals, and needs through lifestyle (p. 282). The idea that quality of

life increases as one accesses cultural activities and social settings is a compelling argument for normalization in the daily lives of the developmentally disabled. Landesman and Butterfield (1987) reported that with normalization comes higher life satisfaction, self-esteem, and personal competence. These elements are viewed as products of involvement with mainstream activities of society. Goals that involve individual in work, self care, and interaction seem related to normalization. Harrison (1987) concluded that "adaptive behaviors can be increased through placements in settings which focus on training adaptive behavior skills" (p. 61). Hemming (1986), for example, found in a five year follow-up of individuals with developmental disabilities that higher ability consumers showed improvements on domestic activities, while those consumers with lower ability showed improvements in domestic activity, responsibility, socialization, and independent functioning.

Studies of Consumer Satisfaction

Quality of life can be measured by many dimensions of an individual's life. Several of the indicators are found in the literature. Landesman (1986) expressed that researchers have not developed procedures to measure 'success' of deinstitutionalization programs at the individual level. Landesman (1986) argued that the success of movement from an institution to smaller residential settings should be evaluated and be sensitive to the

person's own perceptions of quality of life.

Individuals perceptions of quality of life may be determined by the group with whom they associate. It is stated in the Court Plan and Order of Deinstitutionalization (1987) that:

> "By limiting Hissom residents to only other retarded people they are limited to what can be learned from the people they are observing. Retarded people like all other people need consistent involvement with others who will relate to them on a human emotional level" (p. 32).

Jahoda, Markova and Cattermole (1988) reported in a study of individuals with mild developmental disabilities that their social life revolved around a handicapped world. This world of individuals with developmental disabilities becomes a "reference group" for those individuals in institutional settings. Singer (1981) defined a reference groups as one:

> ". . .to which an individual orients himself, regardless of actual membership, calling attention to the fact that such evaluations, attitudes, and behavior may be shaped by groupings other than the person's own (p. 66)."

Further, a reference group can produce feelings of relative deprivation and thus lower an individual's perceived quality of life. Relative deprivation is a sense of satisfaction related to comparisons between one's situation and that of some other group. This comparison is what one uses as a standard to evaluate one's self from others. Individuals with developmental disabilities are defined by society,

their parents, institutional staff, and others as handicapped people. Standards of mental and physical abilities can be based on these groups.

Goffman (1959) contended that individuals build their self using impression management. For individuals with developmental disabilities their level of adaptive development, and ability to control their challenging behavior may obstruct their ability to create a self which would make involvement in normalized activities achievable. Mead (1985) assumed individuals acquire a sense of self based upon "the generalized other." The generalized other allows the individual to understand societal perceptions of one's self. Markova and Cattermole (1988) found individuals with mild developmental disabilities are aware of a stigma associated with being identified as "mentally handicapped" (p. 113). Cooley (1929) felt that individuals adjust their behaviors based upon others' reactions. This is the process by which self develops according to Cooley (1929). The self which is presented by the individual with developmental disabilities shall be further explored in Chapter III.

The court-order mandated that interviews be conducted directly with individuals with developmental disabilities (Baysinger et al.; 1988, p. 84). These consumer interviews were conducted in order for individuals to evaluate services they received and so that they could express their opinions. These evaluations could be contrasted with others' quality of life indicators.

Research Questions

The present research seeks to describe differences within three categories of individuals currently involved in deinstitutionalization in Oklahoma. Stayers (includes those individuals living in Hissom Memorial center in 1991 and in 1992 with whom interviews were completed), Movers (those individuals with whom interviews were completed in 1991 in Hissom Memorial Center and then moved from Hissom Memorial Center to a group home or other community living facilities by 1992), and Community Residents (those individual living in the community with whom interviews were completed in both 1991 and 1992). The quality of life measures (here after referred to as dependent variables) shall be the primary focus of the current study. Three research questions are proposed to focus on the variations within categories and between types of consumers within these categories.

1) Among Stayers is there a difference by type of consumer (combinations of race, sex, and level of retardation), by year, and by interaction of type and year on the dependent variables (Adaptive Development, Challenging Behavior (frequency and severity))?

2) Among Movers is there a difference by type of consumer (combinations of race, sex, and level of retardation), by year, and by interaction of type and year on the dependent variables (Adaptive Development, Challenging Behavior (frequency and severity))?

3) Among Community Residents is there a difference by type of consumer (combinations of race, sex, and level of retardation), by year, and by interaction of type and year on the dependent variables (Adaptive Development, Challenging Behavior (frequency and severity))?

CHAPTER III

Theoretical Orientation

Introduction

The concepts of socialization, environment, and labeling provide a theoretical basis to build upon the literature presented in the previous chapter. Theories are presented in a symbolic interactionist framework which provides a processual approach to understanding the relationships between actors and their environments. According to Ritzer (1988) "symbolic interactionists' primary concern is with the impact of meanings and symbols on human action and interaction (p. 3Ø3)." Theories and concepts of socialization, environment, and labeling are applied to individuals with developmental disabilities who reside in institutional settings, to those who move from an institutional settings, or to individuals living in residential community settings. The following is a review of literature as it pertains to socialization, environment, labeling, and developmental disabilities.

Definition of Socialization

Socialization may be defined in several different ways. One definition may be as simple as a process by which

individuals develop a capacity to become effective participants in the world around them. Gecas (1981) defined the concept of socialization as:

> ". . .having two fairly distinct meanings in sociology . . . One point of view stresses the individual's adaptation and conformity to societal requirements; the other emphasized the individual's development into a self assertive, distinct human being (p. 166)."

But Vander Zanden (1977) defined socialization as:

> ". . .the process individuals develop, through interaction with other people, the ways of thinking, feeling, and acting that are essential for effective participation within society (p. 97)."

Nixon (1979) describes socialization as involving teaching or the induction of beliefs in which individuals' behavior conforms to a group's normative expectations. According to Davis (1948)

> "interactions with others in organized and meaningful way, which is the essence of socialization, can occur only in a stable and familiar group setting where people feel secure and can relate to others intimately and personally (p. 300)."

Cooley (1909) defined the process of socialization as occurring within an individual's primary groups. These groups were characterized by:

> ". . . intimate face-to-face association and cooperation. . . . they are fundamental in forming the social nature and ideals of the individual. The result of intimate association, psychologically, is a certain fusion of

> individualities in a common whole, so that one's very self, for many purposes at least is the common life and purpose of the group. . . . the simplest way of describing this wholeness is by saying that it is a "we." It involves the sort of sympathy and mutual identification. . . (p. 23)."

These definitions provide a basis for the conceptualization of how social selves of individuals with developmental disabilities develop even when limited by the physical constraints of their abilities, by the physical setting of the institution, and by societal labels.

The socialization process is challenged when applied to the developmentally disabled population. As defined in the literature review, this population is limited by some inabilities to perceive, react and develop throughout the life course. The assumption of these definitions of socialization are that the individual has the capacity to grow and develop in a nurturing environment. The reality for an individual with developmental disabilities is that of an institutional environment which may not provide this environment.

The movement of these individuals with developmental disabilities to different settings may require a process of resocialization. The socialization process for these individuals when placed in a different environment (moved to another residence) may be seen as one of resocialization. The results would be the internalization of a new group's standards and values. The result, however, could be a brief period of non-normative behavior while the individual

becomes acquainted with the new environment. Fine, Tangerman and Woodard (1990) reported that the deinstitutionalization of individuals with developmentally disabled may be related to short-term increases in maladaptive behaviors. Intagiliata and Willer (1982) found that continued displays of non-normative (maladaptive) behaviors were significantly more likely to result in reinstitutionalization. Thus, if internalization of the group norms is not accomplished then a primary group "we" feeling as Cooley (1909) described becomes difficult.

Definition of Institutions

The daily life of the institutionalized developmentally disabled is filled with routinized interactions, capricious behaviors and isolation from the public. This is similar to descriptions of the daily lives of the institutionalized mentally ill or criminal populations (Carney, 1980; Goffman, 1961; Rosenhan, 1973). Robertson (1987) defines an institution as "a stable cluster of values, norms, statuses, roles, and groups that develop around a basic social need (p. 93)." These needs may include regulation of sexual behavior, provision of child care, transition of cultural knowledge, reaffirmation of community values, solidarity, care of the ill, distribution of power, leadership, protection of the state, maintenance of social control, investigation of the social and natural world, recreation, and exercise (Robertson 1987, p. 94).

Institutions for the developmentally disabled provide for society care of those who are physically ill, protection of the state, and the maintenance of social control. This macro definition of the institution may be altered and viewed from a micro level as Berger and Luckmann (1967) define an institution as a place of reciprocal process of typification. They suggested that an institution "controls human conduct by setting up predefined patterns of conduct" (Berger and Luckmann, 1967; p. 55). Goffman (1968) referred to this type of setting as the "total institution," for which he suggested four features:

> "First, all aspects of life are conducted in the same place and under the same single authority. Second, each phase of the member's daily activity will be carried out in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing together. Third, all phases of the day's activities are tightly scheduled, with one activity leading at a prearranged time into the next, . . . Finally, the contents of the various enforced activities are brought together as parts of a single overall rational plan purportedly designed to fulfill the official aims of the institution (pp. 295-296).

Institutions for the developmentally disabled across the nation still have similar features to those observed by Goffman (1968) more than 35 years ago (Cullari, 1984; Holburn, 1990; Lakin, Krantz, Bruininks, Clumpner, Hill, 1982; Rotgard, Hill, Bruininks, 1983). This microscopic conceptualization of institutions is quite different from the broad sociological conception of an institution given in the beginning of this section. However, viewing the

institution for the developmentally disabled as an environment of social control and division of society into normal an non-normal will be discussed in the following section.

Definition of Labeling

Social labels are built out of public perceptions of what is believed to be normal or non-normal. What individuals believe to be normal is based upon the socialization process. Negative societal reactions develop when behaviors do not fit these perceptions and frequently will produce a label. Labels in society can range from the positive (such as hero, intelligent, independent, or millionaire) or negative (criminal, poor, mentally ill, or developmentally disabled). Tannenbaum (1938) describes the process as one of:

> ". . . tagging, defining, identifying, segregating, describing, emphasizing, making conscious and self-conscious; it becomes a way of stimulating, suggesting, emphasizing, and evoking the very traits that are complained of (p. 192)."

With institutionalization of the individual with developmental disability comes defining, identifying, and segregating. The "we" feeling described by Cooley (1909) becomes part of the process of segregating and emphasizing differences among groups in society. This process further involves the creation of "stigma". Stigma according to

Goffman (1963) is a gap between what a person ought to be (virtual social identity) and what the person actually is (actual social identity). The primary focus of Goffman's (1963) book Stigma is upon interactions between those who are stigmatized and those who are perceived as "normal". The deviant label of individuals with developmental disabilities stem from socialization. Subsequent tagging and identification of the developmentally disabled population as having differences from the larger population results in the separation of this group from the general population into institutional settings.

"The deviant label once applied is extremely difficult to shed (Goode; p. 34)." Rosenhan (1973) illustrated this point in the examination of what happened when sane individuals represented themselves as having mental disorders. Sane individuals were diagnosed as schizophrenic and admitted into a mental hospital. While inside the institution the patients behaved normally, however, their behaviors were still perceived as abnormal. Thus, Rosenhan (1973) revealed the power of labels and their ability to transform societal reactions of those with the labels.

Deinstitutionalization of individuals with developmental disabilities to smaller community residents is thought to assist the process of normalization (Conroy, Efthimiou, Lemanowiz, 1982; DeWeaver, 1983; Emerson, 1985; Kleinberg and Galligan, 1983; Landesman and Butterfield,

1987). Lakin, Hill, and Bruininks (1986) described normalization as:

> "has set a standard of value against which the quality of services for an historically devalued group of people can be judged. The standard is simply whether the treatment of an individual reflects the acceptance of him or her as a member of the culture. . ." (p. 57).

Emerson (1985) asserted that "normalization has become the ideological cornerstone of the deinstitutionalization movement. . . (p. 283)."

A Synthesis of Socialization, Labeling, Developmental Disabilities And The Institutional Setting

The foundations of labeling, socialization, developmental disabilities and the institutional setting are described in the above discussion. These definitions and concepts are put forth in the Symbolic Interactionist tradition. This approach suggests that:

> "1) Human beings, unlike lower animals, are endowed with the capacity for thought. 2) The capacity for thought is shaped by social interaction. 3) In social interaction people learn the meanings and the symbols that allow them to exercise their distinctively human capacity for thought. 4) Meanings and symbols allow people to carry on distinctively human action and interaction 5) People are able to modify or alter the meanings and symbols that they use in action and interaction on the basis of their interpretation of the situation. . . 6) The intertwined patterns of action and interaction make up groups and society (Ritzer 1988, p. 3ØØ)."

Labeling is based on the symbolic meanings that individuals

develop within the process of socialization. The process of socialization within an institution does not have the characteristics of "we" as described by Cooley (1909). The institutional setting presents a routinized environment in which the individual's interactions are designed to provide the individual with structure. The appearance of normality is not part of the institutional image (Cullari, 1984; Griffith, 1985; Holburn, 1990; Landesman and Butterfield, 1987). Hewitt (1976) suggested that:

> "everyday life consist largely of a flow of routine situations, and many responses in and to them are quite habitual. If one is accustomed to dinner every day at the same hour, sitting down and eating is virtually a matter of reflex" (p. 111).

A non-institutional setting should provide more interactions with others and less reaction to others; thus, social contacts and individual interaction should increase.

Erikson (1964) suggested that "Deviance is not a property inherent in certain forms of behavior; it is a property conferred upon these forms by audiences which directly or indirectly witness them" (p. 11). Thus, definitions of what is considered to be deviant or conforming types of behaviors are developed within the primary group. Schur (1971) felt that application of a deviant label to a particular rule breaker is not a random process. Labeling involved the social audiences determination of whether an act was deviant or not by its reaction to that behavior. Further, Schur (1971) felt that there

were three levels of societal reactions to behavior; significant other, social control agency, and society-at-large. Jahoda, Markova, and Cattermole (1988) suggested that family members (significant others) react more positive to their developmental disabled family members behaviors than institutional staffers.

Within an institutional setting the process of labeling others as deviant may be beneficial for those doing the labeling. Labeling provides a division between those who deviate and those who conform, by providing a sense of "we" for the conforming members of society. Another consequence of labeling, is the preservation and consolidation of social order, stability, and control. Szaz (1986) suggested labeling individuals as "mentally ill" provides power for those doing the labeling. Further, by placing those with labels into "total institutions" labeling can be used as a means of social control.

Cooley's (1985) suggestion that individuals make use of others to adjust behavior could be integrated with Tannenbaum's (1938) process of acquiring a negative label. Cooley (1938) felt that individuals are constantly adjusting their behaviors based upon interactions with others using what he called the "Looking Glass Self." The process is a means to assist the individual in acting in a conforming manner by allowing the individual to perceive others' reactions and make necessary adjustments to behavior. Tannenbaum (1938) described the process of developing a

deviant label. He felt that the individual goes through several stages: first tagged, then identified, next segregated (institutionalized), and ultimately described (psychological exams). Finally, individuals are conscious and self-conscious of their position in society. The label has become a self-fulfilling prophecy. Thus, if individuals recognize they are labeled as being a member of a deviant subgroup then the chances for change are diminished within the institutional setting.

Mead (1985) extended Cooley's idea of the "Looking Glass Self" by suggesting that individuals acquire a sense of self based upon the "generalized other." The acquisition of the "generalized other" develops in stages as the individual interacts with others. These interactions allow the individual to understand societal perceptions of one's self.

The first stage suggested by Mead (1985) is the Preparatory Stage. This is a stage of meaningless imitations by the individual. Symbolic understanding is not possible in this stage. Next, Mead (1985) suggested the Play Stage. During this stage the individual begins to act out different roles. It is in this stage that the individual begins to develop a self by conceiving the self as a third person. This aspect of role taking in the play stage is known as the "significant other." Finally, there is the Game Stage, in which the individual can take on the roles of several others simultaneously. This stage requires greater

cognitive abilities of the individual. For the developmentally disabled, this stage may be quite difficult and for some not obtainable. In this final stage the "generalized other" is formed. This is the ability of the individual to define the behaviors and formulate group expectations. As the individual grows, the "generalized other" grows also.

Mead's (1985) developmental model of the self suggests that individuals acquire the ability to take on perspectives of others. The acquisition of the generalized other for individuals with developmental disabilities in institutions occurs when roles are defined and the interactions become routinized. Further, if the generalized other is not developed as Mead (1985) suggested, the power of the label may become tenuous. Caruso and Hodapp (1988) suggested that public perceptions of the developmental disabled and affective-behavioral qualities which render the individual incapable of functioning in society are the major barriers to normalization movements.

Strengths And Weaknesses: Theories of Socialization and Labeling

The theories presented in this paper represent only a brief part of the body of literature which exists on socialization, developmental disabilities, institutional settings and labeling. Goffman's works on mental illness and institutions is extensive, but his article on the total institution and mental illness (1968) describes similar

situations to those of the developmentally disabled. Individuals with developmental disabilities represent a special population with societally-conceived of characteristics (Caruso and Hodapp, 1988).

The institution is an environment where there is little differentiation between private and public areas (Rosenhan, 1973). Individuals with developmental disabilities are constantly being observed by staff, checked by medical personnel, and examined by staff psychiatric personnel. Lemert (1951) suggested that all people commit acts that violate societal rules, but many transgressions are of minor significance. The institutionalized individual's behavior, however, is often observed and leaves little room for deviation.

Cooley's (1985) formulation of the self conforming to the presumed expectations of others via the "Looking Glass Self" is limited because of its basis in a "normal" population. This limitation is amplified when applied to the developmentally disabled population. The weakness of this perspective is that it does not allow for variations from the norms, and the societal norms are the basis for labels of deviance.

Mead's (1985) theory of the socialization of self through stages presents a better understanding of how developmentally disabled may acquire a self. This analysis of the individual's ability to acquire a self in an institutional setting transcends Cooley's (1985) "Looking

Glass Self." The stages of Preparatory, Play, and Game could be modified to fit the population of the institutionalized developmental disabled; that is, individuals with developmental disabilities could be shown to go through a modified stage process where they learn roles and appropriate behaviors. This could lead to the acquisition of significant others in a limited way and also to a generalized other. However, the normative routinized expectations of the institution would also have to be considered as they are internalized in the socialization process.

There have been many criticisms of the labeling perspective. One suggestion is that the perspective exaggerates the significance of the label in the making of a deviant career. For those with developmental disabilities, the deviant label may become only part of life's course. Further, the labeling perspective is criticized for not being completely accurate. Labeling does not explain the cause or etiology of acts such as rape, criminal homicide, homosexuality, robbery, or child molestation. This perspective is only concerned with the social reactions to these deviations. This is perhaps where its strength in providing insight into developmental disabilities lies. The etiology of some developmental disabilities are known e.g., (head trama, high fever, prenatal-parental drug usage, premature birth, psychosocial deprivation, environmental deprivation). Labeling does not create the developmental

disability, but the social reaction, which follows, does help to create societal treatment of this population. Tannenbaum's (1938) description of tagging, defining, identifying, segregating, describing, emphasizing, making conscious and self-conscious provides an example of the social reaction to developmental disabilities.

Also, the act of labeling does not always produce intensification of the actor's commitment to deviance. However, with the institutionalization of those with developmental disabilities the deviant identity is strengthened by the separation of the group from society. In addition, it is possible to have certain forms of deviant behavior prior to or in the absence of a label; for example, many with mild disabilities can probably exist in society with only minimal stigma.

Labeling may indirectly assist in the oppression of the powerless groups and intensify the rules of the powerful. Rosenhan (1973) describes the oppression and manipulation of those labeled schizophrenic while residing in an institution for the mentally ill. In the case of those with developmental disabilities in the institutional setting, the label appears to be used to classify those with the most severe disabilities and subsequent placements in the most restrictive environments.

CHAPTER IV

METHODS AND ANALYSIS OF THE DATA

Research Design

The research project generating these data was designed to monitor quality assurance for those individuals with developmental disabilities in the state of Oklahoma who were receiving assistance from the Developmental Disabilities Services Division of the Department of Human Services. Interviews were to be conducted with the consumer's primary caregiver (i.e., a parent, social worker or other staff member who was knowledgeable of the individual). Those consumers who were able and present were interviewed personally about their living conditions. However, only 46.0% of this section of the interviews were completed. A lack of adequate interviewing techniques when consumers were unable to verbally communicate or comprehend the questions could have been a possible reason for these low completion rates. During the interview, caregivers were asked about consumer's demographic information, consumer's past living history, adaptive development, challenging behaviors, medical needs, civic involvement, service needs, goals, contact with friends, family, advocates and individuals in

the community. The selection process involved targeting all individuals in Oklahoma receiving support from Developmental Disabilities Services Division of the Department of Human Services. A list of individuals with developmental disabilities was generated from the Developmental Disabilities Services Division of the Department of Human Services. This list proved to be incomplete; individuals not contained in this list were identified as receiving support from the Developmental Disabilities Services Division of the Department of Human Services.

There are an estimated 39,600 individuals with developmental disabilities residing in Oklahoma (Murray, Conroy, Ervin, 1992, p. 1). This number includes both those receiving support and those not receiving support from the Developmental Disabilities Services Division. Out of this total estimated population in Oklahoma, only a small proportion have been contacted and interviewed. Because those individuals not receiving funding have no obligation to participate, are difficult to track, and were not contracted for research, interviews were not conducted with them. In each year, the tracking and recording of information on locations became more complete allowing interviewers in subsequent years to conduct these interviews more quickly. Further, interviewers have become more efficient in gathering the data. Staff training has corrected time consuming mistakes from previous years. This allows the interviewer to conduct a higher number of

interviews on each outing. Therefore, higher numbers of individuals with developmental disabilities continue to be interviewed each year since the beginning of the project (N=2304 in 1991 and N=3572 in 1992). The current list of those individuals with developmental disabilities is the most complete record to date. It is not exhaustive but represents all those known to be receiving funding from the Developmental Disabilities Services Division of the Department of Human Services at the time of interviewing.

The project director at Oklahoma State University began to contact caregivers for the developmental disabled by phone and then by letter to inform them of the purpose of the interviews and to set times for interviews to be conducted. It was necessary to have access to records as well as staff members while conducting the interviews. Teams of interviewers were sent to the residential settings to gather the data. Upon arrival at each residential setting interviewers were given lists of those staff who would be able to participate that day. Staff were informed at the beginning of the interview that the quality assurance surveying was part of a court order and that OSU personnel would be conducting the interviews. Finally, it was made known at each residential setting that interviews might be conducted a second time to assess instrument reliability.

Research Procedures

Data Collection Procedures

The study began in January of 1990 and is an ongoing project to monitor the care received by individuals with developmental disabilities. Shortly after the project began interviewers from the OSU Department of Sociology were trained to administer the survey. Conroy, Lemanowicz, Feinstein, Bernotsky (1990), a research team from Temple University in Pennsylvania, was hired to train the team of researchers. In subsequent years (1991 and 1992) OSU project directors conducted the training of interviewers, although Conroy and his associates from Temple University have remained consultants for the ongoing project.

Residential settings for individuals with developmental disabilities of Oklahoma were contacted, and times for interviews were established. These interviews were to be conducted with the staff at each setting. Interviews took place with the current caregivers of those individuals with developmental disabilities targeted by the monitoring process. The caregivers were instructed that completing the survey was part of a court mandate and that the cooperation of all staff involved with an identified consumer may be necessary in completing the survey. The average amount of time spent filling out the survey was 45 minutes.

Sample Description

The sample used in this research consists of two years of data. The total sample consisted of those individuals with developmental disabilities residing in large state run institutions, foster homes, private or family homes, and group homes receiving support through the Developmental Disabilities Services Division of the Department of Human Services. A subsample, however, used only those who continued to live in Hissom from 1991 to 1992 (Stayers N=231), those who moved from Hissom during 1991 to 1992 (Movers N=44), and those residing in group homes, independent living, semi-independent living, relative's home, their own home, or supportive living in 1991 and stayed there through 1992 (Community Residents N=359).

The range of time between moving from Hissom Memorial Center and the interviewing of caretakers and consumers was between 96 to 58Ø days. This indicates that some questionnaires were not completed within the one-year period (See the limitation section for a discussion of the implications of the range days between interviews). However, 96 days as well as 58Ø days are isolated cases. The mean time lapse was 321.38 days with a standard deviation of 16Ø.82 days for the Movers. For the Stayers the mean time lapse between their 1991 and 1992 interviews was 363.28 days with a standard deviation of 78.ØØ9 days. Residents lapse of time between the 1991 and 1992 interviews was 336.95 days with a standard deviation of 67.72 days.

The demographic characteristics were not similar across categories of sex, race, age, and level of retardation (see Table 1). The Stayers and Community Residents reported similar numbers of males and females surveyed (53.7% males and 46.3% female, 51.3% male and 48.7% female, respectively). The group of Movers were not as equally represented as the other two groups with 72.7% male and 27.3% female. The ages of those in the three groups were fairly consistent with the majority being in their teens, 2Øs and 3Øs. The Stayers were represented by teenagers (18.2%), those in their 2Øs (57.1%) and those in their 3Øs (24.4%). The Movers were represented by teenagers (13.6%), those in their 2Øs (68.2%) and those in their 3Øs (15.9%). The Community Residents were represented by teenagers (9.8%), those in their 2Øs (39.8%), those in their 3Øs (3Ø.6%), and those in their 4Øs (11.1%). The majority of individuals with developmental disabilities in all three categories tended to be Caucasian: Stayers had 81.Ø%, Movers 75.Ø%, and Community Residents 85.2%.

The level of retardation varied for the three categories. The Stayers were primarily represented by those with severe developmental disabilities (14.7%) and those with profound disabilities (79.7%). Movers were represented by those with mild (11.4%), moderate (13.6%), severe (18.2%), and profound (56.8%) levels of developmental disabilities. The Community Residents were represented by those with mild (35.1%), moderate (31.5%), severe (12.5%),

Table 1

Demographic Characteristics and Categories Percentages For Stayers, Movers, and Community Residents in Each Sample Taken

Demographic Characteristics	Stayers (N=231)		Movers (N=44)		Community Residents (N=367)	
Sex						
Males	124	53.7%	32	72.7%	186	50.7%
Females	107	46.3%	12	27.3%	181	49.3%
Age						
5 - 12 yrs.	0	0.0%	1	2.3%	15	4.2%
Teenager	42	18.2%	6	13.6%	35	9.8%
Twenties	132	57.1%	30	68.2%	143	39.8%
Thirties	56	24.4%	7	15.9%	110	30.6%
Forties	1	0.4%	0	0.0%	40	11.1%
Fifty +	0	0.0%	0	0.0%	16	4.5%
Race						
Caucasian	187	81.0%	33	75.0%	314	85.6%
African American	24	10.4%	7	15.9%	22	5.9%
Native American	19	8.2%	3	6.8%	23	6.3%
Other or Unknown	1	0.4%	1	2.3%	8	2.2%
Level of Retardation						
No Mental Retardation	0	0.0%	0	0.0%	1	.3%
Mild	2	0.9%	5	11.4%	123	33.5%
Moderate	10	4.3%	6	13.6%	116	31.6%
Severe	34	14.7%	8	18.2%	46	12.5%
Profound	184	79.7%	25	56.8%	21	5.7%
Unknown	1	0.4%	0	0.0%	60	16.3%

profound (5.6%), and unknown (15.1%) levels of developmental disabilities. Community Residents were represented primarily by those with mild (35.1%), and moderate (31.5%) disabilities. Distributions based on race, sex, and level or retardation are used in the proposed investigation of convergence between types of consumers (combinations of race, sex, and level of retardation), by year, and year by type of consumer for the three categories on the dependent variables.

Questionnaire Rationale

This study makes use of a questionnaire which was developed using many of the same instruments as the ones employed in the monitoring of the closing of Pennhurst in Pennsylvania. Questions on the survey consisted primarily of closed-ended Likert measures. Interviews were generally conducted with the consumer's primary caregivers and consumers when possible. The primary caregiver with whom interviews were conducted were typically social workers, direct care workers, family members, or other staff members who were available. Upon arrival at the state run institutions, lists of consumers were given to the interviewers. These lists contained the consumer's units and workers who had time to meet with the interviewers. During the interview, questions were asked concerning the consumer's demographic information, past living history, contacts with friends, family or advocates, adaptive

development, ability to control challenging behaviors, need for medical services, community contacts, civic involvement, and service needs. These instruments were reported to produce reliable results in past studies. See Appendix A for questionnaire.

The Adaptive Development Scale is the measure of physical capabilities, cognitive attributes, group interactions, and consumer's ability to deal with complex instructions (Murray, Conroy, Ervin, 1992, p. 5). Increased scores on this survey indicate higher levels of independence. Scale items were adapted from Nihiria, Foster, Shellhaas, Lelhan, and the American Association on Mental Deficiency's Adaptive Behavior Scale (1974). This scale was then modified by Conroy and Bradley (1985). Their version (The Behavior Development Scale) included 32 adaptive questions and 14 questions on the ability to control the frequency of challenging behaviors. The current study revised the Behavior Development Scale by adding two questions to the challenging behavior section and also added a section on the consumer's ability to control the severity of challenging behaviors. The version used in the Oklahoma study is known as the Adaptive Development Scale. See Table 17 in Appendix B for the Adaptive Development items.

A Challenging Behavior Scale measures individual ability to control behaviors which are self-injurious, injurious to others, behaviors that damages property, and unusual or disruptive behaviors (Hill and Bruininks, 1984,

p. 382). The instrument contains 16 questions which were divided in two sections by the ability to control the frequency and severity of challenging behavior measured across five dimensions. A higher score on the Challenging Behavior scales indicates the increased ability of an individual to control the frequency or severity of these behaviors. (See Table 18 in Appendix B for both the Challenging Behavior severity and frequency items.)

A Consumer Interview is the third major instrument employed in this study and is the only portion of the interview that directly asks the consumers about their views of their daily lives. This instrument is used as a measure of consumer-perceived quality of life. Similar questions were used by Conroy and Bradley (1985) in their Pennhurst Longitudinal study. (See Table 19 in Appendix B for the Consumer Interview items.)

Several questions labeled Routine Services were included in the quality of life measures. The first is the need for medical services which included the mean number of hours of nursing and physician and neurological services per month that the individual received. Civic involvement included the question: "How often does the person typically participate in organized self-advocacy activities?" Seven responses were possible for this question: daily, weekly, every other week, monthly, quarterly, semiannually, and annually. Social contacts involved questions about weekly contacts the individual had with non-handicapped people in

their neighborhood, during recreational activities, or in commercial settings (stores, restaurants, mall) lasting at least five minutes.

Orientation to three individual goals were included as dependent variables: work, self-care, and interaction goals. Work goals represent the mean of three questions: work skills, skills to obtain, and maintain a job. Self-care goals include the mean of two questions: one on self-care and the other on the reduction of challenging behaviors. Finally, the section on interaction related goals include the mean score of five questions on the total number of goals for the person in the areas: recreation, community living, communication, social skills, and citizenship.

Reliability

Reliability refers to "the quality of measurement method that suggests that the same data would have been collected each time in repeated observations of the same phenomenon (Babbie, 1989, p. G6)." The reliability of instruments used in this research was examined and is attached in Appendix B. Briefly, high interrater reliabilities were found for demographic information, Adaptive Development, Challenging Behavior (severity and frequency), and the Consumer Interview Scales over the two year period. Plus, a high degree of test-retest reliability was found for consumers regarding food quality. See Appendix B for an extended discussion of these reliabilities of the scales.

The reliabilities for the remainder of the questions labeled Routine Services (social contacts, civic involvement, work-skill goals, self-care goals and interaction goals) are discussed in the following section. The criteria for being significant at the .01 level in 1991 with N = 49, r > .35 and in 1992 with N=86, r > .27. The reliability of consumer responses were calculated using Pearson's Product Moment Correlations. Nunnally (1978) has suggested .70 as an acceptable correlation for reliability in basic research (.80 for applied settings). See Table 2 for 1991 and 1992 reliability data on these variables.

The questions on individual social contacts and civic involvement for 1991 and 1992 are shown in Table 2. There were not sufficient data in 1991 to determine the interrater reliabilities on the consumer's social contacts. The 1992 interrater reliabilities for individual social contacts proved to be unreliable with a correlation coefficient of r=.52. However, Devlin (1989) reported interrater reliabilities of .64 and test-retest reliabilities of .90 on the Normalization Scale which contained similar questions to those in the current section on social contacts. The question concerning civic involvement goals was found to be unreliable in 1991 with a coefficient of r=-.02 and also in 1992 with a coefficient of r=.19.

The questions dealing with consumers work skills goals also proved to be unreliable. The questions concerning how many work skills the individual had a correlation

Table 2

Inter-Rater Reliabilities of Medical Services, Civic Involvement, Social Contacts and Goals Items 1991 and 1992

ITEM	CORRELATIONS 1991 (N=49)	1992 (N=86)
Civic Involvement	-.Ø2	.19
Social Contacts	-	.52
Work Skills Goals		
Work Skills	.26	-.Ø4
Skills to Obtain a Job	-.Ø8	.22
Self Care Goals		
Self Care	.62	.42
Reduction of Challenging Behavior	.5Ø	.79
Interaction Related Goals		
Recreational	.25	.66
Community Living	.42	.55
Communication	.6Ø	.36
Social Skills	.61	.71
Citizenship	-	-

Note. To be significant (.Ø1) with N = 49, r > .35 and with N=86, r > .27.

coefficient of r = .26 in 1991 and of r = -.Ø4 in 1992. The question concerning how many goals the consumer had to obtain a job had a correlation coefficient of r = -.Ø8 in 1991 and r = .22 in 1992.

The questions on the number of self care goals had inconsistent results. The question on the number of self care goals was unrelaible with a correlation coefficients of r = .62 in 1991 and r = .42 in 1992. The question on the number of goals to reduce challenging behaviors was unreliable in 1991 with a correlation coefficient of r = .5Ø and reliable in 1992 with a correlaiton coefficient of r = .79.

The remaining items on interaction related goals contained questions on five areas of individual skill development. The only question found to be reliable was the one concerning the number of goals related to developing social skills with a correlation coefficient of r = .71 in 1992. However, this question was unrelaible in 1991 with r = .61. The remainder of questions unfortunately, produced low correlation coefficients. The question concerning the number of recreational goals had a correlation coeffecient of r = .25 in 1991 and r = .66 in 1992. The question on community living goals had coefficients of .42 in 1991 and of .55 in 1992. The question on communication goal had coefficients of .6Ø in 1991 and of .36 in 1992. Finally, the question on the number of goals the individuals had to increase citizenship activities had either a zero reported

or were left blank. Therefore, this question did not have sufficient numbers in 1991 nor in 1992 to calculate a correlation coefficient.

Validity

"Validity is a descriptive term used for a measure which accurately reflects the concept that it is intended to measure (Babbie, 1989, p. G8)." The three basic types of validity are predictive, content, and construct. Predictive validity focuses on how well the instrument estimates an intended variable. Babbie (1989) suggested that content validity refers to the degree to which a measure covers the range of meanings included within a concept (p. 125). Futterman and Arndt (1983) reported strong predictive and content validity coefficients for the Adaptive Behavior Scale. This scale contains items which are similar to the current studies Adaptive Development Scale and Challenging Behavior (frequency) Scale.

The content validity of the research instruments utilized in Oklahoma for this research was assessed using factor analysis. Dunsmore (1993), using the same data as that in the current research, reported all items of the Adaptive Development Scale to load strongly on the first unrotated factor. Dunsmore (1993) also concluded that Challenging Behavior (frequency) items showed strong loadings on the first unrotated factor with item loadings ranging from .73 (rebellious behaviors) to .34 (screams or

yells inappropriately). Dunsmore (1993) further reported on Challenging Behavior (severity) items. Items loaded well but not as high as the for Challenging Behavior (frequency) questions on the first unrotated factor ranging from .56 (use of profane language) to .43 (runs away). In addition, Dunsmore (1993) reported on the validity of the Consumer Interview as having overall weaker but still acceptable first unrotated loadings.

Data Checks

The data were loaded into the OSU mainframe computer using a scantron. Once data were inputted procedures were employed and information arranged so that statistical procedures could properly be used. In the current study, randomly selected interviews from the full 1991 and 1992 data set were checked at the beginning, middle, and end against computer records. Out of approximately 1650 possible coding errors per interview, no errors were detected on three randomly selected interviews. Checks were subsequently conducted to identify the existence of impossible responses in the data. In addition, these three randomly selected interviews were hand checked against computer mathematics (e.g. calculations of subject's scores on scales). These calculations were also found to be completely accurate.

Generalizability of Data

These data were gathered from a sample of individuals with developmental disabilities receiving funds from the Oklahoma Department of Human Services Developmental Disabilities Services Unit. The subjects for this study are those who appeared on both 1991 and 1992 lists. While the sample is described as fully as possible, its representativeness is impossible to know. However, all known recipients of support from The Developmental Disabilities Services Division of The Department of Human Services are included in this sample. The above description of the nature of the sample and the subsample for this research are given so that others can know the composition of them and then, determine the applicability of the results.

Method of Data Analysis

The main focus of the current study is to access within category differences among consumers remaining at Hissom Memorial Center (Stayers), consumers who have moved from Hissom Memorial Center (Movers), and those consumers living in community settings (Community Residents). Analysis of Variance was employed as a statistical technique to examine 1991 to 1992 variations on dependent variables across classifications of type of consumer by race, sex, and level of retardation. The analysis between the 1991 and 1992 scores was conducted only on the Adaptive Development Scale,

and the Challenging Behavior (frequency and severity) Scales for categories of Stayers, Movers, and Community Residents. The rational for not including the other dependent variables (medical services, social contacts, interaction goals, social skill goals, work goals, and consumer interview) was that many cells were empty for several types of consumers among each category. For example, Movers with only 44 subjects distributed across 48 types of consumer by race, sex, and levels of retardation an analysis would be limited and uninterpretable based on the fragmentary data. Further, in all categories there were greatly varying Ns in the analysis, varying amounts of completeness, or low reliabilities of the other dependent variables.

Cook and Campbell (1979) described the elementary Analysis of Variance Model as:

> "a pretest-posttest design with two nonequivalent groups . . . It specifies three components which determine the level of post-test responding. The first is a grand mean of the post-test scores across all individuals, a value that serves to locate the average response on the measurement scale in question. The second is the treatment effect, which is the average value that the treatment adds to, or subtracts from, the post-test scores in the treatment group. The third is the error or residual, which represents the effects of all other factors that contribute to differences between scores (pp. 150-151)."

Previous studies (Schroeder and Henes, 1978; Conroy, Efthimiou, and Lemanowicz, 1982; Conroy, et al. 1990; Conroy, 1992) have employed matching as a method of determining longitudinal differences between categories

on various measures such as the ones in the present study. Babbie (1989) defines matching as:

> ". . .the procedure whereby pairs of subjects were matched on the basis of their similarities on one or more variables, and one member of the pair is assigned to the experimental group and the other to the control group" (p. G4).

In the current study Analysis of Variance is chosen over matching because this method allows for direct comparison of changes within the categories of Movers, Stayers and Community Residents. A matching methodology compares type of consumers between categories which have the same or similar scores on demographic characteristics, such as sex, race, and level of retardation. The differences in a matching methodology and the one employed by the current study is that matching compares similar types of consumers between categories. One limitation of the matching methodology is that it eliminates subjects and lowers the N of matched categories. In addition, matching of types of consumers would change the representativeness of the sample. Rather than a matching methodology, Analysis of Variance was used to examine differences among types of consumers by sex, race, and level of retardation on the dependent variables (adaptive development, the ability to control the frequency of challenging behavior, and the ability to control the severity of challenging behavior) within categories, differences within categories by year, and the interaction of year with type of consumer differences.

The Analysis of Variance procedures were conducted using SAS on a micro computer. First, data were sorted into 1991 and 1992 data sets by identification numbers. Categories of Stayers, Movers, and Community Residents were then sorted into three data sets. Each of these three categories included 1991 and 1992 data on race, sex, level of retardation, adaptive development, ability to control challenging behavior (frequency and severity), medical information, civic involvement, social contacts, work goals, self-care goals, interaction goals, consumer satisfaction, date of interview, and date of birth. These smaller data sets were then down loaded from the main frame computer onto floppy disks. The data set was then checked for inconsistencies on demographic variables (sex, race, and level of retardation) between 1991 and 1992. When inconsistent responses were found between 1991 and 1992 data on race, sex, or level of retardation the response were set to the 1991 record. These records were set to the 1991 data primarily because the group of Movers were in Hissom and these data were considered to be more consistent.

Limitations

The study had several built-in limitations. The first limitation was that the research was mandated by a court order based on a class action law suit. The caregivers answering the questions may have felt obligated to give overly optimistic or inflated accounts of the actual

consumers' behaviors and abilities. This could have been influenced by several factors, including quality of the informants and specificity of the items. Examiners should consider the following:

> a) can the potential informant communicate the observations?, b) Does the potential informant have a sufficient familiarity with the clients?, c) has the potential informant viewed a wide range of the client's behavior?, and d) were the clients likely to perform at their optimal level in the presence of the informant?" (Knapp and Salend, 1983, p. 64).

Caution is necessary when interpreting the 1991 and 1992 data figures as these may not reflect a true cross section of the population of Oklahoma's individuals with developmental disabilities receiving assistance through Developmental Disability Services Division. These data only represent, to the best of our knowledge, those individuals. However, in the course of the data collection individuals have been discovered that do receive funds through the Developmental Disabilities Services Division and were added to the list of those to be surveyed.

The time between interviews was not the same amount for those in each category. The data indicated that for Movers the range of time between changing residences and being interviewed was over one year. Thus, some of these individuals were missed in the interviewing process in 1991. Further, the range of time between interviews varies between 96 and 58Ø days for the Movers. Subjects interviewed within

96 days may have few changes while those interviewed in the 58Ø day range may have experienced greater variations on the dependent variables. The standard deviation of Movers interviews were 16Ø.82 days. This standard deviation was higher than the other categories of Stayers and Community Residents. This inconsistentcy may have been due to the Movers not being in the same location over the interview period of 1991 to 1992. Although these variations in time might be expected with the movement of these individuals into other settings, it limits any statements about the changes occurring on the dependent variables.

Other limitations are that inconsistencies were found in sex, race, and level of retardation for the three categories between the reported levels in 1991 and 1992. The misreporting of sex has been rare. In one case, which has been traced, a legitimate mistake was made by the interviewer when collecting the data. This mistake was traced to the institution's reports and corrected within the quality assurance data set. Inconsistencies in reporting of race and level of retardation have been more common.

The variations of race within this data were usually legitimate and not necessarily carelessness of the caregiver or the interviewer. Many individuals residing in the institution were classified as Caucasian or African American while having diverse genealogies (most common are Native American or African American). When these individuals were placed into community settings their racial status became of

greater importance in receiving assistance from agencies (B.I.A., Bureau for Indian Affairs) for the care and support of these individuals. This limits our ability to trust race as a classification. Further, the majority of data were gathered from caucasions. This limits our ability to make statements concerning variations by race.

The level of reported individual retardation is also highly subjective. There may be acceptable changes in reported levels of retardation from one year to the next. These levels are based somewhat on observable behavior. As reported earlier, the level of retardation was changed if necessary to the what was reported in 1991. For the Movers, some of their records stayed, impairing the ability of new caretakers to know fully about these individual's pasts. Characteristics of the Movers may not have been as well known after they moved into the community where new caretakers were responsible for providing information on the characteristics of the consumer by race, sex, and level of retardation. Several changes had to be made for each group, with the most changes being made in the group of Community Residents. Changes in reported level of retardation may represent the perceived increases in the individuals' behaviors as deinstitutionalization occurs and expectations change with the setting.

There were differences found in reported levels of retardation among the three categories which limits a complete analysis of all types of consumers. The Stayers

were primarily represented by those with severe developmental disabilities (14.7%) and those with profound disabilities (79.7%). Movers were represented by those with mild (11.4%), moderate (13.6%), severe (18.2%), and profound (56.8%) levels of developmental disabilities. The Community Residents were represented by those with mild (35.1%), moderate (31.5%), severe (12.5%), profound (5.6%), and unknown (15.1%) levels of developmental disabilities. Community Residents were represented primarily by those with mild or moderate disabilities, yielding a greater number of consumer interviews completed, higher levels of adaptive development, less medical services received, more social contacts, and general differences from the other two categories in the number of goal related behaviors.

There exists several limitations in the consumer interview. First, there were differences between categories on the responce rate on the consumer interview. There were low percentages of actual interviews with the consumers, especially for Stayers (16.9%). Although, Movers had a completion rate of 72.1%, the small Ns' prevented a comprehensive analysis of the variance among types of consumers. On the other hand, Community Residents had high completion rates of 69.1% on the consumer interview. The Community Residents were the only category where a complete analysis of their responses by types of consumers were possible. Second, interviewers reported that client's answers sometimes appeared to be "yes" even if the interviewer was

unsure of the client's understanding of the questions. Finally, many of the interviewers had little or no experience in working with people having developmental disabilities. Therefore, the interviewers may not have probed for further depth on answers of "yes" when in fact the consumer may have been able to respond more completely.

Two other limitations were the inconsistency and incompleteness of the data. The inconsistency between 1991 and 1992 on demographic variables, such as race and level of mental retardation, presented difficulties when utilizing Analysis of Variance methodologies. The incompleteness of data on several of the routine services made running Analysis of Variance impossible. One reason for the incomplete data was that for some variables a zero could not be distinguished from a blank or missing data. The questions on the number of social contacts were so incomplete as to allow only two matches between 1991 and 1992 data for the category of Stayers by one particular type of consumer by race, sex, and level of retardation.

One final limitation was that interviews were generally conducted by different individuals in 1991 and 1992. Further, the 1992 interviews may have been conducted with different caretakers. Therefore, the question is raised; Are variations on the dependent due to changes in interviewers, caretakers, or consumers? The current research cannot separate these factors.

CHAPTER V

RESULTS

Introduction

The results section applies the literature and theories to the outcomes of the Analysis of Variance procedures. The Analysis of Variance focused on three dependent variables (Adaptive Development, Challenging Behavior (frequency) and Challenging Behavior (severity) as they varied by type of consumer (combinations of race, sex, and level of retardation), differences by year, and interaction by year across types of consumers for categories of Movers, Stayers, and Community Residents.

The following three sections include tables used in reporting the results of the Analysis of Variance for the three dependent variables of Adaptive Development, Challenging Behavior (frequency), and Challenging Behavior (severity) for Stayers, Movers, and Community Residents. In these tables, the two-way analysis will examine each dependent variable by type of consumer, by year, and interaction of type of consumer with year.

Figures are also used in displaying differences between 1991 and 1992 mean scores on the dependent variables for

each type of consumer by race, sex, and level of retardation. The horizontal axis in each figure shall represent types of consumers by race, sex, and level of retardation. Types of consumer are represented by three numbers. The first, is for race where 1 = Caucasian, 2 = African American, 6 = Native American, and 8 = other. The second number is for sex where 1 = males and 2 = females. Finally, level of retardation is represented by five different numbers, where 1 = no mental retardation, 2 = mild levels of retardation, 3 = moderate levels of retardation, 4 = severe levels of retardation, 5 = profound levels of retardation, and 6 = unknown levels of retardation.

The vertical axis contains the mean scores for each of these types of consumers on the dependent variables (Adaptive Development, Challenging Behavior Frequency, and Challenging Behavior Severity) in both 1991 and 1992. Thus, the research questions identified in Chapter Two will be examined here.

Figures shall be supported by corresponding tables which give type of consumer means for 1991 and 1992 as well as overall means for each type of consumer. Additionally, the probability of differences between 1991 and 1992 for type of consumer means are provided. Finally, the total mean for each year is given.

Research Question One: Analysis of Variance for Stayers

Research question one investigates among Stayers if there are differences by type of consumer (combinations of race, sex, and level of retardation), by year, or by interaction of type of consumer and year on the dependent variables.

Adaptive Development

Adaptive Development is examined first (see Table 3). Among type of consumers that stayed at Hissom Memorial Center significant difference are found on their Adaptive Development scores at p = .Ø1 with nine degrees of freedom and an f-value of 23.84. The range among Stayers means scores by type of consumer on Adaptive Development is from 1Ø.39 to 81.Ø6 (see Table 4). The difference between Stayers' 1991 and 1992 mean scores on Adaptive Development are not significant at p = .Ø1. Also, significant differences are found among types of consumers by year with nine degrees of freedom and an f-value of 2.82 at p = .Ø1. Therefore, the difference between years is not consistent across types of consumers. Figure 1 illustrates these differences for the Stayers on Adaptive Development by type of consumer. Stayers' mean scores are given for both 1991 and 1992 for each type of consumer which are represented by more than one individual (see Table 4). Figure 1 reveals that the 1992 mean scores are generally, but not

Table 3

Analysis of Variance by Race, Sex, and Level by Year for Adaptive Development, Challenging Behavior (frequency and severity) For Stayers

Variable	Degrees of Freedom	Mean Square	f	p.
Adaptive Development				
Total	439			
Race, Sex, & Level	9	11216.40	23.84	.01
Subjects (Race, Sex, & Level) error (a)	210	470.51		
Year	1	28.37	.87	.35
Race, Sex, Level, * Year	9	91.58	2.82	.01
Subjects * Year (Race, Sex, & Level) error (b)	210	32.50		
Challenging Behavior (Frequency)				
Total	445			
Race, Sex, & Level	9	1259.96	4.12	.01
Subjects (Race, Sex, & Level) error (a)	213	305.79		
Year	1	2036.56	24.90	.01
Race, Sex, Level * Year	9	229.74	2.81	.01
Subjects * Year (Race, Sex, & Level) error (b)	213	81.80		
Challenging Behavior (Severity)				
Total	445			
Race, Sex, & Level	9	927.66	5.96	.01
Subjects (Race, Sex, & Level) error (a)	213	155.62		
Year	1	642.79	14.31	.01
Race, Sex, & Level * Year	9	172.44	3.84	.01
Subjects * Year (Race, Sex, & Level) error (b)	213	44.93		

Table 4

Stayers 1991 Mean, 1992 Mean, Type of Consumer Mean, and Probabilities on Adaptive Development

Type of Consumer RACE	SEX	LEVEL		1991 Mean	1992 Mean	Type of Consumer Mean	p.
1	1	3	(n=5)	63.75	71.56	67.66	.18
1	1	4	(n=17)	56.76	57.35	57.06	.85
1	1	5	(n=74)	22.30	23.07	22.68	.40
1	2	3	(n=4)	76.37	85.74	81.06	.10
1	2	4	(n=14)	48.21	53.46	50.84	.09
1	2	5	(n=70)	22.42	19.98	21.20	.01 *
2	1	5	(n=10)	27.58	30.16	28.87	.26
2	2	5	(n=10)	14.22	14.38	14.30	.95
6	1	5	(n=11)	17.05	20.46	18.75	.09
6	2	5	(n=5)	10.31	10.47	10.39	.93
TOTAL			(n=220)	27.91	28.42	28.17	

* Indicated a significant difference was found between the 1991 and 1992 means on this type of consumer.

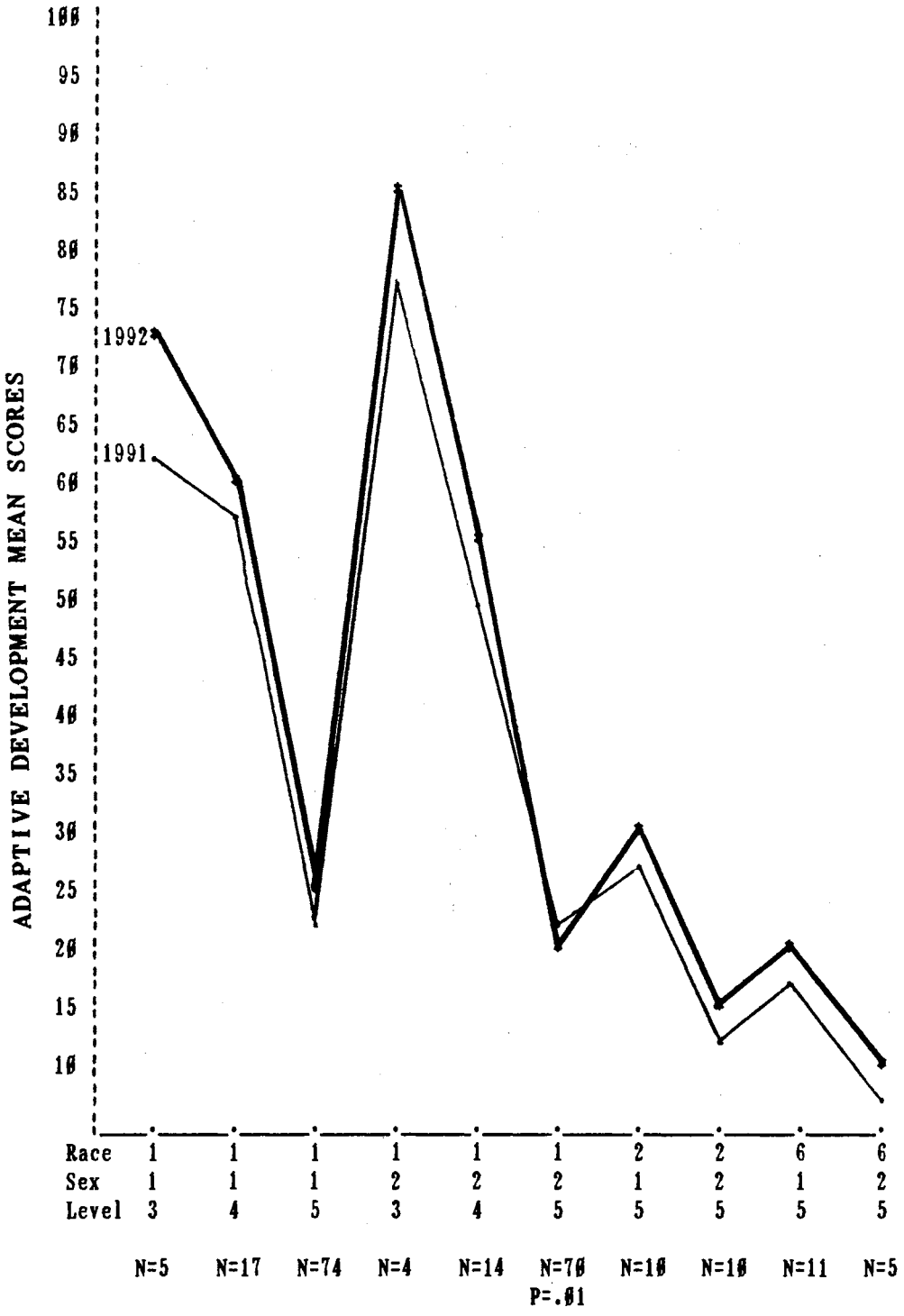

Figure 1. Mean Scores on Adaptive Development by Sex, Race, and Level of Retardation for Stayers.

significantly higher than the 1991 mean scores, except in the case of Caucasian females with profound levels of retardation (type of consumer designated 125). For these individuals a significant difference exists at the .Ø1 level with one degree of freedom and an f-value of 9.21 between their 1991 and 1992 mean scores with the 1991 mean being higher. This differed from the pattern of higher scores in 1992 on the other types of consumers' Adaptive Development mean scores. Finally, an interesting visual observation of Figure 1 is that as the level of retardation increases the Adaptive Development scores tend to decrease.

Challenging Behavior (frequency)

Challenging Behavior (frequency) is examined next (see Table 3). Differences are found to be significant among types of Stayers when grouped by race, sex, and level of retardation with nine degrees of freedom and an f-value of 4.12 at p = .Ø1. The range among Stayers' mean scores by type of consumer on Challenging Behavior (frequencies) is from 72.81 to 97.5Ø (see Table 5). The difference between the ability of consumers to control the frequency of challenging behaviors between 1991 and 1992 is also found to be significant at p = .Ø1 with one degree of freedom and an f-value of 24.9Ø. Additionally, there is a significant interaction found among types of consumers and year on ability to control the frequency of challenging behavior with nine degrees of freedom and an f-value 2.81. These

Table 5

Stayers 1991 Mean, 1992 Mean, Type of Consumer Mean, and Probabilities on Challenging Behavior (frequency)

Type of Consumer RACE	SEX	LEVEL		1991 Mean	1992 Mean	Type of Consumer Mean	p.
1	1	3	(n=5)	67.50	78.13	72.81	.28
1	1	4	(n=17)	68.20	82.17	75.19	.02
1	1	5	(n=75)	83.54	90.00	86.77	.01 *
1	2	3	(n=4)	75.00	82.82	78.91	.27
1	2	4	(n=14)	88.62	89.73	89.18	.70
1	2	5	(n=71)	89.88	90.45	90.16	.68
2	1	5	(n=10)	85.00	87.19	86.10	.68
2	2	5	(n=10)	97.19	97.81	97.50	.17
6	1	5	(n=12)	90.63	90.37	90.50	.93
6	2	5	(n=5)	82.50	95.63	89.06	.06
TOTAL			(n=223)	85.23	89.51	87.37	

* Indicated a significant difference was found between the 1991 and 1992 means on this type of consumer.

differences are illustrated for Stayers in Figure 2. Stayers' means are given for both 1991 and 1992 for types of consumers which are represented by more than one individual. Figure 2 reveals that the 1992 means are generally but not significantly higher than the 1991 means. The higher mean score in 1992 represents an increase in the ability to control the frequency of challenging behavior for Stayers. However, there are significance differences between 1991 and 1992 means in only one grouping (Caucasian males with profound levels of retardation, type of consumer designated 115). The difference between these individuals' (n = 75) 1991 and 1992 mean scores is significant at the .Ø1 level with one degree of freedom and an f-value of 21.Ø4. Finally, visual observation of Figure 2 reveals that as the level of retardation increases the ability to control the frequency of challenging behaviors also increases.

Challenging Behavior (severity)

Challenging Behavior (severity) is examined next (see Table 3). There is a significant difference among types of consumer means at p = .Ø1 for Stayers on their ability to control the severity of challenging behaviors with nine degrees of freedom and an f-value of 5.96. The range among mean scores for Stayers by type of consumer on their abilities to control the severity of challenging behavior is from 76.67 to 98.44 (see Table 6). The difference between 1991 and 1992 on Stayers' scores on the ability to control

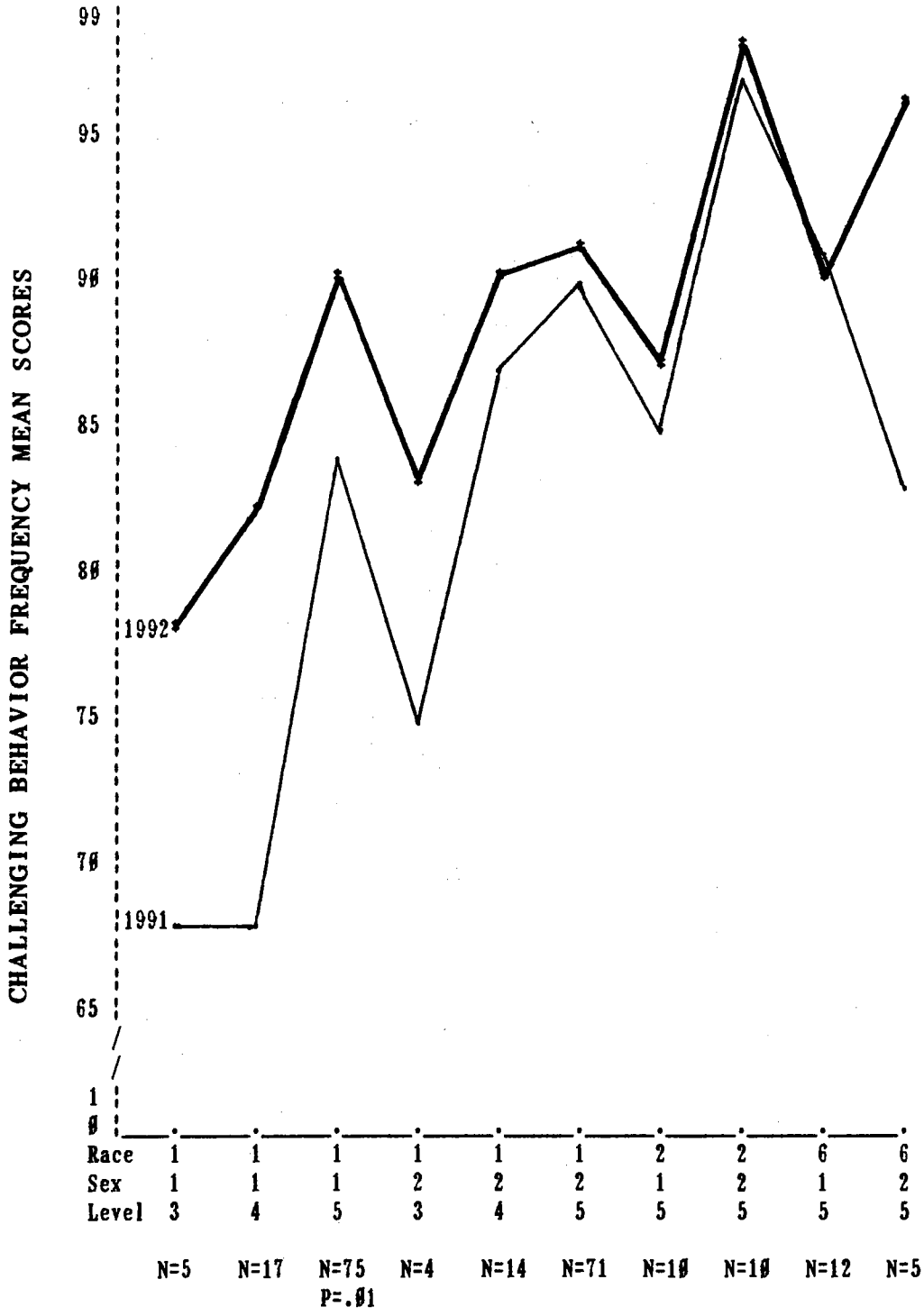

Figure 2. Mean Scores on Challenging Behavior (frequency) by Sex, Race, and Level of Retardation for Stayers

Table 6

Stayers 1991 Mean, 1992 Mean, Type of Consumer Mean, and Probabilities on Challenging Behavior (severity)

Type of Consumer RACE	SEX	LEVEL		1991 Mean	1992 Mean	Type of Consumer Mean	p.
1	1	3	(n=5)	63.33	85.00	76.67	.03
1	1	4	(n=17)	76.47	86.03	81.25	.04
1	1	5	(n=75)	90.78	94.53	92.65	.01 *
1	2	3	(n=4)	84.38	89.07	86.32	.27
1	2	4	(n=14)	93.16	90.33	91.74	.46
1	2	5	(n=71)	94.57	94.19	94.38	.72
2	1	5	(n=10)	92.50	92.92	92.71	.89
2	2	5	(n=10)	98.12	98.75	98.44	.19
6	1	5	(n=12)	93.40	94.97	94.18	.45
6	2	5	(n=5)	91.25	96.67	93.96	.02
TOTAL			(n=223)	93.39	90.99	92.19	

* Indicated a significant difference was found between the 1991 and 1992 means on this type of consumer.

the severity of challenging behaviors is also significant at p = .Ø1, with one degree of freedom and an f-value of 14.31. Further, there is a significant interaction found between types of consumers and year on ability to control the severity of challenging behavior with nine degrees of freedom and an f-value of 3.84 at p = .Ø1. Figure 3 illustrates these differences for the Stayers' mean scores on ability to control the severity of challenging behaviors by type of consumer. Stayers' mean scores are given for both 1991 and 1992 for types of consumers represented by more than one individual. Figure 3 reveals that the 1992 means are generally higher than the 1991 means. In only two of the ten types of consumers (124 and 125) were 1991 means higher, but not significantly. The higher mean score represents the ability of the individual to control the severity of challenging behaviors as perceived by those being interviewed. A significant difference was found between 1991 and 1992 means only in one type of consumer (Caucasian males with profound levels of retardation, type of consumer designated 115). The difference between these 75 individual's 1991 and 1992 means is significant at the .Ø1 level with one degree of freedom and an f-value of 17.87. Finally, Figure 3 indicates a similar pattern as noted in the results of Challenging Behavior (frequency). As the level of retardation increases, there seems to be a trend for the ability to control the severity of challenging behaviors to also increase.

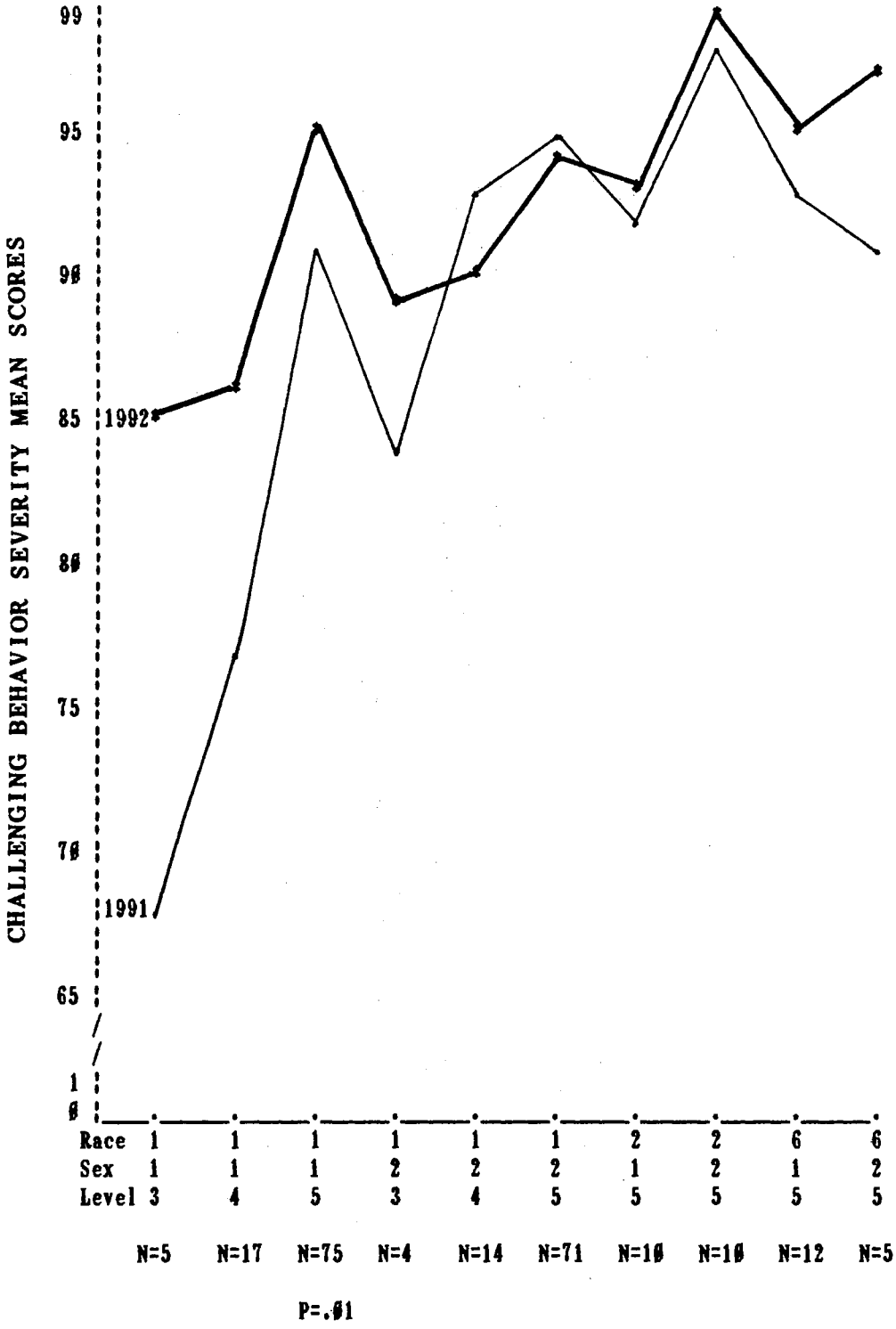

Figure 3. Mean Scores on Challenging Behavior (severity) by Sex, Race, and Level of Retardation for Stayers.

Research Question Two: Analysis of Variance for Movers

Research question two investigates among Movers if there are differences by type of consumer (combinations of race, sex, and level of retardation), by year, or by interaction of type of consumer and year on the dependent variables.

Adaptive Development

Adaptive Development is now examined for Movers (see Table 7). There is a significant difference at p = .01 among Movers by type of consumer on Adaptive Development with seven degrees of freedom and an f-value of 3.47. The range among Mover's means scores by type of consumer on Adaptive Development is from 31.84 for type of consumer 625 to 81.84 for type of consumer 112 (see Table 8). The difference between 1991 and 1992 Adaptive Development means, however, is not significant with p = .10 and an f-value of 5.25. Further, there is not a significant difference between these types of consumers by year with seven degrees of freedom and an f-value of .29 at p = .95. Figure 4 reveals the lack of interaction of type of consumers by year and displays reasonable consistency among consumer scores by year. Additionally, Figure 4 illustrates the 1992 scores are generally higher, but not significantly, than the 1991 scores. However, none of the differences by type of consumer are significant between 1991 and 1992 means at

Table 7

Analysis of Variance by Race, Sex, and Level by Year for Adaptive Development, Challenging Behavior (frequency and severity) For Movers

Variable	Degrees of Freedom	Mean Square	f	p.
Adaptive Development				
Total	71			
Race, Sex, & Level	7	1720.15	3.47	.01
Subjects (Race, Sex, & Level) error (a)	28	495.18		
Year	1	287.08	5.25	.03
Race, Sex, & Level * Year	7	15.64	.29	.95
Subject * Year (Race, Sex, & Level) error (b)	28	54.64		
Challenging Behavior (Frequency)				
Total	71			
Race, Sex, & Level	7	647.48	2.64	.03
Subjects (Race, Sex, & Level) error (a)	28	245.29		
Year	1	4.87	0.02	.88
Race, Sex, & Level * Year	7	119.05	0.56	.78
Subject * Year (Race, Sex, & Level) error (b)	28	213.84		
Challenging Behavior (Severity)				
Total	71			
Race, Sex, & Level	9	203.67	1.35	.26
Subjects (Race, Sex, & Level) error (a)	28	150.47		
Year	1	127.49	1.30	.26
Race, Sex, & Level * Year	9	182.50	1.05	.42
Subject * Year (Race, Sex, & Level) error (b)	28	97.84		

Table 8

Movers 1991 Mean, 1992 Mean, Type of Consumer Mean, and Probabilities on Adaptive Development

Type of Consumer RACE	SEX	LEVEL		1991 Mean	1992 Mean	Type of Consumer Mean	p.
1	1	2	(n=2)	80.86	82.81	81.84	.34
1	1	3	(n=4)	71.88	74.42	73.15	.61
1	1	4	(n=6)	55.34	58.07	56.71	.58
1	1	5	(n=13)	41.23	43.63	42.43	.50
1	2	3	(n=2)	49.61	57.04	53.32	.16
1	2	5	(n=4)	41.99	51.37	46.68	.15
2	1	5	(n=3)	40.37	45.84	43.10	.26
6	2	5	(n=2)	28.52	35.16	31.84	.11
TOTAL			(n=36)	48.96	52.95	50.96	

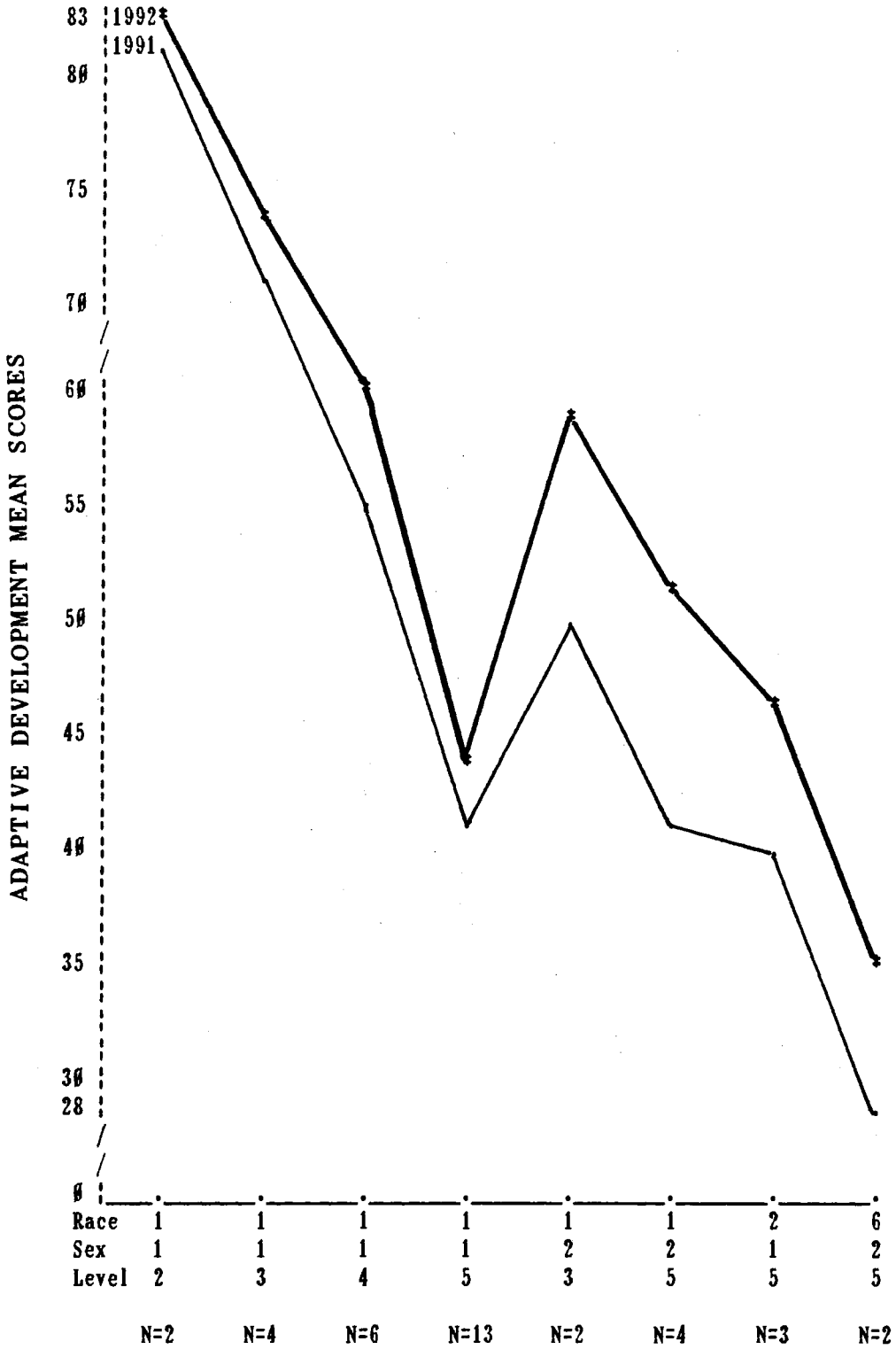

Figure 4. Mean Scores on Adaptive Development by Sex, Race, and Level of Retardation for Movers.

the .Ø1 level. The low Ns among the Movers' may have contributed to the lack of significant variations on the dependent variables. As noted in the discussion of the visual pattern established in Figure 1 there is also a general decline in Adaptive Development means scores as the level of retardation increases for Movers (see Figure 4).

Challenging Behavior (frequency)

Challenging Behavior (frequency) is examined next (see Table 7). There is not a significant difference found among Movers by type of consumer on the Challenging Behavior (frequency) Scale with seven degrees of freedom and an f-value of 2.64 and p = .Ø3. The range among Mover's means scores by type of consumer on the ability to control the frequency of challenging behaviors are from 6Ø.94 for type of consumer 215 to 92.19 for type of consumer 123 (see Table 9). There is no difference between 1991 and 1992 Movers' mean scores on Challenging Behavior (frequency), p = .88, with one degree of freedom and an f-value of .Ø2. Thus, Movers ability to control the frequency of challenging behavior remained very similar between 1991 and 1992 (See totals in Table 9). Finally, no significant difference is found for the interaction of types of consumers by year, with seven degrees of freedom and an f-value of .56 at p = .78. This is reflected in Figure 5. Half of the type of consumers in the category of Movers had mean scores higher in 1991, while the other half are higher in 1992,

Table 9

Movers 1991 Mean, 1992 Mean, Type of Consumer Mean, and Probabilities on Challenging Behavior (frequency)

Type of Consumer RACE	SEX	LEVEL		1991 Mean	1992 Mean	Type of Consumer Mean	p.
1	1	2	(n=2)	84.38	95.32	89.85	.69
1	1	3	(n=4)	85.94	96.10	91.02	.47
1	1	4	(n=6)	79.17	83.34	81.25	.70
1	1	5	(n=13)	89.19	86.78	87.99	.56
1	2	3	(n=2)	95.32	89.07	92.19	.50
1	2	5	(n=4)	83.60	87.50	85.55	.80
2	1	5	(n=3)	61.46	60.42	60.94	.93
6	2	5	(n=2)	98.44	79.69	89.07	.50
TOTAL			(n=36)	84.81	85.33	85.07	

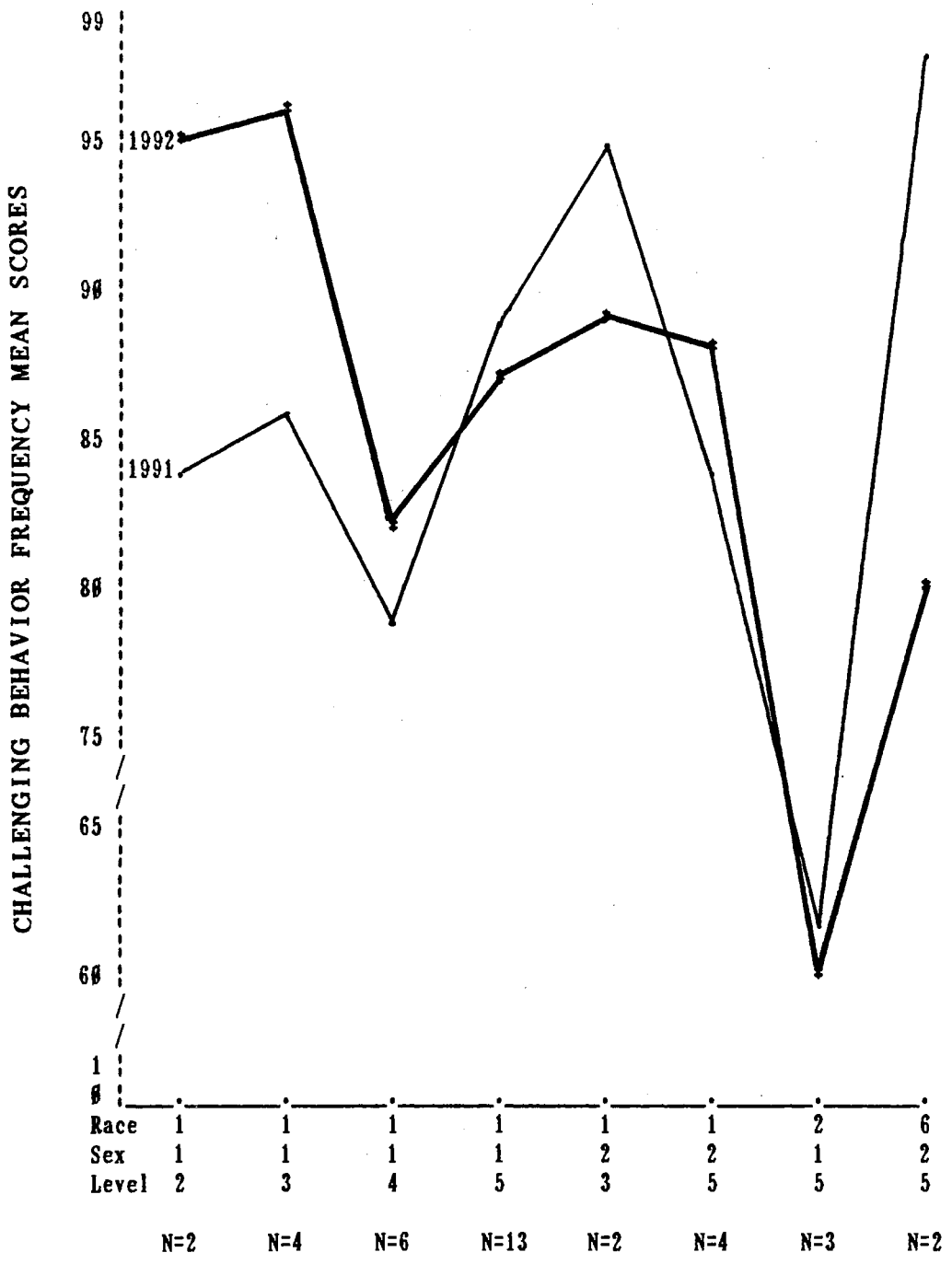

Figure 5. Mean Scores on Challenging Behavior (frequency) by Sex, Race, and Level of Retardation for Movers.

therefore no clear pattern is established on ability to control the frequency of challenging behavior as was seen in the Stayers. No significant differences at the .Ø1 level between 1991 means and 1992 means were found for any of these types of consumers among the Movers (see Table 9). The lack of significance on the ability to control the frequency of challenging behavior among Movers may be due to small Ns.

Challenging Behavior (severity)

Challenging Behavior (severity) for Movers is examined next (see Table 7). There is no significant difference among Movers by type of consumer on the ability to control the severity of challenging behaviors with seven degrees of freedom and an f-value of 1.35 and p = .26. The range of mean scores among types of Movers on their abilities to control the severity of challenging behaviors are from 78.47 for type of consumer 215 to 95.31 for type of consumer 123 (see Table 1Ø). Similarly, the difference between 1991 and 1992 scores on ability to control the severity of challenging behaviors is not significant at p = .Ø1 with one degree of freedom and an f-value of 1.3Ø (see totals in Table 1Ø). Further, there is not a significant difference found at p = .Ø1 between the types of consumers and year with seven degrees of freedom and an f-value of 1.Ø5. Figure 6 illustrates these differences by type of consumer and year for the Movers' means on Challenging Behavior (severity). Additionally Figure 6 reveals that the 1992

Table 10

Movers 1991 Mean, 1992 Mean, Type of Consumer Mean, and Probabilities on Challenging Behavior (severity)

Type of Consumer RACE	SEX	LEVEL		1991 Mean	1992 Mean	Type of Consumer Mean	p.
1	1	2	(n=2)	78.13	88.54	83.33	.64
1	1	3	(n=4)	87.50	96.88	92.19	.43
1	1	4	(n=6)	85.42	92.01	88.72	.35
1	1	5	(n=13)	93.91	91.19	92.55	.23
1	2	3	(n=2)	96.88	93.75	95.31	.66
1	2	5	(n=4)	88.02	95.83	91.93	.50
2	1	5	(n=3)	73.61	83.33	78.47	.19
6	2	5	(n=2)	100.00	89.59	94.79	.50
TOTAL			(n=36)	89.06	91.72	90.36	

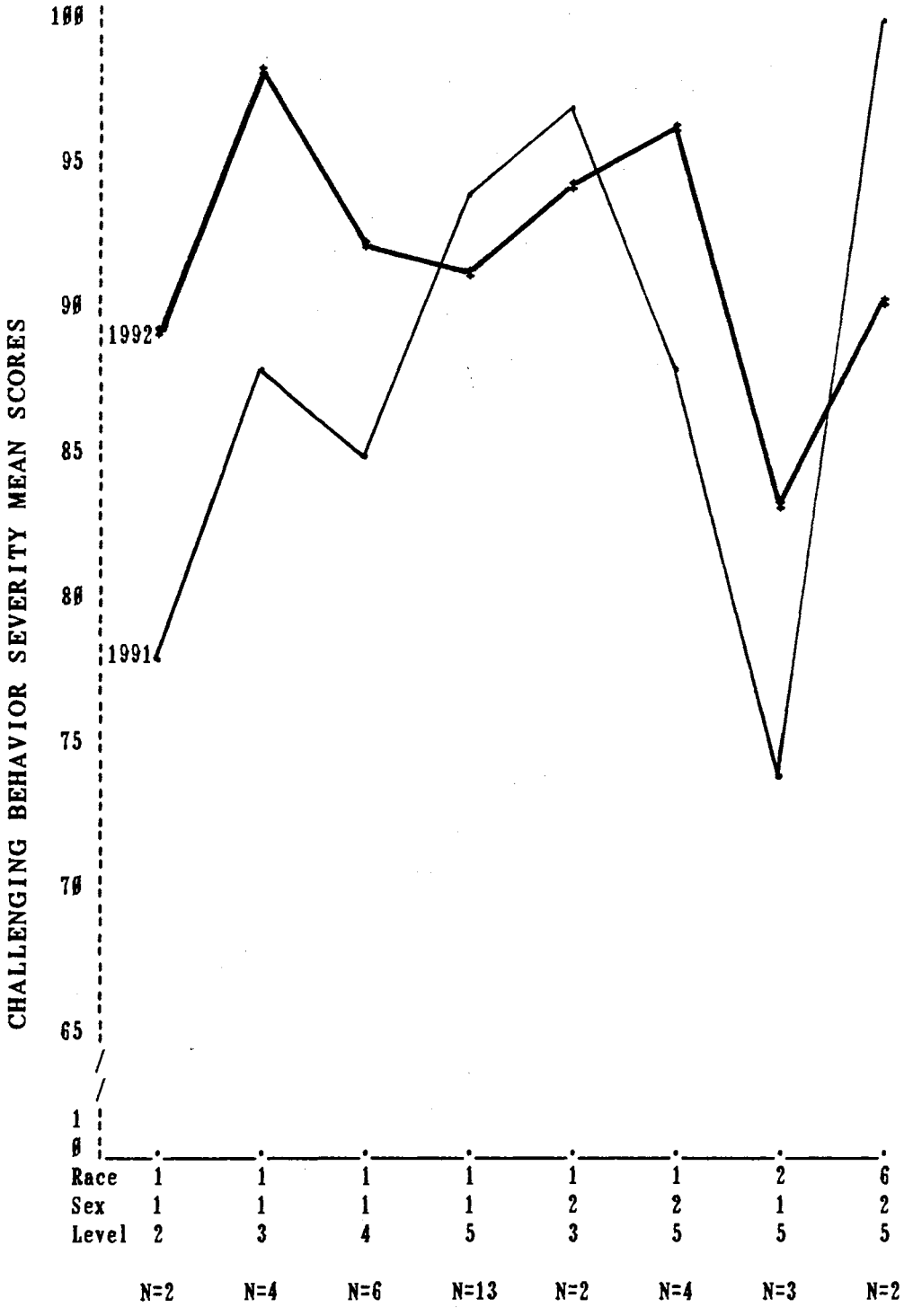

Figure 6. Mean Scores on Challenging Behavior (severity) by Sex, Race, and Level of Retardation for Movers.

means are higher in five of the eight groupings than the 1991 means. In three types of consumers, the 1991 means are higher than 1992 means on ability to control the severity of challenging behaviors. These types of consumers with higher means in 1991 are; Caucasian, males with profound levels of retardation (115), Caucasian females with moderate levels of retardation (123), and Native American females with profound levels of retardation (625). No significant differences are found at the .Ø1 level between 1991 and 1992 mean scores for any type of consumers. Figure 6 appears to have no general patterns by type of consumer, as is seen in the Challenging Behavior (severity) means for Stayers (Figure 3).

Research Question Three: Analysis of Variance for Community Residents

The third research question investigates among Community Residents if there are differences by type of consumer (combinations of race, sex, and level of retardation), by year, or by interaction of type of consumer and year on the dependent variables.

Adaptive Development

Adaptive Development is examined first (see Table 11). Among type of consumers that lived in community settings between 1991 and 1992 there are significant differences found on their Adaptive Development scores at p = .Ø1 with 22 degrees of freedom and an f-value of 7.53. The range of

Table 11

Analysis of Variance by Race, Sex, and Level by Year for Adaptive Development, Challenging Behavior (frequency and severity) For Community Residents

Variable	Degrees of Freedom	Mean Square	f	p.
Adaptive Development				
Total	711			
Race, Sex, & Level	22	5151.65	7.53	.01
Subjects (Race, Sex, & Level) error (a)	333	683.92		
Year	1	157.38	.52	.48
Race, Sex, & Level * Year	22	349.54	1.15	.30
Subject * Year (Race, Sex, & Level) error (b)	333	304.41		
Challenging Behavior (Frequency)				
Total	711			
Race, Sex, & Level	22	195.48	1.18	.26
Subjects (Race, Sex, & Level) error (a)	333	165.76		
Year	1	355.39	5.92	.03
Race, Sex, & Level * Year	22	43.99	.74	.80
Subject * Year (Race, Sex, & Level) error (b)	333	59.79		
Challenging Behavior (Severity)				
Total	711			
Race, Sex, & Level	22	85.49	1.00	.46
Subjects (Race, Sex, & Level) error (a)	333	85.19		
Year	1	142.73	5.65	.02
Race, Sex, & Level * Year	22	13.57	.54	.96
Subject * Year (Race, Sex, & Level) error (b)	333	25.26		

mean scores among types of Community Residents on Adaptive Development is from 33.42 for type of consumer 115 to 96.1Ø type of consumer 222 (see Table 12). The difference between Community Residents' 1991 and 1992 mean scores on Adaptive Development is not significant at p = .Ø1. There is not a significant difference found among types of consumers by year at p = .Ø1. Therefore, the differences between years is reasonably consistent across types of consumers. Figure 7 demonstrates this relative consistency between 1991 and 1992 type of consumer mean scores. Additionally, visual inspection of figure 7 reveals 13 of the 23 pairs of scores were higher in 1991, nine were higher in 1992, and one score was the same for type of consumer. Therefore, a small, yet insignificant decrease in Community Residents Adaptive Development mean scores is observed. However, none of the differences between 1991 and 1992 mean scores for types of consumers are significant at the p = .Ø1 level (see Table 12). Small Ns' may contribute to the lack of significance between these mean scores, only four of the 13 scores which are higher in 1991 have Ns' above 5Ø.

The previous discussions of Figures 1 and 4 on Adaptive Development mean scores by type of consumer there in noted a general pattern of decline as level of retardation increases this pattern seems to exist for Community Residents as well. However, this pattern is more difficult to see in Figure 7. The subjects are compressed into the same size figure as in the previous categories of Stayers and Movers because there

Table 12

Community Residents 1991 Mean, 1992 Mean, Type of Consumer Mean, and Probabilities on Adaptive Development

Type of Consumer RACE	SEX	LEVEL		1991 Mean	1992 Mean	Type of Consumer Mean	p.
1	1	2	(n=54)	85.19	84.24	84.71	.44
1	1	3	(n=5Ø)	77.31	79.97	78.64	.89
1	1	4	(n=19)	66.33	67.11	66.72	.66
1	1	5	(n=12)	26.43	4Ø.41	33.42	.18
1	1	6	(n=27)	66.ØØ	62.21	64.11	.94
1	2	2	(n=58)	85.23	82.54	83.89	.88
1	2	3	(n=5Ø)	81.47	78.77	8Ø.12	.24
1	2	4	(n=2Ø)	58.32	62.66	6Ø.49	.11
1	2	5	(n=5)	52.97	37.5Ø	45.24	.58
1	2	6	(n=18)	68.97	63.67	66.32	.92
2	1	2	(n=2)	88.67	85.16	86.91	.56
2	1	3	(n=8)	84.Ø8	7Ø.22	77.15	.55
2	1	4	(n=2)	53.91	61.33	57.62	.38
2	1	6	(n=3)	61.46	61.46	61.46	1.ØØ
2	2	2	(n=2)	98.Ø5	94.14	96.1Ø	.56
2	2	3	(n=2)	86.33	78.91	82.62	.33
2	2	6	(n=3)	86.46	81.77	84.12	.17
6	1	2	(n=3)	87.76	88.54	88.15	.62

Table 12 (Continued)

6	1	3	(n=2)	63.67	78.52	71.09	**
6	1	5	(n=2)	37.50	50.01	43.75	.59
6	2	2	(n=6)	83.07	80.73	81.90	.48
6	2	3	(n=3)	81.25	80.73	80.99	.79
6	2	6	(n=5)	35.16	50.89	43.03	.50
T O T A L			(n=356)	74.91	73.97	74.44	

**Indicates that probabilities were not calculatable due to within group variations being equal to between group varations.

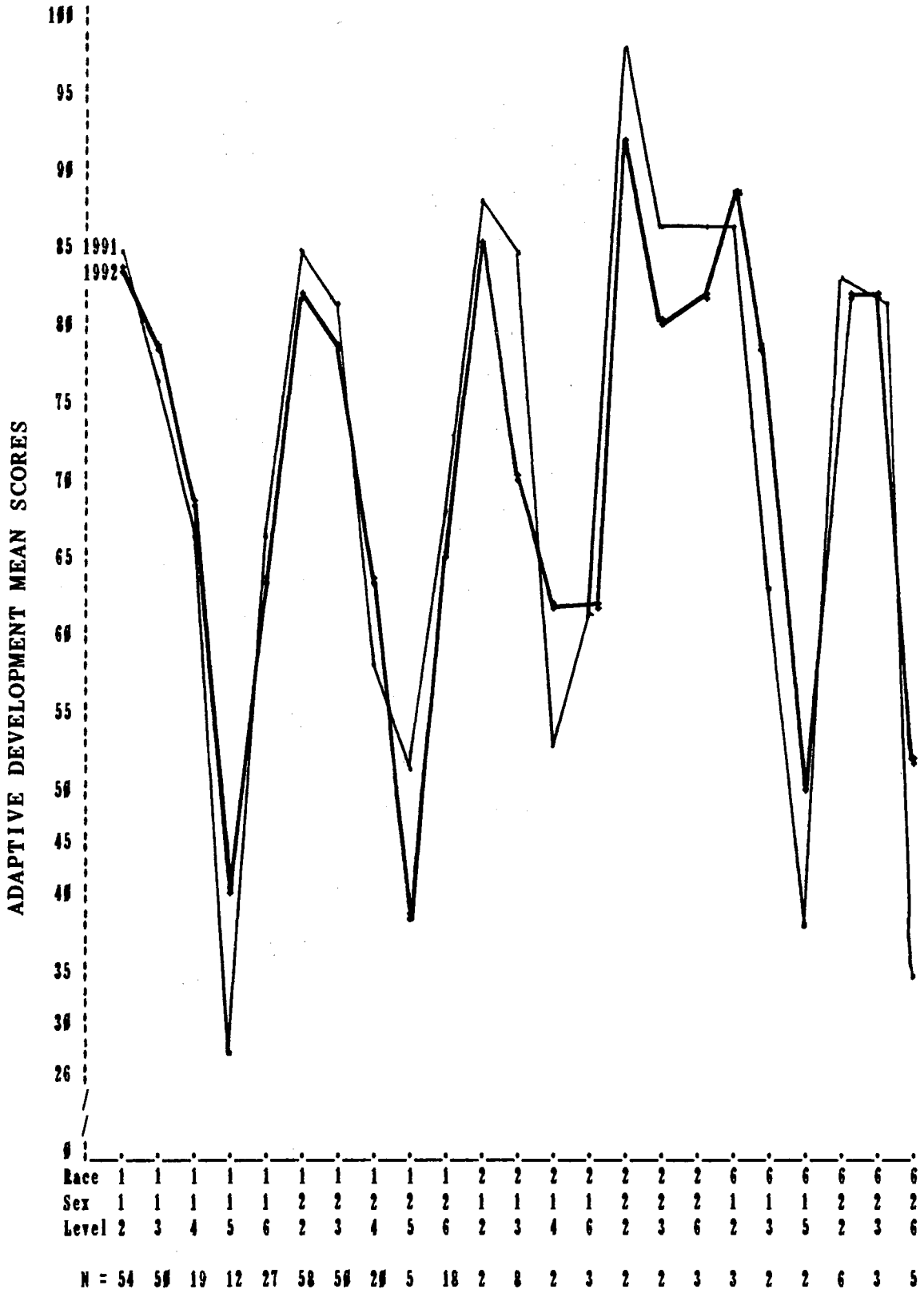

Figure 7. Mean Scores on Adaptive Development by Sex, Race, and Level of Retardation for Community Residents.

are more types of consumers represented. The general decline in Adaptive Development scores observed on Stayers and Movers is also present for the Community Resident.

Challenging Behavior (frequency)

Challenging Behavior (frequency) is examined next (see Table 11). Differences were not found to be significant at p = .01 among types of Community Residents when grouped by race, sex, and level of retardation with 22 degrees of freedom and an f-value of 1.18. The range of mean scores among Community Residents on ability to control the frequency of challenging behavior by type of consumer is from 84.38 for type of consumer 125 to 99.48 for type of consumer 226 (see Table 13). The difference between 1991 and 1992 mean scores on consumers' ability to control the frequency of challenging behaviors is not significant at p = .01 with one degree of freedom and an f-value of 5.02. Additionally, significant interaction is not found between types of consumers and year on ability to control the frequency of challenging behavior with 22 degrees of freedom and an f-value .74. Community Residents' Challenging Behavior (frequency) means are given for both 1991 and 1992 for types of consumers which are represented by more than one individual and graphically displayed in Figure 8. Figure 8 illustrates the relative consistency among Community Residents' 1991 and 1992 means on the Challenging Behavior (frequency) scale by type of consumer. The general

Table 13

Community Residents 1991 Mean, 1992 Mean, Type of Consumer Mean, and Probabilities on Challenging Behavior (frequency)

Type of Consumer RACE	SEX	LEVEL		1991 Mean	1992 Mean	Type of Consumer Mean	p.
1	1	2	(n=54)	93.69	92.59	93.14	.44
1	1	3	(n=5Ø)	91.5Ø	94.75	93.12	.Ø3
1	1	4	(n=19)	9Ø.3Ø	91.12	9Ø.71	.79
1	1	5	(n=12)	93.49	96.Ø9	94.79	.46
1	1	6	(n=27)	89.59	93.4Ø	91.49	.Ø8
1	2	2	(n=58)	94.61	95.96	95.29	.18
1	2	3	(n=5Ø)	94.19	94.38	94.28	.89
1	2	4	(n=2Ø)	91.Ø9	91.1Ø	91.1Ø	.99
1	2	5	(n=5)	77.5Ø	91.25	84.38	.2Ø
1	2	6	(n=18)	87.85	9Ø.45	89.15	.61
2	1	2	(n=2)	87.5Ø	82.82	85.16	.74
2	1	3	(n=8)	93.75	96.Ø9	94.92	.4Ø
2	1	4	(n=2)	98.44	95.32	96.88	**
2	1	6	(n=3)	93.75	97.92	95.83	.18
2	2	2	(n=2)	9Ø.63	87.5Ø	89.Ø6	.5Ø
2	2	3	(n=2)	96.88	1ØØ.ØØ	98.44	.5Ø
2	2	6	(n=3)	98.96	1ØØ.ØØ	99.48	.42

Table 13 (Continued)

6	1	2	(n=3)	100.00	96.88	98.44	.42
6	1	3	(n=2)	95.32	93.75	94.53	.91
6	1	5	(n=2)	84.38	87.50	85.94	**
6	2	2	(n=6)	94.27	92.71	93.49	.20
6	2	3	(n=3)	96.88	95.83	96.36	.42
6	2	6	(n=5)	98.13	99.38	98.75	.48
T O T A L			(n=356)	92.58	93.88	93.23	

**Indicates that probabilities were not calculatable due to within group variations being equal to between group varations.

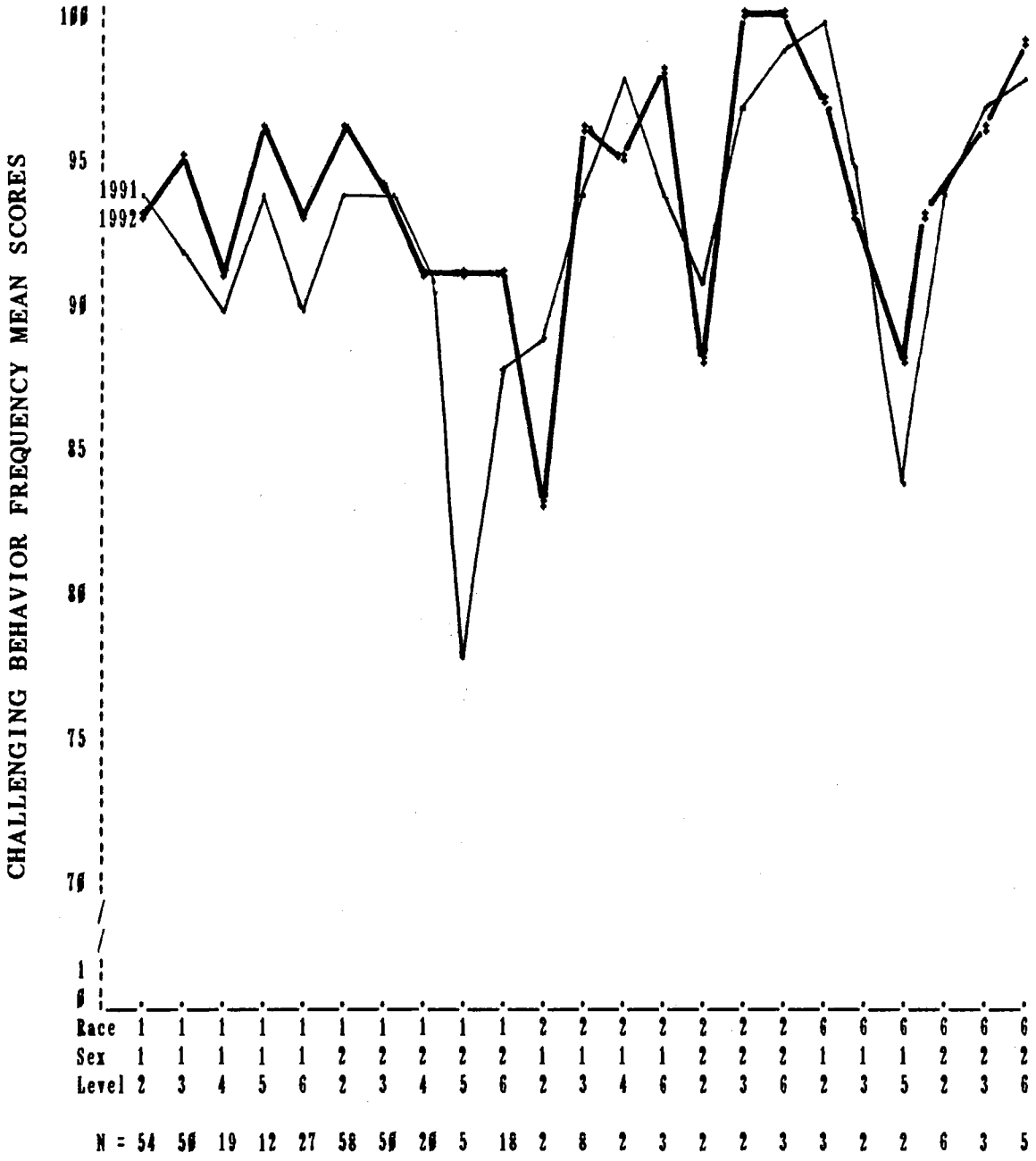

Figure 8. Mean Scores on Challenging Behavior (frequency) by Sex, Race, and Level of Retardation for Community Residents.

pattern established in Stayers' Challenging Behavior (frequency) mean scores is not as clear for the Community Residents, however, some increases are seen in the ability to control the frequency of challenging behaviors as level of retardation increases. Further visual inspection of figure 8 reveals 15 of the 23 pairs of scores are higher in 1992. This suggests that the 1992 means are generally but not significantly higher than the 1991 means (see Table 13).

Challenging Behavior (severity)

Challenging Behavior (severity) is examined last (see Table 11). The differences among types of consumer means are not significant at p = .01 for Community Residents on ability to control the severity of challenging behavior with 22 degrees of freedom, an f-value of 1.00, and p = .46. The range among mean scores for Community Residents by type of consumer on their abilities to control the severity of challenging behavior is from 89.79 for type of consumers designated 125 to 100.00 for type of consumers designated 626 (see Table 14). The difference between 1991 and 1992 Community Residents' scores on the ability to control the severity of challenging behavior is not significant at p = .01, with one degree of freedom and an f-value of 5.65. Further, there is no significant interaction found at p = .01 between types of consumers and year on ability to control the severity of challenging behavior with 22 degrees of freedom, an f-value of .54 and p = .96. Community

Table 14

Community Residents 1991 Mean, 1992 Mean, Type of Consumer Mean, and Probabilities on Challenging Behavior (severity)

Type of Consumer RACE	SEX	LEVEL		1991 Mean	1992 Mean	Type of Consumer Mean	p.
1	1	2	(n=54)	95.18	94.71	94.95	.65
1	1	3	(n=50)	94.38	96.33	95.35	.04
1	1	4	(n=19)	93.20	93.75	93.48	.83
1	1	5	(n=12)	97.57	98.09	97.83	.56
1	1	6	(n=27)	94.37	96.22	95.29	.05
1	2	2	(n=58)	95.26	97.09	96.18	.03
1	2	3	(n=50)	96.13	96.54	96.33	.62
1	2	4	(n=20)	95.73	94.79	95.26	.64
1	2	5	(n=5)	88.33	91.25	89.79	.35
1	2	6	(n=18)	92.94	94.21	93.58	.67
2	1	2	(n=2)	88.54	93.75	91.15	.61
2	1	3	(n=8)	94.27	98.70	96.49	.05
2	1	4	(n=2)	98.96	96.88	97.92	**
2	1	6	(n=3)	97.92	98.61	98.26	.42
2	2	2	(n=2)	93.75	91.67	92.71	.50
2	2	3	(n=2)	98.96	100.00	99.48	.50
2	2	6	(n=3)	99.31	100.00	99.65	.42

Table 14 (Continued)

6	1	2	(n=3)	100.00	97.22	98.61	.27
6	1	3	(n=2)	96.88	95.84	96.36	.91
6	1	5	(n=2)	87.50	90.63	89.06	.21
6	2	2	(n=6)	94.79	93.75	94.27	.80
6	2	3	(n=3)	98.61	98.61	98.61	1.00
6	2	6	(n=5)	100.00	100.00	100.00	1.00
T O T A L			(n=356)	95.08	95.97	95.53	

**Indicates that probabilities were not calculatable due to within group variations being equal to between group varations.

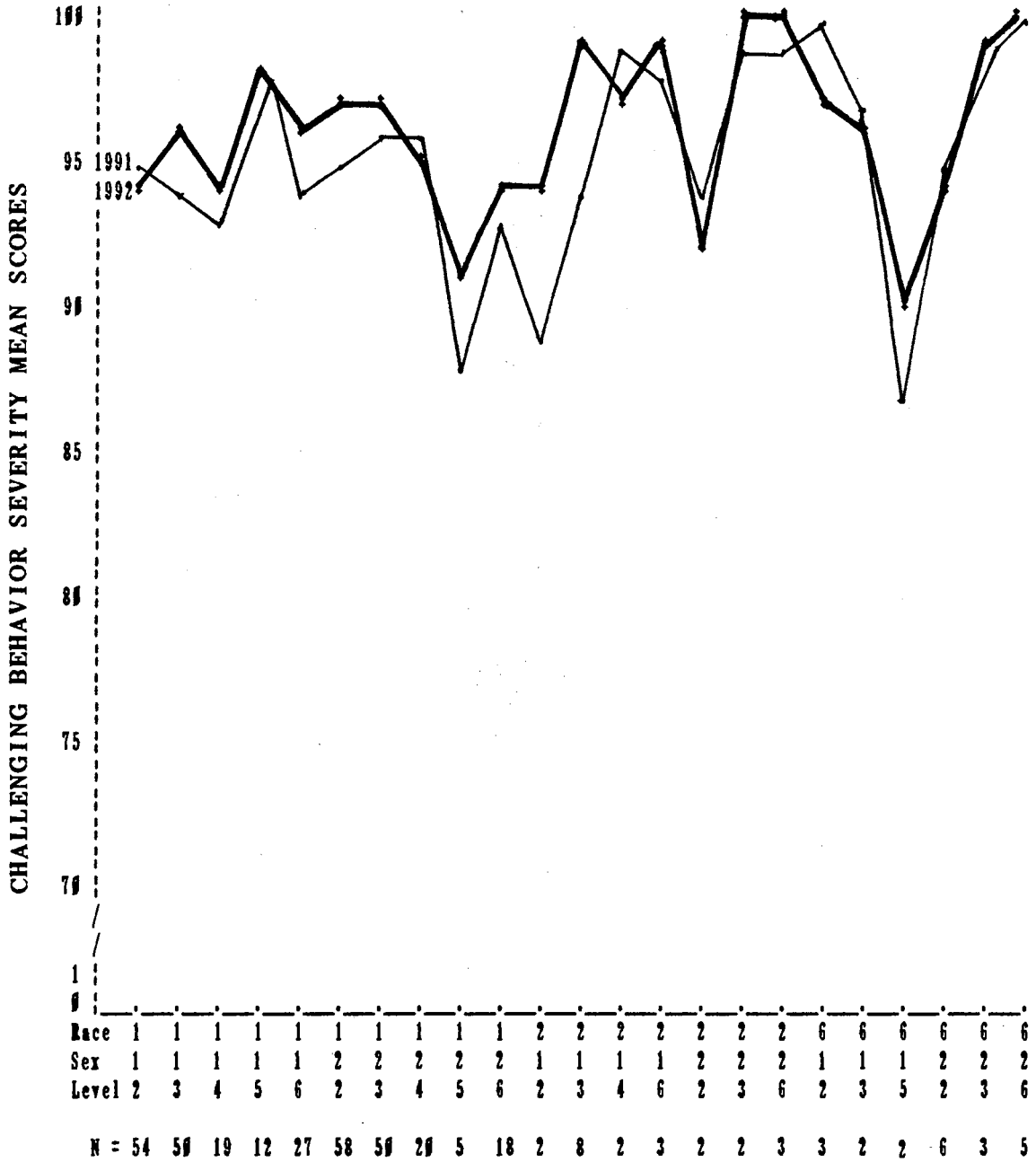

Figure 9. Mean Scores on Challenging Behavior (severity) by Sex, Race, and Level of Retardation for Community Residents.

Residents' Challenging Behavior (severity) means are given for both 1991 and 1992 for types of consumers which are represented by more than one individual and graphically displayed in Figure 9. Figure 9 illustrates the apparent consistency between 1991 and 1992 Community Residents' mean scores on ability to control the severity of challenging behaviors by type of consumer. The general pattern established in Stayers' Challenging Behavior (severity) mean scores is not as clear for the Community Residents; however, some increases are seen in the ability to control the severity of challenging behaviors as level of retardation increases. Additionally, Figure 9 reveals that the 1992 means are generally higher, but not significantly, in 14 of the 23 types of consumer. Two of the means for types of consumers are the same from 1991 to 1992. Finally, Figures 7, 8, and 9 also indicate that 212 of the 344 Community Residents are Caucasians with mild or moderate levels of retardation.

CHAPTER VI

SUMMARY, DISCUSSION AND RECOMMENDATIONS

Summary

The focus of this research was based upon the variance over a one year period within three categories of consumers (Stayers, Movers, and Community Residents). Three research questions were developed from past literature, theories, and the quality assurance project's data. Central to the current research was determining the variance on three dependent (quality of life) variables; by type of consumer, year, and interaction of year by type of consumer. The major finding was that type of consumers must be considered in any conclusions about differences on dependent variables.

Analysis of Variance procedures were employed to examine if mean scores on each dependent variable varied by type of consumer. Analysis of Variance was also used to identify if there were year differences present on the dependent variables. Finally, Analysis of Variance was used to identify interaction among the type of consumers by year.

It is worth noting that it was not possible to make comparisons of Stayers to Movers to Community Residents. Variations in the size of these categories (n=41 for the

Movers, n = 231 for the Stayers, and n = 356 for the Community Residents) and vast differences in types of consumer in each category would produce uninterpertable results. However, the within category comparisons on the dependent variables were the crux of the study.

Summary of Findings for Stayers

The most prominent changes displayed on the three dependent variables occurred in the category of Stayers. Differences were found by the types of consumers on all three dependent variables. There were significant differences in consumers when grouped by race, sex and level of retardation on Adaptive Development, and Challenging Behavior (frequency and severity). Stayers had significant increases in ability to control the severity and frequency of challenging behaviors between 1991 and 1992. Adaptive Development was the only dependent variable not to change significantly for the Stayers between 1991 and 1992. There were also significant interactions found among types of consumers by year for Stayers on all three dependent variables. Therefore, different types of consumers had different kinds of changes between 1991 and 1992, again underscoring the notion that type of consumer must be considered in any conclusions about differences. Generally, 1992 means were higher on all three dependent variables for Stayers. Two general patterns were observed on the dependent variables from Figures 1, 2, and 3. First, as

Adaptive Development means decreased, level of retardation increased. Second, as level of retardation increased the ability to control challenging behavior (frequency and severity) also increased.

Summary of Findings for Movers

The summary of findings for Movers were not as extensive as those for the Stayers. There were significant differences in consumers when grouped by race, sex and level of retardation on Adaptive Development for Movers, but not on Challenging Behavior (frequency) or Challenging Behavior (severity). Again, different types of consumers varied on dependent variables between 1991 and 1992 underscoring the notion that type of consumer must be considered in any conclusions about differences. There were no significant year differences found for Movers on Adaptive Development or Challenging Behavior (frequency and severity). Movers' ability to control the frequency of challenging behavior declined but not significantly between 1991 and 1992. The differences among Movers' scores were consistent across year by type of consumer on all three dependent variables. Generally, Movers' 1992 means on Adaptive Development were higher than the 1991 means but not uniformly or significantly. The Movers' ability to control the frequency and severity of challenging behaviors were only higher in half of the 1992 types of consumers. The general patterns which were observed for Stayers on Adaptive Development are also

present in the Movers. The Movers' Adaptive Development means decreased, as their level of retardation increased. However, as their level of retardation increased their ability to control challenging behavior (frequency and severity) had no clear pattern of increase.

Summary of Findings for Community Residents

Variations in the Community Residents scores were similar to those observed in the Movers. There were significant differences in consumers when grouped by race, sex and level of retardation on Adaptive Development for Community Residents, but not on Challenging Behavior (frequency), or Challenging Behavior (severity). Again, the different type of consumer reflected varying changes between 1991 and 1992 underscoring the notion that type of consumer must be considered in any conclusions about differences. There were no significant year differences found for Community Residents' on Adaptive Development or Challenging Behavior (frequency and severity).

The differences among Community Residents' scores were consistent across year by type of consumer on all three dependent variables. Generally, Community Residents' 1992 means on Adaptive Development were lower, but not uniformly or significantly. The Community Residents' ability to control the frequency and severity of challenging behaviors were generally higher in 1992 than in 1991; however, these were not uniform or significant. The general patterns

observed on Stayers and Movers' dependent variables were as apparent among the Community Residents as were in Stayers or Movers. However, as Adaptive Development means decreased for Community Residents their level of retardation also increased. This pattern was more compressed than observed for the Stayers or Movers. Finally, no consistent increases were observed in Community Residents' ability to control challenging behavior (frequency and severity) as level of retardation increased.

Discussion

The basic premise of the theories presented in Chapter III was that individuals with developmental disabilities residing in what Goffman (1959) described as a "Total Institution" may not have the full capability of defining themselves because of their disabilities and environment. Individuals in Hissom Memorial Center might have then developed ways of thinking, feeling, and acting that were essential for effective participation within the institutional setting. The suggestion could be made that as deinstitutionalization occurred the variations on the dependent variables may have been as much with the consumer as with those individuals who interact with them and observe their behaviors.

The Analysis of Variance revealed variations by type of consumers for all three categories on Adaptive Development. Again, different types of consumers variance between 1991

and 1992 underscoring the notion that type of consumer must be considered in any conclusions about differences.

The characteristics of race and sex are thought to be used in society to stereotype individuals. Stereotypes are, according to Vander-Zanden (1977); "the mental picture we have of a particular people" (p. 445). These "mental pictures" are in turn used to form labels which are applied to various groups. Tannenbaum (1938) suggested labeling as:

> ". . .tagging, defining, identifying, segregating, describing. . . it becomes a way of stimulating, suggesting, and emphasizing. . . (p. 192)."

Sex and race are used within society in this process of associating behaviors with a label. However, because of small Ns from Native Americans, and African Americans no distinction was observed by race. Finally, no patterns by sex or race were observed in figures 1 - 9.

The label "developmentally disabled" carries along with it expectations for consumer behavior. A label of severely retarded might carry the "stigma" as Goffman (1963) described the consumers' "actual social identity", while not allowing for the consumer to achieve their abilities or "virtual social identity".

Discussion on Stayers

Increased focus on Hissom Memorial Center and the subsequent focus upon the Stayers may have insured their improvements--or the appearance of improvement as being

reported by those being interviewed. As seen in the results section, Stayers showed significant increases in their ability to control both the frequency and severity of challenging behavior between 1991 and 1992. These increased abilities might be due to the increased supervision as the numbers of residents at Hissom Memorial Center declined during the deinstitutionalization process. The staff at Hissom who were interviewed may have known more about the consumers as persons and not their labels as ratios between staff and consumers decreased. Researchers have proposed that smaller residential settings are more beneficial to individuals with developmental disabilities in terms of improvement in the quality of life (Conroy; 1992, Murray; 1992, Wilson and Kouzi; 199Ø, Conroy, Lemanwicz, and Feinstein; 1987, Conroy and Bradley; 1985). Thus, as the institution became smaller, it may have become more personal, less rigid, and the goals oriented toward moving individuals to the community. Care givers may have been able to know better the extent of the abilities and developmental levels of those who remained in the institution. Finally, the findings of the current research on Stayers ability to control the frequency and severity of their challenging behaviors is supported by McEvoy (1991) who reported that levels of challenging behavior for institutional groups decreased during a three-month period while residents were undergoing movement into community settings. The increased ability of Stayers to control the

frequency and severity of their challenging behaviors may not have been due to better abilities but to a lack of an ability to act in a challenging manner.

Adaptive Development was the only dependent variable not to change significantly for the Stayers between 1991 and 1992. This finding may support the idea that an institutional environment may not foster adaptive development growth or levels of independence.

Discussion on Movers

The foremost finding for Movers was the variance among types of consumers on Adaptive Development mean scores. Again, the different type of consumer reflected varying changes between 1991 and 1992 underscoring the notion that type of consumer must be considered in any conclusions about differences. Thus, individuals with varying degrees of independence were moved into community settings. Along with the movement into the community might be increased expectations for Adaptive Development (independence) and the ability to control the frequency and severity of challenging behaviors. The socialization of the Movers in the institution may not have allowed them to have the skills to interact within a community setting during the first months. They may have been simply experiencing "cultural shock."

These differences among types of consumers were not reflected in the varying degrees of change between 1991 and 1992 means by type of consumer on the ability to control the

frequency and severity of challenging behaviors. Half of the Movers were higher in 1992 and the other half were lower on the ability to control the frequency of challenging behaviors. Fifteen of the 36 Movers that had a higher ability to control the frequency of challenging behaviors in 1991 than in 1992 were those with profound levels of retardation. This is supported by Kleinberg and Galligan (1983) finding that during the first few months after deinstitutionalization that lower functioning individuals showed increased challenging behaviors. Further, this supports Hemming, Lavender, and Pill's (1981) finding that challenging behaviors can increase between transfer and four months after transfer from the institutional setting.

These findings may be supported by the Labeling Theory that would suggest; within an institutional setting some behaviors are overlooked as relatively "normal" (displays of stereotypical behaviors, sexual behaviors, or screams, yells, or cries inappropriately). Upon transfer to community settings these behaviors then may become problematic and considered inappropriate. Therefore, the institution may instill in those who work, visit, and survey a milieu of abnormality, thus creating lowered expectations, and reports of behaviors. When transferred to the community the expectations are increased and the individual's behavior then seems to decline, based on the new standards, when change has not actually occurred. MacEachron (1983) asserted that the social aspects of a normalized setting to

be associated positively with development of consumers.

Improvements in the Movers' Adaptive Development and Challenging Behavior scores between 1991 and 1992 were not found. These improvements might be expected based on past literature which suggests that smaller residential settings are more beneficial to individuals with developmental disabilities on quality of life measures such as Adaptive Development and Challenging Behavior (Conroy; 1992, Murray; 1992, Wilson and Kouzi; 1990, Conroy, Lemanwicz, and Feinstein; 1987, Conroy and Bradley; 1985). Although this research does not suggest that Movers were better off, no evidence was present to suggest that they were worse off. For the benefits to be observed more time may be necessary.

Several explanations may exist for the lack of variation among Mover's scores on the dependent variables. First, there might not have been sufficient time for improvements to occur for all Movers. Different types of consumers might have varying rates of improvements. This is supported by Kleinberg and Galligan (1983) who found that during the first few months after moving, lower functioning consumers showed increased antisocial behaviors, while higher functioning consumers decreased their antisocial behaviors. In the current study 85.4% of the Stayers and 75.0% of the Movers had severe or profound levels of retardation. McEvoy (1991) reported that levels of maladaptive behavior for community groups increased over a period of three months after being deinstitutionalized.

Thus, the increased interactions with staff members and other residents may have increased the opportunity to exhibit challenging behaviors. Conroy and Bradley (1985) reported the amount of staff time allocated to individuals was higher in small community based programs than found in large state-run institutions. Thus, increased contact by staff members might increase the opportunity to report such challenging behaviors.

Discussion on Community Residents

The Community Residents showed only variations based on race, sex, and level of retardation in their Adaptive Development scores. Simply stated there were differences among the types of Community Residents in their level of independence. This was an expected variation, just as with any group of individuals there are differences in their levels of independence. These variations might be due to differences in socialization or expectations.

An interesting observation of the Community Residents' Adaptive Development Scores was that their mean total declined from 1991 to 1992, but not significantly. The speculation that the Community Residents simply had natural decreases in their Adaptive Development (independence) due to the passage of time could be proposed. Further, the Community Residents' abilities to control the frequency and severity of their challenging behaviors were consistent across types of consumers by year. The apparent consistency

among Community Residents' means on the dependent variables would have been expected because they did not change residents between 1991 and 1992.

Recommendations

Future studies of developmental disabilities need to focus upon the self within those individuals at all levels of disability. This would be possible through increased attention to completion of the consumer interview. Studies of those individuals with mild and moderate disabilities may generally tend to be the focus because more information on abilities and attitudes can be gained. However, individuals with more profound disabilities can respond to questions if given the proper interviewing technique. An interesting observation in the Tables and Figures in this study was that the majority of Stayers were classified as profoundly retarded, 183 of the 231. While a majority of the Stayers' Adaptive Development scores were below 35. Further, the lowest response rate for the consumer interview was obtained in this category. Goffman (1985) suggested:

> "Individuals who are the least ready to project a sustainable self are lodged in a milieu where it is practically impossible to do so" (pg. 23Ø).

Thus, the institutions may not be settings for a self to develop or to be understood completely. Moreover, individuals with developmental disabilities may have a need

to be mainstreamed with a nondevelopmentally disabled population. Individuals with developmental disabilities who moved out of the institution and had different care givers may have had different expectations upon them and different perceptions of their behaviors. This may have been reflected in their lower overall mean scores on the ability to control the frequency or severity of challenging behaviors. Further, when care givers were interviewed concerning the abilities and behaviors of Movers, perhaps they were not as familiar with them as the previous institutional caretakers. A general awareness by interviewers as to the length of time the caretaker has known the consumer may add to the validity of the survey.

Another recommendation may be to include a combination of qualitative and quantitative questions to part of this study including open-ended questions on clients' perceptions of their living situations. Future research on this topic should give more attention to some of these items as reported by the individuals themselves. Survey research does not always measure actual attitudes of those targeted. Thus, I would propose giving more attention to qualitative approaches (observation) along with the survey. This type of study would be more time consuming and require more insight in the analysis. However, it might yield a more valid view of the environments of the developmentally disabled as well as the people themselves. Additionally, the responses of those individuals with developmental

disabilities such as; "If you had one wish, what would it be or would you like to tell me any thing at this time," may indicate areas of improvement, and thus be utilized in improving the quality of life of those with developmental disabilities.

The classification variable, race, needs to be carefully considered when completing longitudinal studies. This particular variable had many difficulties. The determination of individual's race by caretaker varied greatly dependent upon who was answering the question. For example, there were individuals labeled as American Indian in one year and Caucasian in the next--or African American in one year and Native American in the next. One solution to this dilemma may be to classify individuals as; "not of color" or persons "of color". In cases where individuals are classified as; "of color", have another question that addresses the specific race. Further, it may be possible for demographic information to be given to the interviewer prior to the interview. This information could then be verified during the interview.

Another aspect of the developmentally disabled which should be examined is the aging processes. Day (1987) concluded that the elderly mentally handicapped pose an increasing challenge to service providers. Seltzer and Krauss (1987) emphasized the need for more research regarding age related changes on quality of life for the developmentally disabled. Hawkins and Eklund (199Ø)

reported that:

> "Recent amendments to the Older Americans Act and the Developmental Disabilities Act address issues of coordination and collaboration between the aging services and the developmentally disabilities services networks" (pg. 39).

Further, Day (1887) suggested that the life expectancy of mentally handicapped people had increased considerably and is gradually approaching that of the general population. Age might also be considered as criteria for those who are placed in community settings. Salgaras and Nettelbeck (1983) reported that age factors produce significant effects as in ability to control several challenging behaviors. Nonetheless, some findings suggested that young and old benefit equally from a community setting. Hodapp and Zigler (1985), for example, found that once placed in a less restrictive environment younger children with severe mental retardation did not show any greater improvements in adaptive development than did older children in institutional settings but that improvements from both groups did occur slowly over time. Therefore, the addition of age to the analysis for these individuals as they have been deinstitutionalized may be more beneficial in the explanation of movement into community settings rather than race, sex, or level of retardation.

Further, interviews should be conducted from year to year at consistent intervals. For example, when an interview is conducted in June 1991, the next interview

should be conducted in June 1992. This would eliminate the possibility of having individuals whose interviews were conducted from four months apart up to 14 months apart.

Finally, some thought should be given to the diversity among interviewers. Interviewers ranged in ages from early twenties to mid-forties. Differences in gender and life experiences varied as well for the interviewers. Further, the educational backgrounds and experiences of the interviewers may bias their perceptions of questions and answers. These biases could be reflected in the data collection. For example, when gathering information on the level of retardation if level was unknown, a more experienced and knowledgeable interviewer might be able to determine the level rather than marking an unknown. Although many of the same interviewers returned to the project in 1992 from the 1991 staff, questions as to the consistency of their ability to gather data have occurred. However, the question remains: "Did the interviewers change more than those they interviewed?" Perhaps the addition of new interviewers from year to year had some effect on the information gathered. The contention that the same interviewer may be just as different from year to year as different ones is an intriguing notion.

With the limitations of this research in mind, dramatic improvements in the Movers' scores were not revealed. However, different types of consumers might have varying rates of change in the community. More time may be

necessary to see if these improvements occur in the categories. Thus, type of consumer must be considered in any conclusions concerning change in those involved in the process of deinstitutionalization.

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APPENDIX A

QUESTIONNAIRE

OKLAHOMA STATE UNIVERSITY
DEPARTMENT OF SOCIOLOGY
STILLWATER, OKLAHOMA

DEVELOPMENTAL DISABILITIES QUALITY ASSURANCE QUESTIONNAIRE

This document and attachments are confidential and are available only to participants in the assessment project. Contents are not to be read or duplicated without authorization by Developmental Disabilities Services Division or the individual/guardian.

Interviewer	Site Code	ID Number	D.O.B.
[ ] [ ]	[; ; ; ; ; ; ;]	[; ; ; ; ; ; ;]	M M D D Y Y [; ; ; ; ; ;]

Interview Date
M [ ]
M [ ]
D [ ]
D [ ]
Y [ ]
Y [ ]

Type of Facility

- [ ]ESS = Enid State School
- [ ]FC = Foster Care
- [ ]GH2 = Group Home with 4, 5, or 6 Residents
- [ ]GH3 = Group Home with 7 or More Residents
- [ ]HMC = Hissom Memorial Center
- [ ]ICF = ICF
- [ ]IL = Independent Living
- [ ]INC = Incarcerated: (JAIL OR PRISON)
- [ ]MHF = Mental Health Facility
- [ ]MR = ICF/MR Placement
- [ ]OS = Out of State
- [ ]OSD = Oklahoma School for the Deaf
- [ ]PVS = Pauls Valley School
- [ ]RH = Relative's Home or Their Own Home
- [ ]SIL = Semi-Independent Living
- [ ]SUP = Supported Living
- [ ]UN = Unknown
- [ ]OT = Other

Class Status

- [ ]Focus
- [ ]Balance
- [ ]Non Member
- [ ]Don't Know
- [ ]OBRA member

Race

- [ ]White
- [ ]Black
- [ ]Oriental
- [ ]Asian
- [ ]Hispanic
- [ ]American Indian
- [ ]Alaskan Native
- [ ]Other

Sex

- [ ]Male
- [ ]Female

Level of Retardation

- [ ]Not MR
- [ ]Mild
- [ ]Moderate
- [ ]Severe
- [ ]Profound
- [ ]Unknown

Other Disabilities

Visually Impared	Cerebral palsy
Hearing Impared	Physical disabilities
Autism	Mental illness
Other: _____	Feeding Tube
	Tracheostomy

SECTION I: RESIDENTIAL HISTORY/FAMILY AND ADVOCATE CONTACT.

1. What is your relationship to him/her? (principal respondent:)

[ ]A family member

[ ]A non-relative guardian

[ ]A friend

[ ]A direct contact staff person (paraprofessional)

[ ]Case Manager/Social Worker/QMRP

[ ]Other professional or administrator

[ ]Other (Define) _____

_____

[ ]
[ ]

2. When did s/he move here?

M [ ]
M [ ]
D [ ]
D [ ]
Y [ ]
Y [ ]

unknown
life-long resident

3. How many times has s/he changed home addresses in the past year?

[ ]
[ ]

unknown

4. Where did s/he live immediately before coming here?

[ ]ESS = Enid State School
[ ]FC = Foster Care
[ ]GH1 = Group Home with 2 or 3 Residents
[ ]GH2 = Group Home with 4, 5, or 6 Residents
[ ]GH3 = Group Home with 7 or More Residents
[ ]HMC = Hissom Memorial Center
[ ]ICF = ICF
[ ]IL = Independent Living
[ ]INC = Incarcerated: (JAIL OR PRISON)
[ ]MHF = Mental Health Facility
[ ]MR = ICF/MR Placement
[ ]OS = Out of State
[ ]OSD = Oklahoma School for the Deaf
[ ]PVS = Pauls Valley School
[ ]RH = Relative's Home or Their Own Home
[ ]SIL = Semi-Independent Living
[ ]SUP = Supported Living
[ ]UN = Unknown
[ ]OT = Other
[ ]Life long Resident

5. Is the residence private or public?

[ ]Private nonprofit
[ ]Private proprietary
[ ]Public
[ ]Private home
[ ]Other:_____

[ ]
[ ]

6. Has s/he ever lived in an institution? (Mark all that apply.) NO
If no, skip to #7.

[ ]State school
[ ]Private ICF-MR
[ ]Nursing home
[ ]Mental health

6A. What year did s/he leave her/his last institutional placement?

[ ]Currently in institution

Y [ ]
Y [ ]

Lives with family	About once a week or more	About once a month	About every 3 months	Twice a year or less	Never in the past year	No family, or No DDS case manager or No Advocate
						7. In the past year, how often has the family contacted him/her or the staff by phone?
						8. How often did family member(s) (biological/adoptive) visit him/her in the client's home in the past year?
						9. How often did s/he visit in the family's biological/ adoptive home or on outings in the past year?
						10. How often did the DDS case manager make contact with client by phone in the last year?
						11. How often did the DDS case manager make contact with client by visit in the past year?

12. How many DDS case managers in the last year?

[ ]Never had one (Skip to #14)

13. Is the name and phone number of his/her DDS case manager readily available to the client and people with whom they live?

[ ]Yes [ ]No [ ]Not applicable

14. What other advocates made contact with him/her? List all that apply. (IF ANSWER is No Advocate, MOVE TO QUESTION 17).

[ ]Guardian ad litem (Represents Hissom Class members in Homeward bound lawsuit)
[ ]Office of Client Advocacy (Ombudsman)
[ ]Volunteer
[ ]Other (e.g., Protection and Advocacy, short term special guardian)
[ ]OBRA case manager/team member
[ ]No advocate (SKIP TO #17)

About once a week or more	About once a month	About every three months	Twice a year or less	Never in the past year
				15. How often did other advocates or staff contact him/her or family by phone in the past year? (INCLUDE ALL NON-DDS ADVOCATES).
				16. How often did other advocate(s) visit him/her and family in the past year? (Include all non-DDS advocates).

SECTION III: ADAPTIVE EQUIPMENT NEEDS

Does not need	NEEDS but does not have	HAS	Has but needs REPAIR	What adaptive equipment does s/he have or need?
			[ ]	17. Glasses
			[ ]	18. Hearing Aid
			[ ]	19. Wheelchair, walker, braces, cane
			[ ]	20. Helmet
			[ ]	21. Communication Device
			[ ]	21A. Dentures
			[ ]	21B. Oxygen Machine
			[ ]	21C. Suction Machine
			[ ]	21D. Feeding Pump
			[ ]	22. Other: _____ [ ]
				_____ [ ]

SECTION IV: ADAPTIVE SKILLS (BEHAVIOR DEVELOPMENT SURVEY)

This section covers adaptive behavior skills. Please answer yes only to those things that s/he actually does, not for what s/he "might be able to do." Verbal prompts are ok (unless otherwise noted), but do not give credit for behaviors performed with physical prompts (unless otherwise noted). [Give credit for a behavior if it is performed at least 75% (3/4) of the time. Enter zero (0) if the item is not applicable, or if the person is too young or unable, or if there is no opportunity. LEAVE NO BLANKS]

23. How is his/her body balance? (MARK HIGHEST NUMBER THAT APPLIES).
    - [ ] Stand on "tiptoe" for ten seconds if asked
    - [ ] Stand on one foot for two seconds if asked
    - [ ] Stand without support
    - [ ] Stand with support
    - [ ] Sit without support
    - [ ] Can do none of the above

24. Can s/he use silverware? (MARK HIGHEST NUMBER THAT APPLIES)
    - [ ] Use knife and fork correctly and neatly
    - [ ] Use table knife for cutting or spreading
    - [ ] Feed self with spoon and fork - neatly
    - [ ] Feed self with spoon and fork - considerable spilling
    - [ ] Feed self with spoon - neatly
    - [ ] Feed self with spoon - considerable spilling
    - [ ] Feed self with fingers or must be fed

25. Can s/he: (VISUAL AIDES ARE ACCEPTABLE) (MARK HIGHEST NUMBER THAT APPLIES)
    - [ ] Order complete meals in restaurants
    - [ ] Order simple meals like hamburgers or hot dogs
    - [ ] Order soft drinks at soda fountain or canteen
    - [ ] Does not order food at public eating places

26. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES)
[ ]Drink without spilling, holds glass in one hand
[ ]Drink from cup or glass unassisted - neatly
[ ]Drink from cup or glass - considerable spilling
[ ]Does not drink from cup or glass

27. Does s/he ever have toilet accidents? (MARK HIGHEST NUMBER THAT APPLIES).
[ ]Never has toilet accidents during day or night time
[ ]Never has toilet accidents during the day time (but may have problems at night)
[ ]Occasionally has toilet accidents during the day time
[ ]Frequently has toilet accidents during the day time
[ ]Is not toilet trained at all

28. Can s/he: (MARK HIGHEST NUMBER THAT APPLIES).
[ ]Prepare and completely bathe unaided
[ ]Wash and dry self completely
[ ]Wash and dry reasonably well with prompting
[ ]Wash and dry self with help
[ ]Attempt to soap and wash self
[ ]Actively cooperate when being washed and dried by others
[ ]Makes no attempt to wash or dry self

29. Can s/he: (MARK HIGHEST NUMBER THAT APPLIES).
[ ]Completely dress self
[ ]Completely dress self with verbal prompting only
[ ]Dress self by pulling or putting on all clothes with verbal prompting and by fastening (zipping, buttoning, snapping) them with help
[ ]Dress self with help in pulling or putting on most clothes and fastening them
[ ]Cooperate when dressed, e.g., by extending arms or legs
[ ]Must be dressed completely

30. How is his/her sense of direction? Can s/he: (MARK HIGHEST NUMBER THAT APPLIES).
[ ]Go several blocks from grounds, or from home, without getting lost
[ ]Go around grounds or a couple of blocks from home without getting lost
[ ]Go around cottage, ward, yard, or home without getting lost
[ ]Demonstrates no sense of direction

31. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
[ ]Use money with little or no assistance (e.g., assistance with budgeting is OK)
[ ]Use money with minor assistance (e.g., checking for correct change, etc.)
[ ]Use money with some assistance (e.g., being told the correct bills or coins)
[ ]Use money with complete assistance of staff
[ ]Does not use money

32. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
[ ]Choose and buy all own clothing without help
[ ]Choose and buy some clothing without help
[ ]Make minor purchases without help (e.g., snacks, drinks)
[ ]Do some shopping with slight supervision
[ ]Do some shopping with close supervision
[ ]Does no shopping

33. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
[ ]Write complete lists, memos or letters
[ ]Write short sentences
[ ]Write or print more than ten words without copying or tracing
[ ]Write or print own name or other words without copying or tracing
[ ]Trace or copy own name or other words
[ ]Does not write, print, copy, or trace any words

34. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
[ ]Sometimes use complex sentences containing "because," "but," etc.
[ ]Ask questions using words such as "why," "how," "what," etc.
[ ]Speak in simple sentences
[ ]Is nonverbal or nearly nonverbal

35. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
[ ]Read books or other materials suitable for children nine years old or older
[ ]Read books or other materials suitable for children seven years old
[ ]Read simple stories or comics suitable for children at a kindergarten or first grade level
[ ]Recognize 10 or more words
[ ]Recognize various signs, such as "EXIT" or "STOP" or "WOMEN" or "MEN" or Street Signs.
[ ]Recognize no words or signs.

36. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
[ ]Do simple addition and/or subtraction
[ ]Count 10 or more objects
[ ]Mechanically count aloud from one to ten
[ ]Count two objects by saying "one, two"
[ ]Discriminate between "one" and "many"
[ ]Has no understanding of numbers

37. Does s/he clean his/her room? (MARK HIGHEST NUMBER THAT APPLIES).
[ ]Cleans room well, e.g., sweeping vacuuming, tidying
[ ]Cleans room but not thoroughly
[ ]Does not clean room at all

38. Can s/he: (MARK HIGHEST NUMBER THAT APPLIES).
[ ]Prepare an adequate complete meal
[ ]Mix and cook simple foods
[ ]Prepare simple foods requiring no mixing or cooking
[ ]Does not prepare food at all

39. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
[ ]Clear table of breakable dishes and glassware
[ ]Clear table of unbreakable dishes and silverware
[ ]Does not clear table at all

40. Does s/he go to: (MARK HIGHEST NUMBER THAT APPLIES)
[ ]Competitive employment or workshop
[ ]Pre-vocational training, school, or retired
[ ]Performs no outside work

41. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
    [ ]Initiate most of own activities
    [ ]Initiate some of own activities
    [ ]Will engage in activities only if assigned or directed
    [ ]Will not engage in assigned activities

42. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
    [ ]Pay attention to purposeful activities for more than 20 minutes
    [ ]Pay attention to purposeful activities for about 15 minutes
    [ ]Pay attention to purposeful activities for about 10 minutes
    [ ]Pay attention to purposeful activities for about 5 minutes
    [ ]Will not pay attention to purposeful activities for as long as 5 minutes

43. How is s/he at taking care of his/her personal belongings (MARK HIGHEST NUMBER THAT APPLIES).
    [ ]Very dependable, always takes care of belongings
    [ ]Usually dependable, usually takes care of belongings
    [ ]Unreliable, seldom takes care of belongings
    [ ]Not responsible at all, does not take care of belongings

44. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
    [ ]Interact with others for more than five minutes
    [ ]Interact with others for up to five minutes
    [ ]Interact with others in limited ways, e.g., eye contact, handshakes, responsive to touch
    [ ]Does not interact with others

45. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES)
    [ ]Initiate group activities at least some of the time (leader and/or organizer)
    [ ]Participate in group activities spontaneously and eagerly (active participant)
    [ ]Participate in group activities if encouraged to do so (passive participant)
    [ ]Does not participate in group activities (unless physically guided)

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46. Can s/he: (With cane, crutches, brace, or walker, if used). (MARK ALL THAT APPLY)
    [ ]Walk alone
    [ ]Walk up and down stairs alone
    [ ]Walk down stairs by alternating feet
    [ ]Run without falling often
    [ ]Hop, skip or jump
    [ ]None of the above

47. At the toilet, does s/he: (MARK ALL THAT APPLY)
    [ ]Lower pants at the toilet without help
    [ ]Sit on toilet seat without help
    [ ]Use toilet tissue appropriately
    [ ]Flush toilet after use
    [ ]Put on clothes without help
    [ ]Wash hands without help
    [ ]None of the above

48. Does s/he: (MARK ALL THAT APPLY).
[ ]Wash hands with soap
[ ]Wash face with soap
[ ]Wash hands and face with water
[ ]Dry hands and face
[ ]None of the above

49. Does s/he: (MARK ALL THAT APPLY).
[ ]Clean shoes when needed
[ ]Put clothes in drawer or chest neatly
[ ]Put soiled clothes in proper place for washing, without being reminded
[ ]Hang up clothes without being reminded
[ ]None of the above

50. Does s/he: (MARK ALL THAT APPLY).
[ ]Put on shoes correctly without assistance
[ ]Tie shoe laces without assistance (Velcro is ok)
[ ]Untie shoe laces without assistance (Velcro is ok)
[ ]Remove shoes without assistance
[ ]None of the above

51. Is s/he able to: (MARK ALL THAT APPLY)
[ ]Say (sign) at least a few words
[ ]Nod head or smile to express happiness
[ ]Indicate hunger
[ ]Indicate wants by pointing or vocal noises
[ ]Express pleasure or anger by vocal noises
[ ]Chuckle or laugh when happy
[ ]None of the above

52. Does s/he: (MARK ALL THAT APPLY).
[ ]Understand instructions containing prepositions, e.g., "on," "in," "behind"
[ ]Understand instructions referring to the order in which things must be done, e.g., "first do this, and afterward, do that"
[ ]Understand instructions requiring a decision, e.g., "If there's any ham, make a sandwich; but if there's none, open some soup"
[ ]None of the above

53. Can s/he: (MARK ALL THAT APPLY).
[ ]Tell time by clock or watch correctly
[ ]Understand time intervals, e.g., there is one hour between 3:30 and 4:30
[ ]Understand time equivalents, e.g., "9:15" is the same as "quarter past nine."
[ ]Associate time on clock with various actions & events, e.g., 6:00 means dinner time
[ ]None of the above

54. Does s/he: (MARK ALL THAT APPLY).
[ ]Recognize own family
[ ]Recognize people other than family
[ ]Have information about others, e.g., relation to self, job, address, name
[ ]Know the names of people close to him/her, e.g., in neighborhood, at home or day program
[ ]Know the names of people not regularly encountered
[ ]None of the above

FREQUENCY CODING

Not observed in the past month, but has occurred in the past year

Less than (=) five times/week in past four weeks

More than five times/week in past four weeks

SEVERITY CODING

No problem

Minor problem

Major problem

Extremely urgent problem, (completely or nearly intolerable)

No challenging behaviors

The next questions cover problematic behaviors. Does s/he ever:

55. Threaten or do physical violence to others (Malicious Intent)
    Describe: _____ [ ]
    _____ [ ]
56. Damage own or others' property (Malicious Intent)
57. Disrupt others' activities
58. Use profane or hostile language
59. Is rebellious, e.g., ignore regulations, resist following instructions
60. Run away or attempt to run away
61. Is untrustworthy, e.g., take others' property, lie, or cheat
62. Display stereotyped behavior, e.g., rock body, hands constantly moving in repetitive pattern
63. Remove or tear off own clothing inappropriately
64. Injure self
65. Is hyperactive, e.g., will not sit still for any length of time
66. Inappropriate sexual behavior inside the home
    Describe _____ [ ]
    _____ [ ]
67. Inappropriate sexual behavior outside the home
    Describe _____ [ ]
    _____ [ ]
68. Listless, sluggish, inactive, unresponsive to activities
69. Scream, yell, or cry inappropriately
70. Repeat a word or phrase over and over

71. Did s/he display any other challenging behavior?

[ ] Yes Describe _____ [ ]
[ ] No _____ [ ]

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SECTION V: MEDICAL NEEDS

72. In general, how urgent is his/her need for medical care? (MARK ONLY ONE)
    [ ]Generally has no serious medical needs
    [ ]Needs visiting nurse and/or regular visits to the doctor
    [ ]Has life-threatening condition that requires very rapid access to medical care
    [ ]Would not survive without 24 hours medical personnel

73. How often does s/he see a doctor or a nurse (OTHER THAN MEDS ADMINISTRATION)?
[ ]Not in last year
[ ]Once a year
[ ]Twice a year
[ ]Three to six times a year
[ ]Once a month
[ ]Once a week
[ ]Once a day
[ ]More than once a day

74. To your knowledge, has s/he ever had difficulty receiving medical services?
[ ]No problem
[ ]One to three times
[ ]Four to six times
[ ]Seven to nine times
[ ]Over nine

75. Are immunizations up to date?
[ ]Yes
[ ]No
[ ]Don't know

76. What was the date of the last dental examination?
M [ ] never
M [ ] unknown
Y [ ]
Y [ ]

77. What was the date of the last eye exam?
M [ ] never
M [ ] unknown
Y [ ]
Y [ ]

78. Has a doctor ever indicated a history of seizure activity?
[ ]Yes
[ ]No
[ ]Don't know

79. How often does s/he experience seizures (INCLUDE ALL TYPES AND OCCURRENCES)? (MARK ONLY ONE)
[ ]Continuous intermittent seizures during the past year
[ ]More than five per day during the past year
[ ]More than one but less than five per day during the past year
[ ]About one per week during the past year
[ ]About one per month during the past year
[ ]Seven to 11 per year during the past year
[ ]One to six per year during the past year
[ ]Has documented history of seizures but no seizures in past year
[ ]No seizures in past five years
[ ]No seizures

79A. Does this represent a change from the previous year?
[ ]Same [ ]More [ ]Less [ ]Don't know

DRUG USAGE (QUESTIONS 80-85)

DRUG Compare medications received to the Drug Table. If medication appears on the table, insert the numerical code for the drug. (OTHERWISE LEAVE BLANK)

FREQuency of Administration

- TD or total daily dosage if they take several different doses of the same drug in one day
- PRN or when needed
- QID or four times daily
- TID or three times daily
- BID or two times daily
- HS or one time daily
- AVG or average daily dosage if they take a medication less than one time daily

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Drug: ____________________
Frequency drug[ ]
[ ] TD code[ ]
[ ] PRN Dosage
[ ] QID [ ]
[ ] TID [ ]
[ ] BID [ ]
[ ] HS [ ]
[ ] AVG
[ ] Other Units
Purpose Milligram
[ ] behavioral control Gram
[ ] seizure control Milliliters
[ ] other/unknown CC's

Drug: ____________________
Frequency drug [ ]
[ ] TD code [ ]
[ ] PRN Dosage
[ ] QID [ ]
[ ] TID [ ]
[ ] BID [ ]
[ ] HS [ ]
[ ] AVG
[ ] Other Units
Purpose Milligram
[ ] behavioral control Gram
[ ] seizure control Milliliters
[ ] other/unknown CC's

Drug: ____________________
Frequency drug[ ]
[ ] TD code[ ]
[ ] PRN Dosage
[ ] QID [ ]
[ ] TID [ ]
[ ] BID [ ]
[ ] HS [ ]
[ ] AVG
[ ] Other Units
Purpose Milligram
[ ] behavioral control Gram
[ ] seizure control Milliliters
[ ] other/unknown CC's

Drug: ____________________
Frequency drug [ ]
[ ] TD code [ ]
[ ] PRN Dosage
[ ] QID [ ]
[ ] TID [ ]
[ ] BID [ ]
[ ] HS [ ]
[ ] AVG
[ ] Other Units
Purpose Milligram
[ ] behavioral control Gram
[ ] seizure control Milliliters
[ ] other/unknown CC's

Drug: ____________________
Frequency drug[ ]
[ ] TD code[ ]
[ ] PRN Dosage
[ ] QID [ ]
[ ] TID [ ]
[ ] BID [ ]
[ ] HS [ ]
[ ] AVG
[ ] Other Units
Purpose Milligram
[ ] behavioral control Gram
[ ] seizure control Milliliters
[ ] other/unknown CC's

Drug: ____________________
Frequency drug [ ]
[ ] TD code [ ]
[ ] PRN Dosage
[ ] QID [ ]
[ ] TID [ ]
[ ] BID [ ]
[ ] HS [ ]
[ ] AVG
[ ] Other Units
Purpose Milligram
[ ] behavioral control Gram
[ ] seizure control Milliliters
[ ] other/unknown CC's

MEDICATIONS TABLE

01 Acetophenazine
20 Adapin(R)
02 alprazolam
03 amantidine
04 amitriptyline
06 amoxapine
07 amphetamine sulfate
09 Anafranil(R)
06 Asendin(R)
26 Atarax(R)
30 Ativan(R)
40 Aventyl(R)
33 benactyzine
07 Benzedrine(R)
91 bupropion
09 Buspirone
60 carbamazepine
14 Catapres(R)
65 celontin
47 Centrax(R)
10 chloral hydrate
11 chlordiazepoxide
92 chlormezanone
12 *chlorpromazine
81 chlorprothixene
29 cibalith-S
94 clomipramine
13 clonazepam
14 clonidine
15 clorazepate
16 *Cloxapen(R)
16 cloxacillin
95 Clozaril(R)
48 *Compazine(R)
63 Corgard
42 Cylert(R)
24 Dalmane(R)
64 Depakene(R)
80 Depakote(R)
17 desipramine
36 Desoxyn(R)
54 Desyrel(R)
18 Dexedrine(R)
18 dextroamphetamine
62 diazepam
67 dilantin
96 diphenhydramine
80 divalproex sodium
20 doxepin
04 Elavil(R)
97 Endep(R)
33 Equanil(R)
29 eskalith
79 ethosuximide
74 ethotoin
43 etrafon
21 fenfluramine
22 fluoxetine
23 *fluphenazine
24 flurazepam
68 gemonil
55 Halcion(R)
25 *Haldol(R)
25 *haloperidol
26 hydroxyzine
27 iamimine
27 imipramine
03 Inderal(R)
03 inderide
28 isocarboxazid
13 Klonopin(R)
11 Librium(R)
98 Limbitrol DS(R)
29 lithane
29 lithium
29 lithobid
30 lorazepam
31 *loxapine
31 *Loxitane(R)
32 Ludiomil(R)
32 maprotiline
28 Marplan(R)
69 mebaral
51 *Mellaril(R)
70 mephenytoin
69 mephobarbital
33 meprobamate
99 Meprospan(R)
70 mesantoin
34 *mesoridazine
35 *metoclopramide
36 methamphetamine
68 metharbital
65 methsuximide
36 methylphenidate
71 milontin
33 Miltown(R)
38 *Moban(R)
38 *molindone
(hydrochloride)
72 mysoline
03 nadolol
39 naloxone
39 naltrexone
39 Narcan(R)
44 Nardil(R)
52 *Navane(R)
78 Neuramate(R)
10 Noctec(R)
17 Norpramin(R)
40 nortriptyline
45 *Orap(R)
41 oxazepam
40 Pamelor(R)
53 Parnate(R)
73 parmethadione
74 peganone
42 pemoline
23 permitil
43 *perphenazine
17 Pertofrane(R)
75 phenacemide
44 phenelzine sulphate
66 phenobarbital
71 phensuximide
75 phenurone
67 phenytoin
45 *pimozide
21 Pondimin(R)
47 prazepam
72 primidone
48 prochlorperazine
23 Prolixin
82 promazine
03 propranolol
49 protriptyline
22 Prozac(R)
35 *Reglan(R)
50 Restoril(R)
37 Ritalin(R)
41 Serax(R)
34 *Serentil(R)
83 sertraline
20 Sinequan(R)
85 Sparine(R)
56 *Stelazine(R)
58 Surmontil(R)
03 Symmetrel(R)
81 Taractan(R)
60 Tegretol(R)
50 temazepam
51 *thioridazine
52 *thiothixene
12 *thorazine(R)
(hydrochloride)
01 tindal(R)
27 tofranil(R)
84 Trancopal(R)
53 tranylypromine
15 Traxene(R)
54 trazodone
39 Trexan(R)
43 Triavil(R)
55 triazolam
77 tridione
56 *trifluoperazine
86 trifluopromazine
87 trihexiphenidyl
43 *Trilafon(R)
77 trimethadione
58 trimipramine
62 Valium(R)
64 valproic acid
62 valrelease
59 verapamil
89 Vesprin(R)
26 Vistaril(R)
49 Vivactil(R)
88 Wellbutrin(R)
02 Xanax(R)
79 zarontin

Yes	No	Don't Know	Not Applicable	
				86. If s/he receives medications for behavior control, has a written behavior management plan been developed & implemented? (not skip #90)
				87. Has a written behavior plan been approved by a Human Rights Committee in the past year?
				88. Have all people who worked with the person received instruction on how to implement the behavior management plan? [ ]Has plan. Instruction has been provided to all [ ]Has plan. Instruction has been provided to some [ ]Has plan. No instruction has been provided
				89. Have behaviors of concern become less frequent or severe since the behavior management plan started?
				90. If the individual received a drug identified with an asterisk has the individual received a screening for Tardive Dyskensia (an Ames test) in the past year?
				91. Have screening results been positive for Tardive Dyskensia n past yr?

91A. Have any of the following conditions occurred during the last year: (ASK FOR OBRA CLIENTS ONLY) (Mark all the apply)

ILLNESS	ILLNESS
Heart Disease	AIDS
High Blood Pressure	Alcohol Use/Abuse
Injuries:	Anemia
Broken Bones	Anorexia
Concussion	Bladder Problems
Dislocations	unusual Bleeding Problems
Head Injury	Bronchitis
Insomnia	Cancer:
Kidney Disease	Breast
Menstrual Problems	Cervix
Mental Health Problems	Lung
Obesity	Prostate
Physical Disabilities	Uterus
Pregnancies	Other
Pneumonia	Chest Pain:
Polyps in Colon	On Exertion
Seizures	Relieved By Rest
Shortness of Breath:	Cirrhosis
Lying Down	Colitis
Relieved by Sitting	Chronic Constipation/Diarrhea
Stroke	Depression
Suicide Attempts	Diabetes
Tuberculosis	Drug Use/Abuse
abnormal Vaginal Bleeding	Emphysema/Asthma
Weight	Fibrocystic Breasts

SECTION VI: HOME LIVING ARRANGEMENTS/FINANCIAL INFORMATION/SOCIAL INTERACTIONS

[ ] [ ] 92. How many individuals served (non-relatives) reside in the home (if multiple living units, indicate the number of individuals residing in the person's living unit).

[ ] [ ] [ ] don't know 92A. How many direct care staff are on the living unit at any given time during waking hours?

92B. Does the staff:
work shifts, reside at facility, some of both

[ ] [ ] [ ] 93A. What is his/her average weekly income from employment? (ENTER 0-999)

[ ] [ ] [ ] [ ] 93. What is his/her average monthly income from SSI, Social Security or any other source? (ENTER 0-9999)

[ ] [ ] [ ] 94. How much does the client pay per month for residential services? (ENTER 0-999)

More than twice a week	Twice a week	Once a week	2-3 times a month	Once a month	Less than once a month	Not sure or refused	Never	About how often did this person leave the facility to do each of the following in the past year?
								95. Go out to visit with friends, relatives, or neighbors.
								96. Go out to visit a supermarket or food store.
								97. Go out to a restaurant.
								98. Go out to church or synagogue.
								99. Go out to a shopping center, mall or other retail store to shop.
								99A. Go out to movies, arcades, bars, etc.
								99B. Go out to the bank.

CIVIL INVOLVEMENT AND CITIZENSHIP ACTIVITIES

100. Is s/he an adult who has a guardian (not conservatorship) appointed by a court?
[ ]Person is an adult with a guardian
[ ]Person has had a guardian recommended but not yet appointed (SKIP to #102)
[ ]Person is an adult who does not have a guardian (SKIP TO #102)
[ ]Person is under 18 years of age (SKIP TO #102)
[ ]Don't know (SKIP TO #102)

---

101. What kind of guardianship has been ordered? (MARK ALL THAT APPLY).
[ ]General guardian of property
[ ]Limited guardian of property
[ ]General guardian of person
[ ]Limited guardian of person
[ ]Don't know

---

102. Has s/he participated, during the past year, in an organization which supports or promotes self-advocacy by persons with disabilities? (Has attended or sponsored meetings or events of such organizations as People First, or other local self advocacy group).
[ ]Yes
[ ]No (Skip to #104)
[ ]Don't Know (Skip to #104)

---

103. How often does s/he typically participate in organized self-advocacy activities? (CHOOSE ONE).
[ ]Daily
[ ]Weekly
[ ]Every other week
[ ]Monthly
[ ]Quarterly
[ ]Semi-Annually
[ ]Annually

---

104. Does s/he participate (at least four times a year) in a civic organization (Lions Club, Kiwanis, Zonta, Scouts) or Social Club (Garden Club, church group, etc.)?
[ ]Yes Specify: _____ [ ]
[ ]No [ ]
[ ]Don't Know

Yes----------
¦ No
¦ ¦ Don't Know----------

105. Is s/he registered to vote?
106. Has s/he voted in the past two years?
107. Does s/he have a drivers license?
108. Does s/he drive?
109. Has s/he required or sought legal assistance, from a lawyer, in the past year? (IF ANSWER IS NO OR DON'T KNOW, SKIP TO #112).
110. Has s/he received legal assistance from a lawyer in the past year?
111. Was legal assistance sought/received to assist with:(MARK ALL THAT APPLY)
[ ]Civil rights, entitlements, services
[ ]Other civil matters
[ ]Criminal matters
[ ]Other (Describe) _____[ ]

112. Do you think s/he has ever experienced discrimination because of his/her disabilities? (IF ANSWER IS NO OR DON'T KNOW, SKIP TO #114)
[ ]Yes
[ ]No
[ ]Don't Know

113. In what areas: (MARK ALL THAT APPLY)
[ ]Physical access to building
[ ]Access to employment services
[ ]Access to educational services
[ ]Access to other human services
[ ]Access to transportation
[ ]Interaction with non-handicapped neighbors and friends
[ ]Participation in civic events (with non-handicapped individuals)
[ ]Participation in recreation/leisure
[ ]Other
Describe _____ [ ]

==========

SECTION VII: SERVICE PLANNING/DELIVERY

114. Does s/he have an individual habilitation plan (IHP) or individual program plan (IPP) or (IEP) or (IDP) or plan of care?
[ ]Yes, and it is under one year old
[ ]Yes, but over 1 year old
[ ]No written plan (SKIP TO QUESTION #127)

---

115. When was the last team meeting for the individual habilitation plan?
M [ ]
M [ ]
Y [ ]
Y [ ]
(GET THIS FROM IHP OR IPP)
date unknown

==========

Number of goals (#-9)	For the following, what is the total number of goals in IHP/IPP for him/her:
[ ]	116. In work skill areas (get, keep, perform job).
[ ]	117. In recreational activities planning and use (i.e. games, hobbies, sports, arts, and crafts).
[ ]	118. In use of self-care skills.
[ ]	119. In use of domestic skills (including food preparation).
[ ]	12#. In use of community living skills? Use of money; telling time; learning name and address or using ID; basic safety skills; handling emergencies; how to obtain generic community services; travel; health care; use of telephone; decision making about daily living activities.
[ ]	121. In sensory, motor skills? (ambulation; arm use and hand-eye coordination; sensory awareness).

Number of goals (0-9)	For the following, what is the total number of goals in IHP/IPP for him/her:
[ ]	122. In communication skills (vision, hearing, use of verbal language; use of nonverbal communication; use of written language; use of numbers and numeric concepts).
[ ]	123. In reduction of challenging behavior? (See Q 55-70).
[ ]	124. In development of social skills?
[ ]	125. In citizenship instruction?
[ ]	126. In other goal directed activities?

Number of Hours per Month	For the following, what is the total number of hours spent per MONTH for him/her by:	Prescribed but not received. Why not received?
[ ] [ ] [ ]	127. Habilitation Training Specialist: Paraprofessional services spent on habilitation objectives identified in the IHP.	Reason: _____ [ ]
[ ] [ ] [ ]	128. Homemaker Services by certified homemaker.	Reason: _____ [ ]
[ ] [ ] [ ]	129. Occupational Therapy Services:	Reason: _____ [ ]
[ ] [ ]	130. Physical Therapy Services:	Reason: _____ [ ]
[ ] [ ] [ ]	131. Psychotherapy Services by licensed psychologist or psychological assistant:	Reason: _____ [ ]
[ ] [ ]	132. Psychiatric Services:	Reason: _____ [ ]
[ ] [ ]	133. Speech and Communication Therapy:	Reason: _____ [ ]
[ ] [ ]	134. Audiology Services:	Reason: _____ [ ]

Number of Hours per Month	For the following, what is the total number of hours spent per MONTH for him/her by:	Prescribed but not received. Why not received?
[ ] [ ]	135. Nursing Services by RN or LPN:	Reason: _____ [ ]
[ ] [ ] [ ]	136. Pre-Vocational Services: (non paid employment)	Reason: _____ [ ]
[ ] [ ] [ ]	138. Sheltered Employment/ Sheltered Workshop (provided by workshop but receive less than min wage).	Reason: _____ [ ]
[ ] [ ] [ ]	139. Supported Employment: (Paid & supervised by job coach, mobile work crews, job enclave)	Reason: _____ [ ]
[ ] [ ] [ ]	140. Competitive Employment:	Reason: _____ [ ]
[ ] [ ] [ ]	141. Public School (regular classes):	Reason: _____ [ ]
[ ] [ ] [ ]	142. Public School (special classes):	Reason: _____ [ ]
[ ] [ ] [ ]	143. Special School:	Reason: _____ [ ]
[ ] [ ] [ ]	144. Private School: (Paid for by school system)	Reason: _____ [ ]
[ ] [ ] [ ]	145. Private School: (other than above)	Reason: _____ [ ]
[ ] [ ] [ ]	146. Formal infant stimulation or preschool development training program outside of home:	Reason: _____ [ ]
[ ] [ ]	147. Homebound Education:	Reason: _____ [ ]

Number of Hours per Month	For the following, what is the total number of hours spent per MONTH for him/her by:	Prescribed but not received. Why not received?
[ ] [ ]	148. Respite Services:	Reason: _____
[ ] [ ]	149. Any other services prescribed:	Reason: _____
[ ] [ ]	150. Any other services prescribed:	Reason: _____

PART II: CONSUMER INTERVIEW (COPYRIGHT CFA 1986)

These questions should be answered in private by the client. Attempt to interview all clients, even if there is doubt about their ability to respond.

Family _____ Guardian _____ Advocate _____ Favorite thing _____

Hi! My name is _____. Are you ___(name)___. How are you today? Can I ask you a few questions? Is your favorite (food/toy/hobby) _____? I'm going to ask you some silly questions now. Just tell me yes or no, even though they are silly, OK? Do cats fly? Do dogs bark? Which person is happy? _____ Which person is standing? _____Now I've got some questions that aren't so silly. Everything you tell me will be kept private.

[ ] Willing
[ ] Not willing (SKIP TO #25)
[ ] Unable (SKIP TO #25)
[ ] Not here (SKIP TO #25)
[ ] Other (SKIP TO #25) _____

Yes (nice, like, good, always, frequently)	Unsure (sometimes, occasionally)	No (mean, bad, never, don't like)	Did not answer	
				1. Do you like living here or not like living here?
				2. Do you like the people who work with you or not like them?
				3. Do you think the food here is good or bad?
				4. Do you have enough clothes to wear or not enough?
				5. Do you have any really good friends?
				5A. Do you have more than one really good friend?
				6. Are the people who work with you mean or nice?
				7. Do you like the things you do in the day or not like them?
				8. Do you work and earn money?
				9. Please let me check - do you think the food here is bad or good?

Interviewer: Did you use assistive communication devices? Yes No

Yes (choose nice, good, always, frequently)	Unsure (sometimes, occasionally)	No (mean, bad, never, don't choose)	Did not answer	
				10. Do you you choose the food you will eat at home, or does someone choose for you?
				10A. In a restaurant, do you choose the food you will eat or does someone choose for you?
				11. Do you choose the clothes you will buy or does someone choose for you?
				12. Do you choose the clothes you will wear or does someone choose for you?
				13. Do you choose what you will do or does someone choose for you?
				14. Do you choose your own friends or partners or does someone choose for you?
				15. Do you choose how you spend your money or does someone choose for you?
				16. Do you have friends visit you often?
				17. Can your friends visit you anywhere in your home?
				18. Do you visit your family often?
				19. Do you visit your guardian?
				20. Do you visit advocates?
				21. Do you go to places for recreation or stay at home?
				22. Do you ride in a regular van/car or one with a handicap lift?

23. Is there anything else you would like to tell me? (Record response word for word, editor will code.)

Answer: "_____ [ ]
_____ [ ]

24. If you had one wish what would you wish for? (Record response word for word, editor will code.)

Answer: "_____ [ ]
_____ [ ]

24A. Is there something you want to work on your program? (That you are not doing now?) (Verify with staff that they are not currently doing it.)

Answer: "_____ [ ]
_____ [ ]

Interviewer: I believe these responses are: generally reliable not reliable

OBSERVATIONS

26. Is s/he dressed appropriately?
    [ ] Yes Explain: _____ [ ]
    [ ] No _____ [ ]
27. Is s/he clean and groomed appropriately?
    [ ] Yes Explain: _____ [ ]
    [ ] No _____ [ ]
28. Is s/he free of visible bruises, rashes, sores, cuts, or other signs of ill health?
    [ ] Yes Explain: _____ [ ]
    [ ] No _____ [ ]

PART III: PHYSICAL QUALITY
ADAPTED FROM SELTZER, 1982, MEAP RATING SCALE
MODIFIED BY TEMPLE UNIVERSITY, 1983
COMPLETE THIS SCALE FOR THE SMALLEST LIVING UNIT FOR EACH FACILITY.

SECTION 1: EXTERNAL

1. As a neighborhood, how does the area around this site look?
   [ ] Very pleasant and attractive
   [ ] Mildly pleasant and attractive
   [ ] Ordinary, perhaps even slightly unattractive
   [ ] Unattractive, slum-like
2. How attractive are the site grounds?
   [ ] Very attractive - landscaping or very attractive natural growth; well maintained; no litter or weeds, clean paths, neatly trimmed
   [ ] Somewhat attractive - shows signs of care and frequent maintenance
   [ ] Ordinary - somewhat attractive, but poorly maintained or ordinary looking; little landscaping, some weeds or litter
   [ ] Unattractive - no grounds, sidewalks only; show little or no maintenance
3. How attractive is the building in which the client lives?
   [ ] Very attractive - unique and attractive design, excellent maintenance
   [ ] Somewhat attractive - may show some deterioration on close inspection, or design is adequate but not unusually attractive
   [ ] Ordinary - buildings are somewhat attractive but poorly maintained, or are not notable in either design or maintenance
   [ ] Unattractive - buildings are deteriorated or unattractive

SECTION 2: ROOM BY ROOM (Rate each room)

(DO NOT RATE IF LIVES WITH FAMILY AND RATING QUESTIONS ARE INTRUSIVE.)

LIVING ROOM
¦ DINING ROOM
¦ ¦ BEDROOMS
¦ ¦ ¦ KITCHEN
¦ ¦ ¦ ¦ BATHROOM
-¦---¦---¦---¦---¦----------

4. Orderliness/Clutter

No such room
Neat - living spaces are very orderly; there seems to be a "place for everything and everything is in its place"
Some disarray - looks "lived in"; some furniture moved around, magazines lying around, etc.
Cluttered - living spaces are somewhat disorganized and messy; some objects lying about; area seems crowded
Very cluttered - furniture and other objects are in disarray; floor area has objects to maneuver around

LIVING ROOM	DINING ROOM	BEDROOMS	KITCHEN	BATHROOM	
					5. Cleanliness of Walls and Floors (or Rugs)
					No such room Very Clean - both walls and floors are kept very clean, spotless; floors are polished Clean - both walls and floors are cleaned regularly; some dust in corners, fingerprints on walls Somewhat dirty - either walls or floors needed cleaning; considerable dust, fingerprints or stains Very dirty - both walls and floors need a major cleaning; surfaces stained, scuff marks, surfaces dirty to touch
					6. Condition of furniture
					No such room Excellent condition - like new; well-kept, spotless, highly polished or without stains Good condition - not new, but in good condition; slightly worn, small scratches, dusty, a few stains, some dirt in creases Fair condition - older, but still structurally sound; moderately clean Deteriorated - old and in poor repair; some tears, stains, dirt or dust; may be structurally unsound or dangerous
					7. Window areas
					No such room Many windows - living space has large window areas which give an open feeling Adequate windows - windows are sufficient to allow good light; there is no closed feeling Few windows - room tends to be dark, even on sunny days; there is a feeling of being closed in No windows - there are no windows, or the windows are non-functional
					8. Odors
					No such room Fresh - living spaces have pleasantly fresh odor No odors - nothing noticeable about the air; "normal" Slightly objectionable - air is slightly tainted in some way; stale, musty, medicinal Distinctly objectionable - unpleasant odors are apparent

9. Variation in design of residents' rooms (apts.).

[ ] Distinct variation - as if effort was made to vary style and decor from room to room

[ ] Moderate variation - rooms (apartments) are distinct, but there is a general decor throughout

[ ] Nearly identical - some variation in size, shape or furniture arrangement; variation is not noticeable unless looked for

[ ] Identical - no variation except for decorational detail such as paint or rug color

10. Personalization of residents' rooms (apts.).

[ ] Much personalization - most of the furnishings and objects in the rooms belong to the individual; time and energy have been spent in personalization

[ ] Some personalization - residents have added personal objects such as rugs, pictures, chairs, favorite objects

[ ] Little personalization - some family pictures or personal articles, but room does not seem to "belong to the individual."

[ ] No personalization is evident

---

11. Overall physical pleasantness of the facility?

[ ] Quite pleasant

[ ] Pleasant

[ ] Somewhat unpleasant

[ ] Distinctly unpleasant

==========

Poor — Fair — Excellent

[ ] 12. Overall, how would you rate this site?

[ ] 13. How would you rate the quality of food in the refrigerator and cupboards?

[ ] 14. How would you rate the quantity of food in the refrigerator and cupboards?

Cold, impersonal — Neutral — Warm, personal

[ ] 15. How do you perceive staff-consumer/ consumer-staff interactions?

Unfriendly — Tolerant — Friendly

[ ] 16. How do you perceive consumer-consumer interactions?

Pessimistic — Neutral — Enthusiastic

[ ] 17. What are staff's expectations of consumers regarding growth?

Not at all — In minor ways — As much as I've ever seen

[ ] 18. To what extent is the setting handicapped accessible?

No not happy — Neutral — Yes very happy

[ ] 19. Are clients happy here?

APPENDIX B

MEASURES TO MONITOR DEVELOPMENTAL DISABILITIES QUALITY ASSURANCE: A STUDY OF RELIABILITY

Abstract

The reliability of four scales used in measuring quality of life are examined. Adaptive Development, Challenging Behavior (severity and frequency), Consumer Interview, and Physical Quality Scales were examined for reliability. In addition, demographic varibles and medical questions are investigated. The study of reliability makes use of data collected in 1991 and 1992 state-wide in Oklahoma to monitor services provided to individuals with developmental disabilities. High interrater reliabilities were found for Demographic Information, Adaptive Development, Challenging Behavior (severity and frequency) and the Consumer Interview Scales over the two-year period. The Physical Quality Scale was found to be unreliable in the measurment of interviewer site impressions. Finally, a high degree of test-retest reliability was found for consumers regarding food quality.

Introduction

Longitudinal data is vitally important in monitoring the quality of life of individuals who are involved in deinsititutionalization. Emphasis upon the reliability of measures and items used in the analysis therefore, have increased importance. The validity of the measures used are also important, however, reliability for the current study is paramount. Thus, several quality of life measures used in the state-wide monitoring of Oklahomans with developmental disablities are examined for reliability. Included in the current investigation are five measures (Adaptive Development, Challenging Behavior (frequency and severity), Consumer Interview, and Physical Quality), along with demographic information and medical information as the focus of this research. The sample included those individuals receiving support through the Developmental Disabilities Service Division of the Department of Human Services. Data gathered in 1991 and 1992 were used to assess interrater and test-retest reliabilities of these measures. Further, past research has not focused on an entire state population of consumers but only on those in institutions, community centers or other residential facilities. In addition, past research has not included the actual consumers as informants. The only scale in the current study to have been systematically examined for reliability was the Adaptive Development Scale.

Literature on Reliability of Scales

Reliability can be defined as the extent to which a measure or procedure assigns the same value to characteristics each time that it is employed when that measure is employed under essentially the same circumstances.

Several studies over the past 17 years have focused on the adaptive development of consumers. The Adaptive Behavior Scale (Nihira, 1976) was designed in two parts, with the first containing 32 items designed to assess individual skills and habits and the second part containing 16 items focusing on frequency and severity of behavioral disorders. Some of the remaining scales examined in this research have only received occasional attention while others have not been evaluated previously.

Interrater Reliability on Adaptive Development

In 1976, Nihira reported an interrater reliability of $r = .93$ for the Adaptive Behavior Scale in studying a state operated institution in California. Isett and Spreat (1979) also reported interrater reliability coefficients ranging from .42 to .93 on Adaptive Behavior Scale items. These data were collected from a sample of 29 consumers by different interviewers within a two-week period. Silverman, Silver, Sersen, Lubin, and Schwartz (1986) used the Minnesota Developmental Programming System Behavioral Scale (which contains many of the same behavioral skills questions contained in the current study) with a profoundly mentally

challenged population and produced an interrater reliability of r = .98. Devlin (1989) more recently reported a high interrater reliability of r = .95 for Behavior Development Scale and used a time interval between the two interviews averaging 9.13 weeks (Devlin, 1989) The adaptation tested by Devlin is the version of the scale used in the current study (Conroy and Bradley, 1985).

Test-Retest Reliability on Adaptive Development

In studies focusing on the test-retest reliability of the Adaptive Behavior Scale, Isett and Spreat (1979) reported uniformly high Spearman rank correlations for the 32 scale items ranging from r = .85 to r =.97. Isett and Spreat chose 28 individuals at random for participation in the test-retest research which had a two-week time lapse between the first and second interviews. Silverman et al. (1986) also examined test-retest reliability in their study with individuals who were profoundly mentally challenged and found r = .98.

Conroy and Bradley (1985) concluded in the five-year Pennhurst Longitudinal Report that the Behavior Development Scale total is highly reliable with test-retest reliability of r = .96; they also reported an interrater reliability of r = .94. Devlin (1989) also using data collected during the Pennhurst studies, reported a correlation of .91 for test-retest reliability on the Behavior Development Scale.

Interrater and Test-Retest Reliability on Challenging Behavior

The few reliabilities reported for the Challenging Behavior Scale have been consistently lower than those reported for the Adaptive Development Scale. In 1976, Nihira reported an interrater reliability of r = .71 for the Adaptive Behavior Scale, while Conroy and Bradley (1985), reported similar reliability of r = .7Ø for the Behavior Development Scale. Devlin (1989) also reported an interrater reliability of r = .72 for this scale.

Test-retest reliability for The Challenging Behavior Scale has also been examined by Conroy and Bradley (1985) who reported a high correlation of r = .9Ø. In addition, Devlin (1989) reported a test-retest reliability of r = .6Ø on this scale.

Research Procedures

Subjects

Of the 23Ø3 interviews conducted in 1991 and 3599 conducted in 1992, 49 of those in 1991 and 86 of those in 1992 were inadvertently conducted twice. Table 15 displays the distribution of the reliability sample along with the total sample for 1991 and 1992. The ratio of males to females in the duplicated data appears to be consistent with the sample in both years. There is an over representation of whites in both duplicate and the total data set in both

Table 15

Demographic Characteristics of Duplicated Sample and Entire Data 1991 & 1992

Demographic Characteristics	1991				1992			
	*N=49		N=2303		*N=86		N=3599	
	*N	%	N	%	*N	%	N	%
Sex								
Male	25	51.0	1248	54.2	50	58.1	1984	55.3
Female	24	49.0	1056	45.8	36	41.9	1605	44.7
Race								
White	36	73.5	1948	84.6	69	80.2	3017	83.8
Black	7	14.3	200	8.7	14	16.3	320	8.9
Other	6	12.2	155	6.7	3	3.5	241	7.3
Level of Retardation								
Mild	4	8.2	302	13.1	19	22.1	777	21.6
Moderate	4	8.2	302	13.1	14	16.3	631	17.5
Severe	13	26.5	358	15.6	21	24.4	626	17.4
Profound	26	53.0	786	34.1	24	27.9	901	25.0
Unknown	2	4.1	555	24.1	8	9.3	664	18.4
Type of Facility								
State Institution	43	87.8	884	38.4	19	22.1	891	24.8
ICF	1	2.0	752	32.7	13	15.1	921	25.6
ICF / MR	2	4.1	227	9.9	11	12.8	357	9.9
Group Home	3	6.1	305	13.2	19	22.1	625	17.4
Supportive Living	-	-	2	>.01	11	12.8	199	5.5
Private Home	-	-	98	.04	5	5.8	365	10.1
Foster Care	-	-	33	>.01	7	8.1	102	2.8
Semi-Indep. Living	-	-	16	>.01	1	>.01	89	2.5

* Indicates Duplicated Data

years. Also levels of retardation seem to be consistent in both years. Finally the duplicated data in 1991 does not reflect the sample population in the facilities from which they were drawn. In 1991 the duplicated data came primarily from the State-Run institutions, while in 1992 this data reflected a more even distribution across facilities (institutions, intensive care facilities, group homes, and supportive living).

The current research project was designed to monitor quality of care provided to consumers in the state of Oklahoma. Questions on the survey consisted primarily of closed-ended likert measures. Interviews were generally conducted with the consumers' primary caregivers who were asked about demographic information, consumers' past living history, adaptive development, challenging behaviors, medical needs, civic involvements, services provided, consumers' perceptions of their environment and consumers' contacts with friends, family or advocates. These interviews in some cases were conducted with family members, friends, or other individual when outside the institutional setting. These informants would be preferable due to their knowledge of scope the individuals' lifestyle and behaviors. Researchers also included interviews of the consumers directly to index consumer satisfaction (only 46% of the consumers were capable of responding to these questions). Additionally, the quality of the physical surroundings were rated by the interviewers.

In order to examine interrater reliability of the instrument duplicate interviews were selected. In both 1991 and 1992, surveyors who did not know that interviews were being conducted a second time were assigned to consumers (N = 49 in 1991 and N = 86 in 1992). In addition to having different interviewers when gathering the duplicate data, interviews were frequently conducted with different caregivers. In 1991 the range of time between visits was three days to five and a half months, with the average time between visits being approximately two months. The average time between interviews in 1992 was three and a half months with a range of three days to nine and a half months. It was made known at each residential setting that repeat interviews might be conducted a second time for reliability purposes. The average amount of time spent filling out the survey was one hour. Only 12 of the 49 consumers in 1991 (24.5%) and 43 of the 86 in 1992 (5Ø.Ø%) were able to be interviewed both times.

Data were entered into the university mainframe computer for each year. Debugging procedures were employed, and the data were cleaned so that no coding errors would interfere with future statistical and research procedures. The reliability of consumer responses were calculated using Pearson's Product Moment Correlations. Nunnally (1978) has suggested .7Ø as an acceptable correlation for reliability in basic research (.8Ø for applied settings).

Results

Table 16 shows the correlations among the demographic characteristics for both 1991 and 1992. These were highly reliable. Of the 14 correlations, only four were less than r = .9Ø. The least reliable was level of retardation with r = .85 in 1991 and r = .73 in 1992.

Residential data was considerably more varied and less reliable than the demographic variables with correlation coefficients between r = .47 in 1992 (adverage monthly income) to r = .99 in 1991 (date person moved) (See Table 16). Similarly for items dealing with individuals' medical needs were highly reliable while others were not. Questions which generally called for the caregivers' subjective apprisal such as, urgency of need for medical care had lower coeffecients reported. Additional, question such as; date of last medical checkup, date of last dental exam, history of seizure activity, and frequency of seizures experienced had coefficients above r = .56 in each year.

The most consistent scale used in this research was Adaptive Development (See Table 17). It generated correlation coefficients of .96 in 1991 and .93 in 1992. Four of the 32 items in the measure, however, had lower reliabilities. The question asking about consumer participation in group activities had a reliability of only .49 in 1991 and .58 in 1992. The question concerning consumers' ability to understand time generated a correlation

Table 16

Correlations Across Subjects 1991 and 1992 on Categories of Information

Categories	Correlations 1991 (N=49)	Correlations 1992 (N=86)
Demographic		
Race	.89	.97
Sex	1.00	.98
Level of retardation	.85	.73
Date of birth	.97	1.00
Month	.97	1.00
Day	.99	1.00
Year	.99	1.00
Residential Information		
Date person moved here	.99	.70
Private or public residence	.59	.55
Adverage monthly income	.98	.47
Medical needs		
How urgent is need for medical care	.22	.40
Date of last medical checkup	.62	.56
Date of last dental exam	.93	.63
History of seizure activity	.64	.85
How often seizures experience	.80	.86

Note. To be significant (.01) with N = 49, r > .35 and with N=86, r > .27.

Table 17

Correlations 1991 and 1992: Adaptive Development Scale

Adaptive development items	Correlations 1991 (N=49)	Correlations 1992 (N=86)
Body balance	.89	.88
Use of table utensils	.93	.85
Eating in public	.68	.74
Drinking	.79	.85
Toileting	.87	.84
Bathing	.78	.88
Dressing	.83	.90
Sense of direction	.79	.76
Money handling	.67	.70
Purchasing	.69	.61
Writing	.91	.69
Sentences	.86	.82
Reading	.90	.67
Numbers	.85	.71
Room cleaning	.77	.76
Food preparation	.89	.81
Table clearing	.89	.82
Job complexity	.74	.72
Initiative	.53	.59
Attention	.70	.52
Personal belongings	.63	.71
Interaction with others	.57	.45
Participation in groups	.49	.58
Walking and running	.92	.87
Self-care at toilet	.86	.90
Washing hands and face	.89	.83
Care of clothing	.76	.77
Shoes	.84	.83
Pre-verbal expression	.67	.83
Complex instructions	.74	.69
Understands time	.49	.57
Awareness of others	.66	.72
Scaled total	.96	.93

Note. To be significant (.01) with N=49, r > .35 and with N=86, r > .27.

of .49 in 1991 and .57 in 1992. Consumers' interactions with others scored the lowest of all with correlations of .57 in 1991 and .45 in 1992. The ability of the consumer to show initiative also had lower correlations with .53 in 1991 and .59 in 1992.

The Challenging Behavior Scales (see Table 18) showed slightly less interrater reliability overall than the Adaptive Development Scale with .74 in 1991 and .69 in 1992 on the frequencies of behaviors and .69 in 1991 and .72 in 1992 on severity of behaviors. Several of the items on these scales, specifically those concerning appropriateness of behaviors, were problematic. Both frequency and severity of inappropriate sexual behaviors in public were particularly unreliable in 1991 (.Ø2 and .Ø8) and in 1992 (-.Ø4 and -.Ø4). Another item which did not generate acceptable correlations was "unresponsive to activities." Both frequency and severity measures of this item generated correlations of .32 and .2Ø in 1991 and of .ØØ and .28 in 1992. Some items had low correlations in only one of the two years. Frequency of inappropriate clothing removal, for example, showed r =.Ø8 in 1991 but r = .76 in 1992. Frequency of consumers' rebellious behavior produced correlations of .14 in 1991 but .55 in 1992. Further, the frequency of consumers' untrustworthy behavior generated a correlation of .61 in 1991 but only .12 in 1992. In 1992 the items concerning severity of untrustworthy behavior generated inconsistent correlations of .63 in 1991 and -.Ø7

Table 18

Correlations 1991 and 1992: Challenging Behavior Scale

Challenging behavior items	Correlations 1991 (N=49)	Correlations 1992 (N=86)
Frequency		
Physical violence to others	.60	.51
Damages property	.60	.28
Disrupts activities	.65	.39
Profane or hostile language	.80	.45
Rebellious	.14	.55
Runs away	.69	.39
Untrustworthy	.61	.12
Stereotyped behavior	.49	.32
Removes clothing inappropriately	.08	.76
Injures self	.32	.32
Hyperactive	.64	.59
Inappropriate sexual behavior (home)	.65	.41
Inappropriate sexual behavior (public)	.02	-.04
Unresponsive to activities	.32	.00
Screams, yells, cries inappropriately	.58	.27
Repeats a word / phrase	.76	.37
Scaled total	.74	.69
Severity		
Physical violence to others	.72	.60
Damages property	.44	.31
Disrupts activities	.63	.38
Profane or hostile language	.73	.63
Rebellious	.26	.53
Runs away	.53	.39
Untrustworthy	.63	-.07
Stereotyped behavior	.33	-.06
Removes clothing inappropriately	.41	.37
Injures self	.54	.23
Hyperactive	.68	.77
Inappropriate sexual behavior (home)	.45	.37
Inappropriate sexual behavior (public)	.08	-.04
Unresponsive to activities	.20	.28
Screams, yells, cries inappropriately	.68	.43
Repeats a word / phrase	.88	.35
Scaled total	.69	.72

Note. To be significant (.01) with N = 49, r > .35 and with N=86, r > .27.

in 1992. Severity of stereotyped behaviors also produced different correlations between years with a .33 in 1991 and a -.Ø6 in 1992.

Interviews with consumers themselves produced higher reliabilities in 1991 than in 1992, with a Consumer Interview Scale total correlation of .93 and .65 respectively (see Table 19). Individual item correlations, however, ranged between r = .17 and r = .87. Two of the items in 1992 showed markedly lower correlations for the items concerning use of non-handicapped transportation and leaving home for recreational purposes, with r = .3Ø and r = .17 respectively.

The results on the Physical Quality Scale (see Table 2Ø), unfortunately, produced extremely low correlations. Total scale correlations of r = -.13 in 1991 and r = .ØØ in 1992 are unacceptable. A few items, however, approached statistical significance at least; for example, those dealing with dining room odors in 1992 (r = .31) and bedroom odors in 1992 (r = .28).

Finally, one question on the consumer interview appeared twice as a measure of test-retest reliability of consumers' responses. Early in the interview the consumer was asked "How do you feel about the food here?," and then later the consumer was asked, "Let me check, did you say the food here is bad or good?" A correlation between these two items, as a measure of test-retest reliability, was extremely high among the 12 interviews in 1991 (r = .91) and

Table 19

Correlations 1991 and 1992: Consumer Interview

Consumer interview items	Correlations 1991 (N=12)	Correlations 1992 (N=43)
Feel about living here	.64	.49
Feel about people who work with you	.55	.43
Feel about the food here	.54	.38
Have enough clothes	.54	.45
Any real good friends	.51	.48
People here mean or nice	.64	.48
Like day activities	.50	.49
Make money	.69	.48
Like food check	.68	.44
Pick what you will eat	.76	.49
Pick cloths you buy	.68	.46
Pick cloths you wear	.59	.55
Pick free time activities	.70	.60
Pick a friend for free time	.68	.53
Pick how to spend money	.71	.49
Have friends visit	.58	.55
Friends visit anywhere you want	.51	.70
Visit with family	.82	.54
Visit with guardian	.81	.40
Visit with advocates	.87	.42
Leave home for recreation	.77	.30
Use non-handicapped transprotation	.73	.17
Scaled total	.93	.65

Note. To be significant (.01) with N=12, r > .50 and with N=43, r > .35.

Table 20

Correlations 1991 and 1992: Physical Quality Scale

Physical quality items	Correlations 1991 (N=49)	Correlations 1992 (N=86)
Neighborhood attractivness	-.14	.08
Site grounds attractive	-.13	.15
Building attractive	-.10	.01
Living room orderly	.09	.03
Dining room orderly	-.13	.11
Bedrooms orderly	.10	.09
Kitchen orderly	.09	.05
Bathroom orderly	-.13	-.11
Living room floors clean	-.02	.07
Dining room floors clean	-.10	.14
Bedrooms floors clean	-.02	.03
Kitchen floors clean	-.11	.13
Bathroom floors clean	-.06	.17
Living room furniture condition	-.05	.10
Dining room furniture condition	-.02	.09
Bedrooms furniture condition	-.01	.03
Kitchen furniture condition	.00	.06
Bathroom furniture condition	-.10	.05
Living room windows area	-.11	-.01
Dining room windows area	-.28	.11
Bedrooms windows area	-.24	.13
Kitchen windows area	-.19	.00
Bathroom windows area	-.18	.08
Living room odors	-.16	.16
Dining room odors	-.23	.31
Bedrooms odors	-.22	.28
Kitchen odors	-.10	.15
Bathroom odors	-.13	.21
Residents' rooms variation	.05	.13
Personalization rooms	.01	.05
Pleasantness of overall site	-.16	.12
Overall rating	-.13	-.07
Quality of refrigerator food	-.07	.02
Quanity of food	.05	-.01
Staff-consumer interactions	-.10	.06
Consumer-consumer interactions	-.10	.00
Staff's expectations of consumer growth	-.19	.06
Oriented toward measurement	-.02	.18
Is setting handicapped accessable	-.29	.11
Scaled total	-.13	.00

Note. To be significant (.01) with N = 49, r > .35 and with N=86, r > .27.

the 43 interviews in 1992 (r = .96). Equally high were the correlations for all 2,304 interviews in 1991 (r = .94) and all 3,599 in 1992 (r = .94).

Discussion

These results from the instrument used state-wide in Oklahoma appear to be consistent with past research. The Adaptive Development Scale produced high reliabilities similar to those reported in past literature (Nihira, 1976; Isett and Spreat, 1979; Devlin, 1989). The Challenging Behavior Scale produced lower reliabilities, as in past research, but results reported here were somewhat lower than those reported by Devlin (1989).

Some questions in both the Adaptive Development Scale and the Challenging Behavior Scales, however, could be improved to produce an even more reliable measure. For the Adaptive Development Scale, questions concerning situations in which caregivers were asked to make more subjective appraisals of consumer behavior (such as consumer initiative, attention, interacting, or understanding of time) seemed most problematic. If these questions could be connected to more tangible behaviors, higher correlations might be achieved.

Several areas of inquiry were problematic on the Challenging Behavior Scale. One of these is the appropriateness of sexual behavior. The responses by caregivers tended to be even more inconsistent for behaviors

in public than in the home. Behavior in public probably occurs less often and requires more subjective appraisal. These consumers are not often in public, and different caregivers are likely to witness different ranges in public compared to home behavior. A second area dealt with questions on the appropriateness of consumers' behaviors. The term "appropriate" appears to be highly subjective and when combined with questions concerning sexuality this subjectiveness is magnified. Instructions which tie appropriateness to specific behaviors which are observable might increase reliability.

Further, the questions about consumer untrustworthiness, rebelliousness, destructiveness, and stereotypical behaviors produced correlations which varied in reliability. These questions also have similar problems of caregiver-consumer interaction and the subjective appraisals which are made by caregivers when presented with a rarely observed event and asked to give concrete responses to questions.

The demographic information produced highly reliable results. This suggests that caregivers can and do give reliable information when the responses are very concrete, and limited (e.g., sex, age, and race). The information about residential history and medical needs, however, showed extremely inconsistent reliabilities.

The results from interviewing consumers suggest that consumer responses can be consistent and researchers can

plan to interview them. The slightly lower interrater reliabilities reported in 1992 may be in part due to a larger and more varied population in that year's sample. The 1992 sample included more individuals from the moderate and mild classifications for individuals with developmental disabilities than the 1991 sample. Sigelman, Budd, Winer, Spanhel and Schoenrock (1981) have suggested that individuals with developmental disabilities may respond "yes" when in doubt about a question. Less diversity in 1991 may account for less variation in scores. The more homogeneous population included in this report in 1991 may account for the higher reliabilities reported on several scales in that year. The differences between the 1991 and 1992 reliabilities on the consumer interview may also be due, in part, to conducting fewer interviews in 1991.

Knapp and Salend, (1983) also suggest caution when interpreting reliabilities of behavior development as well as challenging behavior, asserting agreement may be spurious.

> "Interrater reliability can be influenced by several factors, including quality of the informants and specificity of the items. . . . Examiners should consider the following: a) can the potential informant communicate the observations?, b) Does the potential informant have a sufficient familiarity with the consumers?, c) has the potential informant viewed a wide range of the consumers' behavior?, d) are the consumers likely to perform at their optimal level in the presence of the informant?" (Knapp and Salend; 1983, p. 64).

These reliabilities might also be improved by using both the consumer interviews and the responses of caregiver on adaptive development questions. One method which could be suggested is that consumers' responses be compared to caregivers' responses on each item to give a measure of experienced compared to observed reliabilities.

The interviewers' impressions of physical site varied greatly and was not a reliable measure in this research. Interviewers apparently need much more specific guidelines and probably should have instructions which attach site appraisal to their concrete observations. The low reliabilities of items on the Physical Quality Scale reflect biases and personal perspectives of each individual interviewer. It is not the intent of the Physical Quality Scale to get into value judgments.

Finally, it merits mention that some of the higher reliabilities reported in 1991 may be due in part to a higher number of institutionalized, lower functioning consumers in this sample. Past research has concluded that these consumers tend to be more stable over time with regards to their behavior and challenging behaviors (Nihira, 1976; King, Soucar & Isett, 1980; Horn & Fuchs, 1987; Fine, Tangerman & Woodard, 1990). The larger and more evenly distributed sample in 1992 probably gives a more accurate appraisal of overall consistency in caregiver responses and consumer perceptions.

Implications

There are several implications which may be drawn from the current study. These represent suggestions for quality assurance data gathering efforts in the future. First, that the Adaptive Development Scale as used in Oklahoma is a reliable measure of individual abilities and further, indicates independence. Second, some items included on the Challenging Behavior and Physical Quality scales need to specify parameters on questions which use termonology such as; disrupt, inappropriate, unresponsive or attractiveness, orderly, and clean. These terms require the interviewee to subjectively appraise various situations, personal and physical. If consistent data is to be gathered consensus needs to be determined as to these terms meanings. Finally Finally, that increased efforts be made to gather information from the individuals themselves. This information may provide the richest insight into the quality of life of individuals with developmental disabilities.

VITA 2

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Doctorate of Philosophy

Thesis: DEVELOPMENTAL DISABILITIES QUALITY ASSURANCE: A STUDY OF DEINSTITUTIONALIZATION IN OKLAHOMA

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OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
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Principal Investigator(s): Richard A. Dodder, Brien L. Bolin

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Comments, Modifications/Conditions for Approval or Reasons for Deferral or Disapproval are as follows:

Signature: Marcia K. Tilley
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Date: February 3, 1993