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FACTORS RELATING TO SUCCESSFUL PLACEMENT IN A MINIMAL SUPERVISION PROGRAM FOR MENTALLY RETARDED ADULTS

by Scott Rahl

A THESIS

Submitted in partial fulfillment of the requirements of the Master of Arts Degree in the Graduate Division of Rowan College of New Jersey

May 1995

Approved by _

John W. Klanderman Ph.D.

ABSTRACT

Scott Rahl
Factors Relating To Successful Placement
In A Minimal Supervision Program
For Mentally Retarded Adults
1995

Dr. John Klanderman Graduate Program Of School Psychology

The purpose of this study is to determine what characteristics are significant in determining successful adjustment to residence in a minimal supervision apartment program for mentally challenged adults. The subjects consisted of nine women and four men, all of whom are mentally deficient to varying degrees, and four of whom suffer from mental illness as well. The subjects range in age from 22 to 76 with a mean age of 43. The subjects intellectual functioning levels, as determined by their psychological evaluations, were examined along with the rate at which they completed daily living tasks as detailed by their Individual Habilitation Plans. Factors such as the presence of mental illness and length of time residing in the community living program were also taken into account in order to determine any relationships between these factors. Finally, staff people employed at the residential program ranked the subjects from most to least successful in adapting to the residential program. The results indicated what appears to be a relationship between intellectual functioning level and the rate of completion of daily living tasks, as well as a relationship between mental illness and difficulty in completing daily living tasks.

MINI-ABSTRACT

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The purpose of this study is to determine what characteristics are conducive to successful adjustment to residing in a minimal supervision program for the mentally challenged. The results seem to indicate relationships between intellectual functioning level, the presence of mental illness, and performance on daily living task completion.

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CHAPTER I

NEED AND PURPOSE

The purpose of this study is to determine characteristics that contribute to successful adjustment to living in a minimal supervision placement for mentally challenged adults. This study is being conducted with clients of a provider agency that operates community living programs, both group homes and supervised apartments, for the mentally challenged.

The subjects of this study are thirteen adults, nine women and four men. All suffer from mental deficits to some degree, while, in addition, four subjects suffer from psychoses as well. Also, several subjects suffer from various chronic medical problems, such as heart disease and hypertension. The subjects came to the program from institutions or from their family home.

HYPOTHESIS

My hypothesis in undertaking this study is that factors relating to a diagnosis of mental illness in addition to mental retardation, as well as a history of institutionalization and a lack of family contact, can all contribute to difficulty in living in a minimal supervision community setting.

HISTORY

The provider agency that operates the program under

observation in this study is a privately owned agency which has been in operation since 1981. The agency operates group homes and supervised apartment programs in Southern New Jersey, as well as similar programs in Pennsylvania. The agency serves approximately 125 clients each in New Jersey and Pennsylvania. Funding for the agency is provided by the Department Of Human Services, Division Of Developmental Disabilities of the states of New Jersey and Pennsylvania, which represent and place each client with the agency. The goal of the agency is to help the clients to achieve normalization, a concept which, along with the concept of mainstreaming, has become much more prevalent in special education in recent years. A 1990 study by Edward Zigler, Robert M. Hadapp, and Mark R. Edison indicates that, twenty-five years ago, the consensus of special education favored special class placement for the mentally retarded, while today, virtually all mildly retarded children are in mainstreamed classes.

The first private facility designed specifically for the care of ratarded people opened in 1848 in Barre, Massachusetts. This was followed two years later by the first public facility in Boston, founded by Samuel Gridley Howe and later to become the Fernald State School in Waltham. By 1890, the study by Zigler et al. states that

there were about 20 residential schools in 15 states.

New York City and Cleveland were the first to establish school classes for problem children in the 1870's, with the first classes specifically for mentally retarded children appearing in Providence in 1894. (Zigler, et al. 1990)

The latter part of the mineteenth century saw the initiation of a host of special services for retarded people, including numerous social institutions and services for the blind, deaf, and mentally ill as well. By the early twentieth century, however, the causes of mental retardation were thought to be primarily genetic, and stereotypes abounded of retarded people as poverty stricken, illegitimate, and criminal (Zigler, et al. 1990). Retarded people also were thought to be feeble-minded at this point in history, and showed little improvement on intelligence tests over time. Disappointment over this poor performance lead Fernald to study the life status of 646 retarded children released from the Waverly facility. The findings of Fernald's study showed that over half of the former residents had made at least a fair adjustment to life outside the institution, leading Fernald to change his previously held view that nearly all mentally retarded people should remain in the

institutional setting indefinitely in favor of a stance that this population does not deserve to suffer the "life long segregation" of being institutionalized (Zigler, et al. 1990). Nevertheless, rampant misguided fears and beliefs about retarded people caused institutions for the retarded to be filled to capacity from the 1920's to the 1960's. While there were educational services for mentally retarded children at this point, once these services were terminated, children were sent directly to institutions as adults in order to, according to a supervisor of special classes in Boston,

"safeguard the public from inefficiency, unemployment, pauperism, vagrancy, degeneracy, and all the other social consequences of feeblemindedness." (Zigler, et al. 1990, p.3)

By the 1950's, most retarded students were able to support themselves after their school years. Also, at this point, many parents did not want to institutionalize their children due to the poor reputation of these facilities.

More recently, the treatment of mentally retarded individuals has moved toward the concepts of normalization and deinstitutionalization. The widespread movement toward deinstitutionalization in the United States, according to Zigler, et al., can be attributed to a series of indictments of large institutions in the 1960's,

depicting the poor conditions prevalent in these facilities. Also, advocacy groups such as the National Association of Retarded Citizens were effective in exerting pressure to change existing institutions.

Normalization, which, according to Zigler, et al.,

"is based on the idea that each person has the right to experience a style of life that is normal within his or her own culture" (Zigler, et al. 1990, p. 5)

criginated in Scandanavia and spread to the United States. The study by Zigler, et al., states that, under the original concept of normalization, all individuals should be allowed to participate in activities common to similar age members of the society. However, their study further states that Wolfensberger's book in 1972 caused the focus of normalization to shift from normalization of lifestyle to normalization of services. Wolfensberger equated normalization of services available to the retarded with attainment of a more normal lifestyle.

Wolfensberger's view of normalization lead to the PASS model, which evaluates the adequacy of living alternatives based on the degree to which they approximate normal living settings (Zigler, et al. 1990).

A 1987 report by Sharon Landesman and Earl C.

Butterfield also focuses on the concept of normalization.

Their definition of normalization seems to expand on the

definition given in the study by Zigler et al. The study by Landesman and Butterfield defines normalization as

"an ideology of human services based on the proposition that the quality of life increases as one's access to culturally typical activities and settings increases. Applied to individuals who are mentally retarded, normalization fosters deinstitutionalization and the development of community based living arrangements." (Landesman and Butterfield, 1987, p.809)

Along with the highly debated and emotionally charged issue of normalization, Landesman and Butterfield also discuss the concept of least restrictive environment in their report. Closely tied to normalization, the concept of least restrictive environment states that the places where people live, learn, work, and play should not restrict their involvement in the mainstream of society (Landesman and Butterfield, 1987).

Landesman and Butterfield indicate that, while there are those who cite the phenomenal progress of previously institutionalized individuals after they were moved to small community homes and give vivid descriptions of conditions that still exist in institutions, there are also those who cite stories of deinstitutionalized people who are isolated, neglected, or abused in the community. At the heart of the debate, according to Landesman and Butterfield, is to what extent the environment affects the functioning of the retarded, and also, what types of

environments are best for whom. According to Landesman and Butterfield, proponents of deinstitutionalization and normalization feel that the risk involved in deinstitutionalization is worth the better quality of life promoted by living in the community, and state that self-esteem, life satisfaction, and personal competence are viewed as products of involvement with mainstream activities of society. Landesman and Butterfield go on to say, however, that opponents of deinstitutionalization cite the need of the mentally retarded to have protective, caring, and cheerful environments, and fear that living in the mainstream community may lead to isolation. A 1985 report by Alan D. Miller expounds on this issue by citing three criticisms of deinstitutionalization: 1) mental hospitals are dumping large numbers of unprepared patients into unprepared communities; 2) the discharged patients tend to live together and form enclaves, where they often live in poverty; and 3) the patients are not staying out of the hospital for very long, instead often going in and out of the hospital several times (Miller, 1985).

A 1989 study by Laura L. Robinson indicates that living in the community is more advantageous to mentally retarded people as an alternative to institutionalization. She states that those who live in institutions face a double barrier. They must deal with their limited capacity

for learning and judgment and also with the stigma of the label "mentally retarded." Robinson says that a person assuming this label becomes part of

"a group of individuals considered by this society as deviant or different." (Robinson 1989, p. 119)

Ultimately, according to Robinson, the desired result of normalization of the mentally handicapped individual is the increased ability of the mentally retarded to obtain acceptance and function as independently as possible in the community. She states that the theory underlying normalization is that society will more willingly accept mentally retarded members of society who resemble the non-retarded in appearance and behavior. Robinson states that deinstitutionalization is an important step in the process of normalization, as well as a desirable aim for all but a few retarded people. She says that the goal of community living is to provide retarded individuals with the greatest opportunity possible to realize their highest potential. Robinson indicated that the National Association Of Superintendents Of Public Residential Facilities For The Mentally Retarded suggests a three part approach to deinstitutionalization. The first part is the development of alternative community methods of care and training. The second part is the return to the community of all residents who have been prepared, through programs of habilitation and training, to function adequately in appropriate local settings. The third part is the establishment and maintenance of a responsive residential environment which protects human and civil rights and which contributes to the expeditious return of the individual to normal community living (Robinson, 1989).

Robinson states that underlying the movement toward deinstitutionalization is the assumption that community care will improve the quality of life of mentally retarded people. She feels that inhabitants of community residences benefit from the individualized attention and the opportunity to become more self-reliant. She states that others in the community are more likely to respond favorably to residential facilities if the home conforms with the appearance of others in the community.

Robinson states in her report that many obstacles hinder the deinstitutionalization process, such as adequate funding, a lack of available housing, lack of community support, and prejudice toward the mentally retarded. She cites statistics that show that from ½ to ½ of all community residences for the mentally retarded have met with resistance to some degree from the neighbors. The most common rationales for community opposition, according to Robinson, are the fears of property owners

that property values will decline as a result of close proximity to a group home, and their fear of being near the mentally retarded based on any misconceptions they may have. Robinson notes that fourteen states have enacted statutes that specifically protect the mentally retarded against discrimination, but that these are sometimes difficult to enforce. She also notes, however, that studies have shown that group homes do not have a deleterious effect on the community (Robinson, 1989).

A 1990 study by K. Charlie Lakin, Robert H. Bruininks, Tsuey-Hwa Chen, Bradley K. Hill, and Deborah Anderson indicates that the number of residents with mental retardation in facilities with more than 300 residents decreased by 52% from 143,000 to 69,000 between 1977 and 1987, while the number of residents with mental retardation in facilities with 15 or fewer residents increased from 40,400 to 131,200, including an increase from 20,400 to 80,900 in facilities of six or fewer residents. The study by Lakin et al. goes on to say that deinstitutionalization in the 1970's and 1980's focused primarily on mild, moderate, and severe mental retardation, and left large numbers of people with profound retardation remaining in large institutions. The study notes that in subsequent years, however, that deinstitutionalization efforts were expanded to include this group as well.

A 1993 study by Tsuey-Hwa Chen, Robert H. Bruininks, K. Charlie Lakin, and Mary Hayden points out that much of the impetus for increasing community living opportunities for people with mental retardation has been the assumption that it will naturally promote increased participation in culturally typical activities and relationships, and increase use of community resources and services. They indicate that research has shown that, in general, domestic and community participation of individuals living in small residential settings is much higher than for those in institutional settings.

LIMITATIONS

There are several limitations for this study. I have access to only six months of data for each subject pertaining to their Individual Habilitation Plan (IHP) goals and also six months of data for those subjects who participated in behavior modification programs. Also, background information on the subjects is also limited to that information contained within their agency files.

ASSUMPTIONS

An assumption of this study is that the six staff people who document the data pertaining to completion of the subjects IHP goals that will be a part of this study do so in an accurate and consistent manner, and by using the same guidelines.

OVERVIEW

Following a review of literature pertinent to my study, my intention in doing this study is to examine the rate of the subjects Individual Habilitation Plan goal task completion over a six month period of time, data derived from psychological testing, and any other significant circumstances of the clients being studied. After discussing ratings given by staff people who work with the subjects on a daily basis regarding which subjects are the most and least successful in adapting to the program setting, I will examine whether or not any relationships exist between intellectual functioning, as determined by psychological testing completed by an independent psychologist, and success in completion of daily living tasks as dictated by the subjects IHP's. I will also discuss any similarity or disparity in the ratings of the staff people who work with the subjects under examination. Finally, I will draw conclusions regarding the importance of intellectual functioning and factors such as mental illness and isolation from family members as contributors to success in living in a supervised apartment program for the mentally challenged.

CHAPTER II

REVIEW OF LITERATURE

Numerous studies have examined the role that institutions and less restrictive community living placements have played in the lives of mentally challenged people of varying functioning levels. The following is a review of studies pertinent to my own study.

In studying mental retardation, the 1990 study by Zigler, et al. stated that, in order to optimize the development of retarded persons, caretaker continuity is important, socially fulfilling interaction with friends and acquaintances must be encouraged, and the opportunity for enjoyable and stimulating activities and an appropriate physical environment must be provided.

A 1990 journal article by Gary N. Siperstein, David Reid, Mark Wolraich, and Paul O'Keefe studied the roles of various professionals and the perceptions they held in providing services for the mentally retarded. Their research stated that physicians perceive individuals with mild mental retardation as requiring at least a supervised apartment setting. This expectation was more pessimistic than that of social workers or educators, who believed that the mildly mentally retarded can function successfully in an unsupervised apartment setting. All three groups

selected a supervised apartment as the most likely placement for a person with severe mental retardation. Thus, the study by Siperstein et al. states that When parents are faced with the prospect of placing their child in a residential facility, they are given a worst case scenario by their health care professionals or social service workers. The study states that information about the capabilities necessary for placement in the various residential settings is required if parents are to make an appropriate and informed decision. Along those lines, the study by Siperstein et al. cites a study by Schalock and his associates in which they identified personal maintenance skills, social skills, and symbolic operation skills as related to success in independent living placements. Also, a study by Crnic and Pym is cited as finding domestic skills, communication skills, and self-help skills related to success for group home residents, while Waller and Intagliata found that people who were returned to institutions from community residences had poor social skills but adequate self-care and community living skills (Siperstein, et al. 1990). Overall, three skill areas have been associated with successful adjustment in community settings, according to the study by Siperstein et al. They are domestic skills, social skills and self-help skills. Their study

indicates, however, that it was necessary to specify which domestic, social, and self-help skills were needed for the various types of community living settings. To study this, Siperstein and his co-authors administered the Prognostic Beliefs Scale to workers of group homes, supervised apartment programs and institutions. Results of the study indicated that the following items were identified nearly unanimously as being essential for successful placement in an unsupervised apartment: "dressing and toileting independently," "drinking from a cup unassisted,' and "using a lock and key." Eighty percent of the respondents agreed that "anticipating hazards appropriately," "cooking a meal unsupervised," "following a one-stage command," and "eating with utensils," were essential for success in an unsupervised apartment setting. For the supervised apartment setting of Siperstein's study, the items thought to be most important for successful placement were "dressing and toileting independently," "drinking from a cup unassisted," and "eating with utensils." The other capabilities thought to be necessary for success in this placement were to "follow a one-stage command," "anticipate hazards," "act appropriately toward strangers, " and "recognize traffic signs." Six other capabilities were judged as being helpful, though not essential, for successful placement

in a supervised apartment placement. These are the ability to "sustain a friendship," "schedule daily activities," "budget for monthly expenses," "cook a meal unsupervised," "use public transportation independently," "find way in unfamiliar surroundings," and "indicate symptoms verbally." These helpful skills, however were judged to be essential for successful placement in an unsupervised setting, according to Siperstein and his associates. None of the capabilities noted by specialists in their study were considered essential for successful placement in a group home. Six capabilities were noted as being helpful for successful placement in a group home, however. These are the ability to "join in a single conversation," "sustain a friendship," "choose appropriate clothes to wear," "anticipate hazards," "find way in unfamiliar surroundings," and "indicate symptoms verbally," (Siperstein et al. 1990) Regarding results of their study, Siperstein and his associates noted that, as expected, more complex skills were considered to be essential for success in a more challenging Living environment. However, they note surprise at the result that no living skills discussed by the respondents were considered essential for successful placement in a group home. They also stated their surprise at finding that no respondents found "sustaining a friendship with another person" to be

essential for success in any living environment, given the recent emphasis on social skills and social functioning (Siperstein, et al. 1990). They also note that, in addition to the aforementioned skills, respondents found "taking medication" and "knowing where and when to seek help in an emergency" as essential for successful placement in an unsupervised apartment setting.

The 1993 study by Lakin et al. states that it is important to gather data on characteristics and expectancies of individuals in community based placements in order to plan and evaluate the nature of services needed and the appropriateness of services provided. This data also serves to show the feasibility of community services for those persons still living in less integrated settings, as well as for comparing and contrasting various community placement options. Lakin et al. attempted to determine the characteristics of residents of both group homes and foster homes. Their study focused on the following eleven areas: health/physical condition, adaptive behavior, problem behavior, placement history, case management, day program participation, special services, family contacts, friendships, leisure activities, and programs in self-help skills/community-living skills. The study was done on 336 persons with mental retardation, 51% of whom were male, 49% of whom were female, between

the ages of 0 and 79. The level of mental retardation in the sample in the study by Lakin et al. was mostly moderate and severe.

Results of the study by Lakin et al. indicated that the most frequently reported problem behavior was disrupting the activities of others, which was reported less frequently for foster home residents than for group home residents. The frequency of uncooperative behavior was higher in group homes, and children in group homes were more frequently reported to intentionally damage property than were foster home residents (Lakin et al. 1993). With regard to self-care skills, results of the study by Lakin et al. showed that foster home residents were reported to be less independent in this area, while group home residents were the most independent in this area. However, Lakin and his co-authors report that a substantial number of people in all program types displayed a high degree of independent or nearly independent functioning on basic self-care skills. With regard to home and community living skills, the study by Lakin et al. showed that foster homes housed more people who were reported to be unable to, or to require extensive assistance to perform these tasks, while group homes tended to have higher proportions of residents who were able to perform in this area independently. Their

study reports that the proportion of residents who required some degree of assistance with home and community living activities was substantially higher than those who needed assistance with self-care activities. Foster care residents were reported to be least independent in the various aspects of home and community living, whereas group home residents were reported to be most independent in tasks such as buying groceries, according to the study by Lakin et al. In the area of household task completion, the study by Lakin et al. showed that foster home residents were less likely and group home residents most likely to be expected to participate in household tasks.

A similar study comparing the characteristics of residents of group homes and foster homes was completed using a multivariate approach by Chen et al. in 1993. Their study focused on five areas of personal competence and training needs: self-care and functional living skills, community living skills, home living skills, problem behavior, and training program goals and objectives. Also, they focused on three other components of community participation and adjustment: leisure activity, family contacts and relationships, and community assimilation and acceptance. They state three reasons for undertaking this study: 1) group homes and foster homes are by fax the fastest growing models of care within the various

state residential care systems; 2) these are the facilities that are best able to provide the most desirable, appropriate, and beneficial residential experiences based on the philosophy of normalization; and 3) the need for increased policy research on small scale programs to assess their current status and improve their functioning as residential care options. Their purpose in undertaking this study was to see if the aforementioned characteristics distinguished between residents of foster homes and group homes. The study by Chen et al. defines a foster home as "a residence owned, or rented by, a family as their own home, with one to six people with mental retardation," while a group home is defined as "a residence with staff providing care, supervision, and training for one to six people with mental retardation." (Chen, et al. 1993, p.392)

The results of the study by Chen et al. indicated that 86% of their subjects were classified correctly into their original residential placement groups according to their individual characteristics, skills, activities, behavior, and program goals. The study further indicated that personal self-care competencies and community oriented adaptive behaviors were the least important factors in distinguishing between residents of the two different types of facilities. The results of this study found

primary differences in factors assessing the extent of social involvements, particularly in community assimilation and acceptance and home living skills (Chen et al. 1993). Differences were also found in problem behaviors, family contacts/relationships, emphasis on program goals related to community living skills, and recreational/leisure activities. Foster homes were found to be higher in community assimilation and acceptance in the neighborhood and lower in degree of perceived problem behaviors, while group homes were higher in home living skills, family contacts/relationships, recreational/leisure integration, and community living training goals (Chen, et al. 1993). The authors of this study indicate that their results show that the most efficient way to distinguish between foster home and group home residents is to look at their patterns of relationships and activities, rather than at their personal characteristics. Also, they feel that whether one lives in a foster home or group home has a substantial influence on lifestyle. As a result of their study, Chen et al. suggest improvements in family involvement for foster home residents, as well as a greater emphasis on domestic participation and community based leisure activities for foster home residents. They further state that improving relationships with neighbors is one important potential goal for group home residents.

In a 1988 study by Claire Ann Colburn-Sullivan,
Stanley J. Vitello, and William Foster, the authors say
that deinstitutionalization provides

"the mechanism to enable persons who are retarded to experience the autonomy, choice, freedom, dignity, respect, and independence afforded to more valued members of our social order." (Sullivan, et al. 1988, p. 76)

They conducted a case study through participant observation of six moderately mentally retarded male residents of a group home. The subjects ranged in age from 23 to 53, and four subjects suffered from Down Syndrome. The residents have institutional histories ranging from 17 to 37 years, according to the authors of this study. Also, the authors noted that five of the residents were involved in sheltered employment, while the sixth subject participated in a competitive employment training program. The principal author of this study observed the subjects engaging in daily activities, such as eating, dressing, working, and socializing. The author took notes on the subjects, which were periodically reviewed to determine the occurrence of emerging behavior patterns and/or relationships (Sullivan, et al. 1988). Any emerging patterns of behavior then became the focus of subsequent observation. The extensive notes taken by the authors of this study were divided into two categories of adaptive behavior: daily

living skills and socialization skills. Under the heading of daily living skills, the results of the study by Sullivan et al. indicated that all residents demonstrated competencies in personal living areas such as toileting, brushing teeth, washing and combing hair. Staff assistance was needed in tasks such as matching clothes, shaving, and cutting fingernails. The subjects used eating utensils, but needed to be reminded to put smaller portions on their plates, according to the authors of this study. The subjects performed domestic skills with minimal supervision, such as making a bed, changing their sheets, and completing their laundry. Daily chores in which the subjects participated with minimal supervision included cooking, setting the table, and washing the dishes. Weekly chores completed with considerable prompting by staff were noted to be such things as cleaning the bathroom, vacuuming, and dusting (Sullivan, et al. 1988).

Community living skills that were focused on in the study by Sullivan et al. were the use of money, the telephone, and safety precautions. Regarding the use of money, the authors note that most of the subjects recognize coins and the dollar bill, while none can count more than a few coins, make change or anticipate getting change from a purchase without being reminded. The

subjects do not budget their own money and are only given a few dollars at a time for small purchases. Regarding telephone use, the study by Sullivan et al. indicates that the subjects can phone their families with assistance from staff in dialing the phone. Most subjects reportedly only can converse for a brief period of time due to poor speech skills and lack of language experience. The subjects reportedly follow safety precautions such as wearing seat belts in a vehicle, but are also reportedly too trustworthy of strangers, according to Sullivan et al.

With regard to socialization skills, the study by Sullivan et al. indicated that pursuing relationships with one another appeared to be difficult for the subjects. The exception to this, however, was the caring relationship that was observed between roommates. Leisure activities engaged in by the subjects of the study by Sullivan et al. included those chosen by the subjects, such as watching television and listening to music, and those arranged by the staff, such as going to a movie or a dance. Activities chosen by the subjects were found to be lacking in variety. The authors note that, since activities conducted outside the group home are planned and chosen by the staff, the subjects engaged in some passive integration in the community, but little active integration, or resident selected activities. Regarding coping skills, the subjects

were found to have acceptable manners, including table manners and exchanging greatings when introduced to a stranger, and to be able to follow rules. The subjects questioned or defied authority only six times over the six month course of the study by Sullivan et al. The subjects were found to need improvement in dealing with anger and hurt

"due to their lack of experience in verbalizing their feelings and their lack of social understanding of situations in which they find themselves." (Sullivan et al. p. 80)

The authors recommend enhanced development of community living skills, increased access to community activities, and participation by the subjects in planning their own recreational activities as possible improvements that can be made in this living situation.

Regarding employment opportunities for the mentally retarded, a 1990 study by Kathryn Haring and David Lovett cites studies in which the employment rate for individuals with mild and moderate mental retardation ranged from 77% to 92%, with most subjects employed in unskilled and semi-skilled positions and having limited self-sufficiency and income. Haring and Lovett note this in a study of 58 subjects from twelve high schools who had received special education services. Each subject was mentally retarded and most had concurrent secondary disabilities. The subjects in Haring and Lovett's study fell into three

general categories of mental retardation -- mild to moderately retarded, moderately to severely retarded, and severely and profoundly retarded. Results of the study by Haring and Lovett encompassed three areas: employment, residential status, and the degree of independence in community mobility. Regarding employment, Haring and Lovett found that 67% of their subjects were in employment related placements, with 6% being competitively employed. Family members of the subjects, as well as residential staff, were reported to be very involved in maintaining employment for the subjects. Thirty-eight percent of the subjects were employed in sheltered workshops, with extremely low wages, and no hope of movement to a more normal environment. Another 18% were in day activity programs, where they were not paid conducive to their employment, according to Haring and Lovett. One subject was in the military and another was a volunteer. Both of these subjects were in the mild to moderate range of mental retardation, as were two of the subjects who were competitively employed, according to the authors of this study. A majority of the subjects classified as mildly mentally retarded had no employment related placement, while the majority of the subjects in the moderate to severe level of mental retardation were in sheltered employment.

In terms of their residential status, results of the study by Haring and Lovett indicate that 98% of the subjects lived either with their families or in restrictive agency environments, such as group homes, nursing homes, or state institutions. Only one subject observed in this study lived independently. A majority of parents of subjects in the Haring and Lovett study, when interviewed about their child's residential status, expressed a wish for a less restrictive environment for their child than that in which they currently reside.

Haring and Lovett indicated that, for the most part, the subjects in their study demonstrated some degree of mobility or community access. One subject had a drivers license, 38% relied on public transportation, while 29% relied on sheltered agency transportation and 16% relied on family and friends for transportation. Three subjects in the study by Haring and Lovett had no community mobility.

Haring and Lovett felt that the results of their study indicated that a large majority of the subjects they studied were not working or living in their least restrictive environment and were provided no contact with their non-disabled peers. They also found limited residential and employment options for the subjects, with no agency providing supportive employment or transitional

services (Haring and Lovett, 1990). Also, no training to promote competitive employment and no residential training programs were available to enable the individuals to become more independent or competent. Overall, Haring and Lovett found their subjects to be poorly adjusted to adult life, perhaps, they suggest, due to a failure of the special education system or a lack of transitional services and adequate adult services.

A 1993 study by R.M. Foxx, Gerald D. Faw, Steve Taylor, Paula K. Davis, and Rosalia Fulia focused on promoting and enhancing the involvement of institutionalized mildly mentally retarded adults in their community placement process. In phase one of their study, six subjects--four men and two women--were interviewed regarding where they would like to live. Results of phase one of the testing done by Foxx et al. indicate that the subjects had specific community living lifestyle preferences and were very capable of expressing those preferences when given the opportunity. Phase two of the study by Foxx et al. was conducted in order to identify the subjects strongest lifestyle preferences. This was done by having the subjects choose between items they had chosen as being lifestyle preferences in phase one in order to narrow down the subjects strongest lifestyle preferences. The results of phase two of this

study, according to Foxx et al., indicate highly individualized lifestyle preference selections on the part of the subjects, as well as a great disparity between what the subjects and group home employees considered to be important items.

Phase three of the study by Foxx et al. was to evaluate a program to teach subjects to assess the availability of their lifestyle preferences. In the training program, the authors of this study indicate that social workers review with subjects their chosen lifestyle preferences, using pictures to reinforce the subjects choices. The subject is then taken to a group home or similar facility and then questioned to ascertain if his lifestyle preference can be met at that facility. Results of the overall study by Foxx et al. indicate that the group training procedure increased the subjects lifestyle preference questioning and reporting during and after simulated tours of group homes. The authors of this study felt that the results underscore the importance of ensuring that clients are actively involved in the placement process.

A 1991 study by Burd et al. makes the assertion that people with mental retardation residing in both large institutions and community based group homes may be at risk for inappropriate use of psychotropic medications

to treat disorders such as schizophrenia and bipolar disorder. As there have been few studies of the use of psychotropic medications in a group home setting, Burd et al. felt that group home residents need to be monitored closely due to a lack of knowledge of the needs of the mentally retarded by physicians in the community, and because safeguards available to protect residents of institutions may not be in place for residents of a group home (Burd et al. 1991). In order to study this issue, Burd et al. instituted a statewide survey over a six month period to determine medication usage in the state of North Dakota in 1988 for all group home residents. This survey included questions regarding residents age, IQ, adaptive behavior, previous medication usage, and previous care settings. The survey also sought information regarding a psychiatric diagnosis for which any medications were prescribed, and specific behaviors targeted by the use of the medications.

Results of the questionnaire were obtained on 97% of the group home residents in the state of North Dakota at the time of the study by Burd et al. A total of 408 men and 401 women were included in the results.

Eighty-one different medications were being taken by the residents of the North Dakota group homes in this study, including medications for depression, anxiety, seizure

disorders, hypertension, and other conditions. The results indicated that 37% of the subjects were taking one or more of the 81 medications, including 157 males and 144 females. No significant association was found in the study by Burd et al. between IQ level and frequency of drug use. The results of their study also indicate that the presence of a psychiatric diagnosis was associated with a lower incidence of anticonvulsant prescriptions and a higher incidence of prescriptions of other psychoactive medications. Also, 33% of those North Dakota group home residents, 12% of the total group, were receiving two or more medications. Two residents in the study were receiving six different psychoactive medications, 49 residents were receiving medications from two or more drug categories, and 49 residents were receiving two or more medications from the same drug category. On the basis of their study, Burd et al. suggest that more attention be focused on establishing a psychiatric diagnosis and specific target symptoms to be treated by medications, as well as on establishing criteria for the reduction and elimination of psychoactive medication use when appropriate. They also suggest that the use of psychoactive medications in the absence of a psychiatric diagnosis be avoided, that behaviors targeted by the drug use be continually monitored, that the drug be periodically

withdrawn to be sure it is still necessary to reduce symptoms, and that nonmedical intervention be implemented whenever necessary to reduce the need for long term pharmacotherapy (Burd et al. 1991).

With regard to community living for the mentally retarded, some have argued that even those with the most severe mental handicap can live in community settings, given access to appropriate supervision and development opportunities, while others argue that institutional care is more suitable for people with severe handicaps who need to be in a more sheltered environment.

A 1992 study by Sean Conneally, Grainne Boyle and Frances Smyth evaluated the progress of eleven individuals with a severe and profound mental handicap who moved from an institution to two small group homes. The institution also served as a day facility and continued to serve as such as the subjects moved to the group homes. The purpose of the study was to examine the quality of life after the subjects moved to group homes compared to before. Five subjects were functioning in the severe range intellectually, while six were found to be functioning in the profound range intellectually.

Emphasis in the study by Conneally et al. was placed on evaluating changes in the total quality of life of the residents. A series of measures were taken prior to moving

to the group homes and reported two years later. The measures taken included assessment of adaptive behavior, assessment of maladaptive behavior, and observational data.

Results indicated that, overall, the two groups increased their levels of adaptive behavior between the time the two measures were taken.

For eight of the eleven individuals, levels of maladaptive behavior were reduced over the duration of the project. There was a wide range in the level of maladaptive behavior in this study. Some of the subjects saw dramatic reductions in the amount of maladaptive behavior in this study. Some of the subjects saw dramatic reductions in the amount of maladaptive behavior, with most of the reduction occurring in the first year after moving to the small group homes. At the end of the second year after moving to a group home, some individuals still displayed significant amounts of maladaptive behavior, according to the study by Conneally, et al.

Overall, the level of interaction did not change significantly over the period of the study. The amount of interaction between residents was minimal in both group homes, according to Conneally, et al.

Conneally, et al. also report that the subjects increased the amount of personal possessions and clothing

they owned after moving to the group homes. Conneally et alalso report that the variety of the leisure activities engaged in by the subjects increased over the course of the study. In addition, the variety and frequency of outings of the individuals in this study increased over the two year period, but still remained a low number compared to other individuals (Conneally, et al. 1992).

In summary, the eleven individuals in this study of severely and profoundly mentally retarded individuals made significant progress following a move from an institution to a small group home. However, while the group home placement may have contributed to a significant improvement in the individuals quality of life, Conneally et al. note that other changes in the subjects lives occurring at the same time make it impossible to conclusively attribute all of the individuals progress to the effects of moving to the group home. Improvement in the quality of life based on the move to the group home is thought to be due to different elements such as the size of the group home, attitudes and orientation of staff members, location of the group home, access of residents to more domestic activities, and procedures and policies of the group homes (Conneally, et al. 1992). In particular, Conneally et al. note that the small size of the two group homes in this study was thought to lend

itself to smaller resident to staff ratios, which, in turn, could contribute to growth by the residents.

SUMMARY

The previous studies of community living facilities for the mentally retarded give an indication of the benefits of deinstitutionalization and normalization. The studies I have discussed seem to indicate the importance of family involvement and community involvement in enabling the mentally challenged to reach their fullest potential.

CHAPTER III

DESIGN OF THE STUDY

This chapter will begin with a description of the subjects in this study, as well as a description of the setting in which the study takes place. A description of the measures and design used in this study will then be provided, along with a restatement of the hypothesis of the study and a discussion of the method of analysis that will be used to discuss the results of the study.

SAMPLE

The study consists of thirteen subjects, four of whom are male and nine of whom are female. Their ages range from 22 to 76, with a mean age of 43. All thirteen subjects were included by virtue of their residence at a supervised apartment program for the mentally challenged in Southern New Jersey. All subjects suffer from deficits in mental capacity to some degree. Eleven subjects were born suffering from mental retardation, and one became mentally impaired due to an automobile accident at the age of seventeen. In addition, the mental and intellectual capacity of one subject diminished for an unknown reason. Four subjects suffer from mental illness in addition to mental retardation. One subject suffers from bipolar disorder. One subject suffers from schizophrenia. One subject suffers from clinical depression, while the fourth subject suffers from pervasive developmental disorder.

Regarding their intellectual functioning, eight subjects were found to be mildly mentally retarded using the WATS-R on their most recent psychological evaluation, while three subjects function in the borderline range of intellectual functioning. One subject was found to function in the moderate range of mental retardation, while one subject was found to function in the severe range of mental retardation in terms of intellectual functioning. Also, three subjects suffer from seizure disorders, All thirteen subjects are on a fixed income, and are provided for financially by the state of New Jersey through the Social Security program. All subjects have lived in their residential setting for a minimum of six months, with six of the subjects living at the residential program for as long as 8-10 years.

<u>SETTING</u>

The setting for this study is a supervised apartment program consisting of eight apartments and operating in Southern New Jersey. Subjects are placed in this setting by the Division Of Developmental Disabilities of the state of New Jersey, which also provides funding for the program.

MEASURES

In this study I will be examining the characteristics which may be contributing factors to successful living in a residential placement such as the one in which the

subjects of this study reside. Among the factors which will be examined are intellectual functioning, history of mental illness, effectiveness in completing daily living tasks as noted by the subjects respective Individual Habilitation Plans, and family contact.

Also, those who serve as staff people at the program site where the subjects reside will serve as raters of the degree of success of the subjects in adapting to their residential setting. This will be done by asking the staff people to rank the subjects from highest, or those subjects considered to be most successful in living at the residential program, to lowest, or those subjects thought to be least successful in living at the residential program. A possible variable that may be confounding in this study could exist if different raters use different criteria in determining the level of success in the residential setting of the subjects.

PROCEDURE

After obtaining rankings from the employees of the residential program regarding the level of success of the subjects in living at the residential program, I will then discuss the subjects in terms of the factors that may contribute to or hinder their success in the residential program.

Regarding the goals for each subjects Individual

Habilitation Plan goals, subjects will be graded by the residential program staff each month on a scale of 1-4, depending on whether they completed the task independently—that is, without any assistance or prompting—or with a single prompt or reminder, multiple prompts or reminders. or with physical assistance by a staff person.

I will examine all information available on each subject, compare this information with the ranking provided by the residential program staff, and examine any potential relationships that exist between the characteristics of the subjects and the rankings of the residential program staff.

TESTABLE HYPOTHESIS

My hypothesis in undertaking this study is that the level of one's intellectual functioning will be a factor in the success with which one adapts to living in a community living program for the mentally challenged. In addition, I hypothesize that factors such as the presence of mental illness and the amount of family contact one has will also be factors in how successful one is in adapting to such a placement.

ANALYSIS

All factors as noted above relating to the subjects residential placement, such as the presence of mental illness, level of intellectual functioning, degree of

family contact, and the success with which the subjects complete daily living tasks, will be examined to determine if any relationships exist between these characteristics and successful adaptation to life in the residential program.

<u>SUMMARY</u>

This study is intended to examine the characteristics which lead to successful placement in a minimal supervision placement for the mentally challenged. Factors such as the presence of mental illness, degree of family contact, level of intellectual functioning, and success in completing daily living tasks will be considered to determine if any relationships exist between these characteristics and the success with which the subjects adapt to the residential placement. In addition, the residential program staff will rank the subjects in terms of which subjects are thought to be the most and least successful in functioning at the residential program, and these rankings will be examined for similarities and differences between them, as well as for relationships between these rankings and the success with which the subjects complete daily living tasks. This will be done to test the hypotheses that intellectual functioning and the presence of mental illness, as well as degree of family contact, are important factors in the adjustment of the subjects to the residential program.

CHAPTER IV

ANALYSIS OF RESULTS

RESULTS OF STAFF RANKINGS

Regarding staff rankings used in this study, as Table 4.1 indicates, all five staff who rated the subjects ranked subject #2 either first or second in terms of success in living at the residential program. Similarly, all staff rated subject #12 among the most successful in the residential program. All five staff ranked subject #9 near the middle in terms of successful performance at the residential program. All staff involved in this study ranked subject #5 near the bottom of the rank order in terms of successful placement at the program. Finally, all staff members ranked subject #3 as the least successful in adapting to the residential facility. Among the other eight subjects of this study there was wide variation among the rankings given by the staff members at the residential program. While some staff ranked certain subjects as being highly successful, other staff ranked the same subjects as being far less successful. One possible reason for this could be that different staff people have had different experiences with the various subjects which could, of course, lead to different perceptions of the subjects success or failure at the residential program. Also, another possible reason for

SUBJECT #	STAFF 1 RANKING	STAFF 2 RANKING	STAFF 3 RANKING	STAFF 4 RANKING	
ī	4th	llth	5th	10th	7th
2	lst	lst	lst	2nd	2nd
3	13th	13th	13th	13th	13 t h
4	7th	7th	llth	12th	llth
5	10th	12 t h	12th	llth	12 th
6	5th	9th	3rd	3rd	4th
7	3rd	10th	10th	9th	10th
8	12th	8th	9th	8th	9th
9	6th	5th	7th	5th	8th
10	8th	4th	2nd	4th	3rd
11	11 th	6th	6th	6th	6th
12	2nd	2nd	4th	lst	1st
13	9th	3rd	8th	7th	5th

TABLE 4.1 STAFF RANKINGS OF SUBJECTS

for disparity among staff rankings could be that the staff used different criteria to rank the subjects in terms of their success at the residential program. When asked to rank the subjects, staff were asked to rank the subjects from highest to lowest in terms of which subjects were most successful in functioning at the residential program and which subjects were least successful. This question is open to a wide range of interpretations such that, while the focus of the provider agency is to assist the subjects with improving their daily living skills, some staff may have ranked subjects based on their daily living skills, while others may have used criteria such as their behavioral or social adjustment to determine the degree of success at the residential program. Another potential factor leading to the disparity among staff ranking of subjects could be attributed to the potential for personal biases resulting from personality conflicts between the staff and the subjects.

Among the comments given in support of the rankings given by staff on the subjects in this study, subject #2 and subject #12 were described as being "self-reliant," "independent," "good with daily living," and "always pleasant." Conversely, among the subjects in this study who were ranked consistently lower by staff of the residential program, subject #3 was described as being

"angry" and "needing much physical assistance," while one staff indicated that the fact that subject #13 "needs attention" was a reason for ranking this subject lower in terms of success, although Table 4.1 clearly shows that other staff rankings indicate some disagreement with regard to this subject.

RESULTS OF INTELLECTUAL FUNCTIONING LEVEL VS. RATE OF DAILY LIVING SKILL TASK COMPLETION

with regard to the performance of the subjects on daily living skills during the course of this study, there seems to be a relationship between intellectual functioning, as measured by an independent psychologist using either the WAIS-R or Stanford-Binet on the subjects most recent psychological evaluation, and the rate of success at which the subjects completed their respective daily living tasks. Table 4.2 shows the results of the subjects daily living task completion during the course of this study, along with the level of intellectual functioning according to the subjects most recent psychological evaluations.

In examining the results of the subjects success in completing daily living objectives, these results appear to be mixed. This study obtained instances where there appeared to be a relationship between intellectual ability and daily living skill performance, such as with subjects 1, 2, 6, and 12, for example. These subjects were

SUBJECT #	FUNCTIONING LEVEL	IHP %	MENTAL ILLNESS	FAMILY CONTACT
1	Mildly MR	44%	NONE	None
2	Borderline MR	93%	Nonė	Very Little
3	Borderline MR	20%	מֿסק	Weekly
4	Mildly MR	56%	Schizo- phrenia	On holidays
5	Mildly MR	39%	Depressi	on Holidays
6	Mildly MR	83%	None	On holidays
7	Mildly MR	55%	None	Very Little
8	Moderately MR	76%	None	Frequent
9	Mildly MR	60%	None	None
10	Şeverely MR	98%	None	None
11	Mildly MR	55%	None	Occasional
12	Mildly MR	43%	None	None
13	Borderline MR	89%	Bipolar Disorde:	On holidays

TABLE 4.2 SUBJECTS FUNCTIONING LEVEL VS. IHP TASK COMPLETION PERCENTAGE, PRESENCE OF MENTAL ILLNESS AND FAMILY CONTACT

considered to be mildly or borderline retarded, and performed at or beyond expectations in terms of daily living skill performance according to their IHP's. Conversely, subjects 3, 4, and 5, also found to be at the mildly retarded or borderline range of intellectual functioning, scored below expectations, perhaps due to the added presence of mental illness, including schizophrenia, clinical depression, and pervasive developmental disorder (PDD), any of which could adversely affect one's level of motivation. Therefore, while the results of this study, as noted in Table 4.2, appear to indicate a relationship between the subjects intellectual functioning and performance in completing IHP tasks measuring daily living skills, the results also seem to indicate that the presence of mental illness can be an equally important factor in success in living in a minimal supervision community living program. In contrast to this possible relationship is subject #13 who, despite the presence of bipolar disorder, completed 89% of the daily living IHP objectives asked of the subject over the course of the study. It is also interesting to note that two subjects, subjects #8 and #10, scored within the moderate and severe range of mental retardation, respectively, yet subject #8 completed 76% of the objectives and subject #10 completed objectives at a rate

of 98%. In addition, subject #10 shows a particularly high level of motivation to complete any tasks asked of him. The success of these two subjects in the residential program setting, despite their lower level of intellectual functioning compared to the other subjects, would seem to weaken the potential relationship between intellectual functioning and completion of daily living objectives. The success of subjects #8 and #10 in completing daily living objectives may be due, in part, to the fact that they have each resided in the minimal supervision setting for approximately 8-10 years and, therefore, have grown accustomed to the expectations of the residential program and can more easily meet these expectations despite their somewhat diminished mental capacity. Thus, in addition to, or in lieu of, intellectual ability, factors such as experience and longevity in the residential program may contribute to successfully meeting the expectations of the program in this case.

Family contact did not appear to be a factor in the performance of any of the subjects on daily living skill tasks, because several subjects have no family contact at all, while those that had family contact had such contact only once or twice a year on holidays. One subject in this study had weekly contact with a parent, but performed poorly on daily living skills, which would seem

to indicate that the family contact was not a positive factor in the performance of this subject, and, due to the tumultuous nature of the relationship between the subject and the parent, may have been a negative factor-

In terms of socialization, several subjects in this study performed well in terms of daily living skills, and were considered successful in this regard, but exhibited poor social skills. This would seem to indicate that success in one area, such as in daily living skills, should not be generalized to indicate overall success for a subject in all areas.

It also should be noted in discussing the results of this study that staff judge, on a daily basis, the level of completion of the subjects on their daily living objectives. In doing so, the subjects are rated based on whether they completed the objectives independently—that is, without any assistance or verbal prompting—with one or multiple verbal prompts, or with physical assistance. It is also noted whether the subject refused to complete the objective or did so unsatisfactorily. A major assumption underlying this study is that the staff involved in working with these subjects and in grading the extent to which they completed their daily living objectives graded them in an accurate manner. It is a concern that staff may have graded the subjects

inaccurately on occasion, either by giving them more or less credit then they deserve for completing an objective, or by grading them for completing an objective prematurely, without actually knowing whether or not the subject completed the objective and to what extent they may have done so. Obviously, the presence of these potential factors could affect the results of the study.

CHAPTER V

SUMMARY AND CONCLUSIONS

This study has been conducted to determine what characteristics are conducive to successful adjustment to living in a supervised apartment program for mentally challenged adults. The subjects of this study included nine women and four men, all of whom are mentally impaired to varying degrees. The focus of this study was intended to be on what allowed some residents of the residential program to adjust to the program in a positive way, while others experienced greater difficulty in adjusting to the residential program.

The concepts of deinstitutionalization of the mentally challenged and emphasis on a more normalized style of life for this population are issues that have been more controversial and open to greater debate over the last thirty years. Numerous studies have been conducted to attempt to determine the impact of deinstitutionalization on the mentally challenged, as well as to what extent normalization is a practical goal for this population. Overall, as the research studies I have alluded to in this study would seem to indicate, the conclusion appears to be that mentally challenged people of all functioning levels can benefit from being mainstreamed into society if they are appropriately placed

in facilities that offer a level of supervision that is appropriate for their functioning level. Studies seem to indicate that exposure to community living in which one interacts with the community, takes part in managing one's own life to as great an extent as possible, and learns appropriate socialization and daily living skills, will ultimately be beneficial in allowing one to live more normally and happily than was thought to be possible in the past.

This study indicates that there appeared to be a relationship between the subjects intellectual level of functioning and the extent to which the subjects completed daily living tasks expected of them. Also of importance, however, were factors such as the presence of mental illness and longevity in residing at the supervised apartment program. Subjects in this study who suffered from some type of mental illness in addition to mental retardation seemed to experience increased difficulty in completing their daily living tasks as noted on their Individual Habilitation Plans, possibly indicating a relationship between mental illness and performance on daily living tasks. In addition, two subjects who were found to be lower functioning intellectually were also found to be highly successful in terms of completing daily living tasks. This would seem to conflict with any

relationship which may exist between intellectual functioning and the ability to perform daily living tasks. However, this may be explained by the longevity that the subjects share in residing at the program, which could allow the subjects to complete the tasks asked of them on a consistent basis due to their years of experience in doing so. Also part of this study were rank order ratings by staff people employed at the residential program. These ratings showed some consistency in terms of which subjects were the most and the least successful in living at the residential program but also showed some disparity as well, perhaps due to the raters possible use of different criteria to judge the subjects.

Future studies of this type may want to focus on areas such as socialization skills in terms of how such skills contribute to one's success or failure in a minimal supervision setting such as the one in this study. While this study focused on daily living skills as a criteria for success in this environment, it did not focus on socialization. Thus, while subjects in this study may have been considered successful based on their daily living skills, these same subjects are, in some cases, weak in the area of socialization. Future studies, if they use staff ratings as a part of the study, should be sure that all raters use the same criteria to judge

the subjects and avoid generalizations regarding success based on one criteria alone. Finally, the goal in placing all mentally challenged individuals in community living settings should continue to be to ensure that these individuals are placed in a setting that is an appropriate one in terms of meeting their physical, emotional, social, and occupational needs so that this population can reap the maximum possible benefit from such a placement.

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