# DIFFERENCES IN QUALITY OF LIFE BETWEEN SUPPORTED LIVING AND GROUP HOMES: A LONGITUDINAL COMPARISION

By

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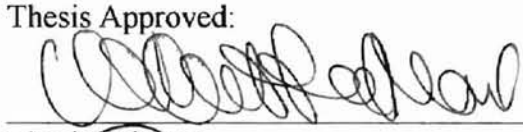

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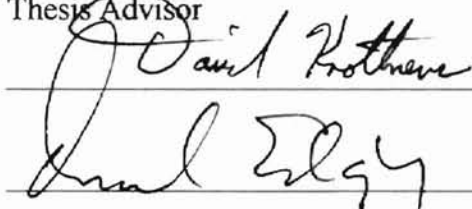



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# CHAPTER I

# INTRODUCTION

Since the early 1980's there has been an extensive and continual reevaluation of the services provided by the Department of Human Services (DHS) to those individuals with developmental disabilities. Based on the principle belief that people with developmental disabilities deserve the opportunity to participate, contribute and experience life within the same social arena as other citizens, there has been a movement from institutional based services to an expanded system of community based services and programs. This has led to the transitional movement from institutional residential placement to a more widespread attempt at community integration. Both changes in ideology and legislation have continued to shift more people with developmental disabilities to community based treatment options, and the demand for community placements has increased.

## Need for the Study

As more community placements are being developed in response to changes in ideology, an interest arises as to how and to what degree these new community placements reflect or enhance the objectives of the changing ideology. There is a need to better understand the degree to which these community options succeed in developing a "normal" or typical cultural environment and in what ways that could be conducive to an increased quality of life. Another related interest is the degree to which these new

community placements retain aspects of the institutional placements they are being developed to replace.

Much research has focused on the differences between newly developed community options and the previously widespread institutional model of residential treatment (Conroy, Efthimiou, and Lemanowcz, 1982; Thompson & Carey, 1980; McCormik, Balla & Zigler, 1975). Some studies have looked at specific differences within types of settings, such as comparisons based on the size of group homes (Helmig, 1994). Research is needed to explore how these newly developed community options differ between one another in creating an environment that enhances and allows for an increased quality of life.

**Review of Literature**

The purpose of this review is to give a general idea of work done in the area of developmental disabilities in regards to the trend towards deinstitutionalization and the variety of community placements. Much of the research in this area has centered around the study of institutions and various differences between them. Studies have tended to focus on the effects of different environmental aspects of the facilities such as the size of institutions (Balla ,1976), staff training(McCormik, Balla & Zigler, 1975), care practices (Ibid.; Campbell, 1971) and location in the community(Eyman, Demaine & Lei, 1979). Other studies discussed focus more on the effects of deinstitutionalization(Kleinberg and Galligan, 1983) and comparison studies of the effects different community programs and institutions of different sizes have on the consumers residing in them(Conroy, Efthimiou & Lemanowicz, 1982; Balla, Butterfield

& Zigler, 1974). The most relevant studies cited are concerned with the changes in various abilities, behaviors and quality of life indicators for individuals in different community placements(Kleinberg & Galligan, 1983; Eyman, Demaine & Lei, 1979). Another purpose of this review of literature is indicate areas of interest where research is lacking and could serve to enhance the general understanding of the issue of quality of life and the deinstitutionalization of people with developmental disabilities.

In the center of the deinstitutionalization debate is the issue of size and structure. Institutions are designed to provide very centralized services to large numbers of individuals. This was primarily based on the ideas of economies of scale, or that larger centralized institutions would tend to be more cost effective than smaller specialized community options. Likewise, it has been assumed such large centralized institutions would be more likely to attract professional staff and services. However, these arguments have lacked sufficient scientific evidence to support them. The debate has primarily taken place in the area of ideology (Conroy, 1992). In fact, recent evidence suggests that these assumptions of the economies of scale do not seem to apply to institutions for people with developmental disabilities. "Contrary to classical economic beliefs, the large facilities do not appear to enjoy cost savings through economies of scale"(p. 14).

In a study of seventy people living in the Pennhurst Center in Pennsylvania who were matched with a sample of seventy individuals whom had moved into community placements (Jones, Conroy, Feinstein, and Lemanowicz, 1985) researchers compared the cost of care for individuals in these two settings . The amount of public money spent for

each individual was traced, and the total cost for care in each of the two groups was compared. People living in the community were shown to be receiving more services and at lower overall cost then those living in the institutions. The institutional care was costing approximately $47,000 per person per year, as compared to $40,000 per person per year residing in the community placements.

Another concern related to the nature of institutions is the notion that the centralized location will result in better specialized care and more services. In a review of the literature concerning the relationship of institution size to the quality of care, Balla (1976) suggests that care seems to be better in smaller community based institutions. However, among small community based facilities there was considerable variation in the quality of life.

Studies suggest institutions can very greatly from each other (Butterfield & Zigler 1965; Zigler, Butterfield & Capobianco, 1970). For instance, access to schooling and the availability of fully qualified professional services were found to vary greatly between the institutions according to a study conducted by Klaber (1969). It was also observed that some facilities promoted dependent behavior and others did not. One observation seems to exemplify the principle of normalization, in that Klaber suggests that children who had increasingly more interactions with people who were not retarded seemed happier.

Research on the effects of institutionalization tend to reflect the general idea that interaction with individuals whom are not retarded and interaction in more normalized environments is very beneficial. A longitudinal study across four institutions looked at

the effects of institutionalization on children (Balla, Butterfield, and Zigler, 1974). They found that the life experience of the children before being institutionalized played an important role in behavior after institutionalization. Also, a greater variability of behaviors was shown in children who had homes that they were discharged to frequently.

Much research has focused on the effects of deinstitutionalization and in turn suggests some of the effects of institutions on individuals. One study observed increases in abilities and functioning of deinstitutionalized individuals over a 2.5 year period (Kleinberg and Galligan, 1983). It is of interest that the improvement in functioning in adaptive behaviors resulted soon after deinstitutionalization. The researchers suggest that this could indicate already developed behavior to which the community environment was more conducive. This could also indicate the effect of the institutional environment on suppressing such behavior.

A study comparing a group of individuals who moved from an institution and into community placements and a matched group who stayed in the institution showed significant growth in adaptive behaviors (Conroy, Efthimiou, and Lemanowicz, 1982). The researchers found that those individuals who moved from more "deprived" cottages, or cottages that were less normalized and individualized, showed more gains from being deinstitutionalized. These results further the understanding of how an individual's environment can effect development. Other studies also documented increases in behavior development for people moving from institutions to community

placements (Aanes and Moen, 1976; Thompson & Carey, 1980; Hemming, Lavender, & Pill, 1981; Murray, 1994; ).

An earlier study utilizing a matched sample design, compared a group of individuals who had moved from a mental deficiency hospital to group-homes with a group of individuals that remained in the hospital (Cambell, 1971). It also found initial improvements among those that moved to group-homes. The area of focus was personal independence and self care. The study is somewhat limited in that those who moved to group-homes were not assessed until after they had resided in the group-homes for six months. The increases among those in group-homes showed significant improvements after six months. However, after a year the group that stayed in the hospital showed significant improvement, but those who moved had not. Campbell observed that the staff of group-homes tended to do things for the residents that they could do themselves. Overall, the findings still showed group-homes to be an undoubted improvement compared to hospital care in the area of personal independence.

One study comparing different types of settings including large central institutions, smaller regional institutions and group-homes in the United States to similar settings in a Scandinavian country. The researchers found interesting differences in the nature of care provided (McCormik, Balla & Zigler, 1975). Findings suggested that institutions built in the United States for people with developmental disabilities had as the goal to house the greatest number of people at the least cost. In comparison, the facilities in the Scandinavian country were based less on economic principles and instead on the principle of Normalization. Generally care practices in the Scandinavian country were

more resident-oriented, whereas those in the US were more institution-oriented. This finding did not generally hold true for group-homes which were found to have no significant difference between the two countries. As would be expected, large institutions in both countries were the most institution-oriented in regards to care practices, with smaller institutions next, and group-homes were characterized by the most resident-oriented care practices. The principles of normalization implemented in the facilities of the Scandinavian country seemed to result in less institution-oriented care. Such institutional focus is a major concern in avoiding the effects of a "total institution" as described by Goffman (1961).

Some researcher's findings support the assertion that principles of normalization have beneficial effects in the behavior development of individuals with developmental disabilities (Eyman, Demaine & Lei, 1979). Looking primarily at foster-care homes and board-and-care homes, the researchers found that some of the principles of normalization are related to the development of individuals with development disabilities. Factors such as blending of facility and neighborhood, location and proximity of services, and comfort and appearance, all seemed to significantly increase the growth of adaptive behaviors.

Schroeder and Henes (1978) found an increase in adaptive behaviors in a matched sample study of residents moving from a regional institution into community group home settings. Out of a study of 19 individuals, significant gains in scores were reported in the areas of self-help, communication, and socialization.

Other findings support this idea of increased normalization effecting adaptive behaviors in a positive manner (MacEachron, 1983). In a comparison of more "normalized" cottages to the older institutional type setting of a large state school, researchers found an increase in adaptive behavior scores for the individuals residing in the more "normalized" setting. MacEachron's findings suggested that IQ scores were the strongest predictor of higher adaptive behavior, however, when IQ scores were controlled for, the level of normalization still had a significant effect. The results of the field experiment led the researchers to state that the concept of normalization was multi-dimensional and had no simple translation into empirical indicators. Findings seemed to indicate the social aspects, more so than the physical aspects of normalization, had an effect on the development of the residents.

**Community Placement in Oklahoma**

The closing of Hissom Memorial Center in Oklahoma as a result of the Homeward Bound vs. The Hissom Memorial Center (1987) was both a catalyst and a result of this move toward deinstitutionalization. Litigation and the subsequent negotiation of a consent decree led to the reevaluation of the service system that had been developed and implemented throughout the State of Oklahoma. The results were not only the closing of Hissom Memorial Center and the relocation of those who had resided there, but also a further expansion and increased emphasis on community service options for the treatment of those with developmental disabilities.

Another result of this change of focus from institutional treatment to community placement and support was the Omnibus Budget Reconciliation Act

(OBRA). OBRA was established to regularly assess those individuals with developmental disabilities who had been placed in nursing facilities. The purpose of OBRA is to identify those individuals whose need for care and services could be better met and who could benefit from and be more productive in a community setting.

Community placements vary from private homes and foster care to settings such as group homes and supported living. Level of care and services available differ between different types of residential placements. These differences could greatly impact the lives of those individuals placed in each type of setting. The type of community placement differed between those who moved from Hissom Memorial Center and those who moved from nursing facilities, Those who moved from Hissom Memorial Center typically were placed in supported living arrangements as court decreed. People who moved according to OBRA policy were most regularly placed in a group home setting.

Group Homes in Oklahoma range in size, serving as home environments for up to twelve individuals (Helmig, 1994). Supported living placements typically serve two to three residents with a maximum of six, according to the goals outlined in the court order . The service objectives for supported living are defined as intending to provide whatever level of care and programs of support needed (Homeward Bound vs. Hissom Memorial Center, 1987). Group home staffing centers around shifts of two to three caregivers at the residence at a time. There are typically one to two caregivers working shifts at supported living placements. Supported living environments tend to have a closer one-to-one ratio between caregivers and residents than do group homes.

Previous research has looked at the effects of various environmental factors of both institutional placements and community placements(Balla, Butterfield, & Zigler, 1974; Balla, 1976; Aanes & Moen, 1976; Thompson & Carey, 1980). Different aspects such as size, staff turnover, training of staff, location of placement in regards to the community, and others have been studied to better understand how these factors might conceptually alter the type of social interactions within a facility as well as the quality and orientation of care practices, have been studied. This study will attempt in contrast, to further the understanding of differences that occur between two types of community placements, Supported Living and Group Homes. The quality of life for individuals residing in the two types of placement will be compared in an attempt to distinguish differences that may develop between these two types of community-based treatments. As the trend towards deinstitutionalization continues, the relative success and the quality of life for individuals in different types of community placements may help broaden our understanding of effective forms of care, and the comparative desirability of different community settings.

# CHAPTER II

# THEORETICAL ORIENTATION

## Symbolic Interactionism

The foundation of Symbolic Interactionism was developed by George Herbert Mead at the University of Chicago. Though Mead taught primarily philosophy from 1894 to 1931, his ideas had a great influence on the development of theory in sociology. *Mind, Self and Society: From the Standpoint of a Social Behaviorist* (1934), Mead's seminal work, was developed from the class notes of his students in an attempt to preserve his mostly oral tradition (Kuhn, 1964). This and other works (Mead, 1938; Blumer, 1969) set the foundation of Symbolic Interactionism as a major theoretical perspective within the discipline of sociology. This study will utilize many of the basic assumptions of Mead's tradition, as well as more recent work that has built upon it.

Symbolic Interactionism views the social world as an ongoing process of emergence flowing from the social interactions of individuals. Mead (1938) places special emphasis on how this process is grounded in social interaction and the symbolic meanings created and perpetuated through it.

Mead's ideas are founded in the basic ideas of behaviorism, that is that organisms act upon their understanding of the possible pleasure as compared to the possible pain in relation to their choice to act. Behaviorism thus assumes that an organism responds to a situation by comparing alternative actions, and chooses the one that they feel from past

experience will result in the most positive outcomes. Mead embraces these assumptions but extends them into the social world. He feels humans respond in the same basic way that other organisms respond to their environment, but humans are essentially different from other animals in that human being have the capacity to think and interact within a social context (Mead, 1934). It is this distinction that separates symbolic interactionism from radical behaviorism, by shifting the focus from stimuli and response, to the mysterious and sublime interaction between a human actor and the social world. Through this the actor and the social world become an ongoing and dynamic process of building up, tearing down, and redesigning both actor's selves and the society as structure. In Mead's view, the key to this process is found in the actor's ability to interpret the social world (Ritzer, 1992).

Symbolic Interactionism acknowledges that actors have the capacity to think, and that it is through interaction with others that the actor learns to interpret, modify, and create symbolic meaning. Interaction plays a very important part in the development of this ability. By being engaged in social interaction with others, an actor begin to learn the meanings and symbols used for communication. This includes fundamentally language and social narratives, but also more subtle forms such as symbolic gestures and body language. Through social interaction comes the development of a self capable of, and requiring self-reflection. And likewise, it is through self-reflection, the ability to view ones self as an object from outside oneself, that allows for social interaction. This seemingly paradoxical and ever-occurring dynamic is what is meant by the term *emergence*.

Mead designates three general stages through which interaction between a society and an actor develops this capacity of the mind into a self. The first is *the preparatory stage*, which consists of learning through simple imitation. The second is *the play stage*, here through play an individual develops the ability not only to imitate, but to take on the role of a significant others. At this stage actors begin to play roles of those in society with which they interact. The third stage is *the game stage*, it is in this stage through interaction with others in a game of understood and accepted rules, that an actor begins the process of identifying with a generalized other. This idea of a generalized other can be understood as developing the ability to view oneself from the perspective of society in general (Mead, 1934). Mead acknowledges that society presupposes the individual and is implemental in the development of a self, but still views the individual as having the capacity for thought and the freedom to act. The combined actions and interaction of individuals meshed in a pattern of meanings is the basis of society.

The idea of a self produced through self-reflection is further described as the *looking-glass self*, a term developed by Charles Horton Cooley (1902). The looking-glass self imagines the possible perceptions of others towards itself and is then affected in various ways. In this way social interaction plays an integral part in growth and development.

People with developmental disabilities, like all people, develop self awareness through interactions with the people they frequently encounter. People with developmental disabilities interact with others in society, however in many ways these interactions are controlled and influenced by society's choice of how to care and provide

treatment or services for these individuals. The nature of a residential setting has a tremendous effect on the nature of the opportunities its residents have in social interaction. And this in turn influences the development of those individuals with developmental disabilities.

This perspective implies that different environments vary in their conduciveness to the types of social interactions necessary for growth and development (Helmig, 1994). It also suggests that the closer an environment is to typical society, the more representative its residents will be in developing socially in a manner typical of that society.

Social interaction serves to create social reality through the interpretation and communication of symbolic meaning ( Mead, 1938). Giving symbolic meaning to an object or situation defines the social reality around that object or situation. This is done frequently through the choice of words and the use of symbolic language. For example, consider these words -- madman, imbecile, simpleton, demon possessed, or mentally deficient -- all have been used to describe people with developmental disabilities at different times in various societies. From the perspective of symbolic interactionism it can be argued that each term differs somewhat from the others in the symbolic meanings in which it is immersed. The way a given society defines people with developmental disabilities is linked to how that society treats those individuals, and through the process of self-reflection it shapes how those individuals define themselves, society and their place in it.

In this way symbolic interactionism is concerned with how we define and in doing so "create" frameworks of understanding. According to Paul C. Higgins, in his book, *Making Disability: Exploring the Social Transformation of Human Variation* (1992), we make disability through our beliefs, behaviors, and practices. The term *disability* in this way is not such a tangible thing as we often mistake it to be, but a construct often times indicating as much about how we understand things to be, as to how they are. "We put our understanding into practice by how we act toward disability, through our practices we create our understandings of disability, and our practices provided further testimony to our understanding. Each gives rise to and justifies the other."(Higgins, 1992). Through conceptualizing our physical , mental and emotional variations, we create different symbolic categories and frameworks.

It is from this framing of social reality, that we create what is social reality. Higgins point out how this occurs in a very real way using the example of counting those individuals with disabilities. Who we choose to define as disabled, or what we choose to define as a disability, produces the numbers we count. "Through conceptualizing, categorizing, and counting human variation, we begin to make and give shape and magnitude to disability"(ibid.). From such a perspective, Higgins suggests that our concern is not whether or not we are right in our framing of reality, but how useful it is in comparison to other frameworks.

**History of Ideology and Treatment**

The present changes in ideology and the resulting reevaluation of the ways in which society attempts to treat and/or help people with developmental disabilities are

more fully understood within a historical context. The history of the symbolic meanings surrounding people with developmental disabilities and their subsequent treatment by society is very informative in that it reveals the subtle but powerful ways inwhich the widespread ideas of a society create social environments with all their inherent consequences.

Scheerenberger (1983) traces the history of society's treatment of people with developmental disabilities from ancient times to the present. What is known about the treatment of people with developmental disabilities during ancient times varies from evidence of informal care within nomadic tribes, sometimes with prescribed shamanic like roles, to evidence of widespread infanticide and ritualized exile.

The rise in public programs for people with developmental disabilities began in the mid-nineteenth century. According to Scheerenberger, residential programs grew rapidly due to two social forces -- the idea that people with developmental disabilities could be helped by treatment, and the result of industrialization and urbanization in undermining the informal care that previously existed.

In Foucault's work Madness and Civilization: A History of Insanity in the Age of Reason (1965), the rise of asylums for the insane and fools is traced to the shifting and changing of beliefs. He suggests that in earlier times such deviants were considered a part of the nature of human society, and were categorized in broad terms such as madness. They often led an easy wandering existence. Though sometimes driven from towns in an elaborate ritual type manner, they were allowed to roam freely in the countryside.

During this time Christianity had a positive influence in promoting humanistic attitudes toward the care of people with disabilities. Families and the church took care of individuals within their communities. The Roman Catholic church regarded those individuals with developmental disabilities as God's children of innocence (Helmig, 1994).

Toward the beginning of the Renaissance, people of madness became regarded as possessing some sort of secret and forbidden knowledge. The image of the madman flourished in art and literature (Foucault, 1965). This image was that of a hero-fool who through the gift of his own innocence, naivety or madness could bring others face to face with their own forms of madness in a kind of divine comedy of errors. This symbolic place for the fool became the central theme of the farces and soties of the late middle ages, and continued throughout the development of Western thought. The fool, madman, and simpleton "is no longer simply a ridiculous and familiar silhouette in the wings: he stands center stage as the guardian of truth -- playing here a role which is the complement and converse of that taken by madness in the tales and satires"(Ibid.). Cervantes' *Don Quixote* (1950) is a good example of the continued influence of the fool as hero, as is the more contemporary Randle P. McMurphy from Ken Kesey's novel *One Flew Over the Cuckoo's Nest* (1962).

Foucault suggests that as these ideas began to flourish during the Renaissance, there emerged a unique method of dealing with such individuals. Throughout Europe people described as madmen, sots and fools were forced aboard ships hired to take them away. It is unclear as to the origins of this practice, but it is reminiscent of both the

ritual exiles of earlier days, as well as the holy pilgrimages to sacred shrines. It quickly resulted into an effective way of ridding one's city of such individuals. This practice and the image of *the ship of fools* so influential in the art and literature of that era is linked to the symbolic meanings of the time.

The sight of such ships drifting from port to port of unsuspecting cities can be described as an inverse of the adventures of Jason and his crew in the Argonaut cycles and the tales of Ulysses. The hero-fool image is superimposed upon both -- the mythical journey of the lost heroes drifting from adventure to adventure until their deliverance -- as well as the ancient scapegoat ritual in which people who came to represent the sins of the community were beaten with clubs and chased from society into exile in the wild. The corresponding development of this practice and symbolic artist theme is linked, because "it symbolized a great disquiet, suddenly dawning on the horizon of European culture at the end of the middle ages"(Foucault, 1965).

As the Renaissance progressed, the Roman Catholic church's views toward mental illness and retardation began to change. People with such disabilities were believed to be possessed by demons, or overtaken by sin. Many of the former charitable institutions of the church closed and were replaced by government almshouse. These almshouses employed severe methods of treatment such as whipping to drive out demons (Scheerenberger, 1983). Many people with developmental disabilities were burned at the stake in public executions.

This was the time of the great witch hunts, during which the crime of heresy was punishable by burning at the stake. Heresy was the crime of believing something

contrary to the teachings of the Roman Catholic Church. However, it was an offense against the State as well as the Church. Since the reign of the Roman Emperor Constantine, the Christian church was considered the basis of law and order (Szasz, 1970). The effort on the part of church and state to seek out heretics and punish them is a classic example of the power embedded in the meanings given to the nature of the world. The ideas of the Renaissance, though influenced to a great extent by the ideas and images of the Christian faith, began to strip away the power held by the Roman Catholic Church. During this time, expansion of new ideas began to change the view of the nature of the world.

The birth of modern science made many early advances in the area of medical treatment. However, in many ways both science and medicine were still influenced by the ideology of the time. It was believed that if one could not be cured by the drugs available at the time, than the cause was the devil. Though the power of the Catholic Church was greatly reduced by the protestant reformation. Protestant leaders such as Martin Luther and John Calvin also considered those with developmental disabilities to be possessed by Satan, and suggested they be drowned in nearby rivers (Helmig, 1994).

With the development of science and the age of reason, such deviants began to be seen as a threat because they were sick instead of the manifestations of sin, and society began its wide spread confinement of such individuals. During this transition, the scapegoat function became internalized and the symbolic language changed from theological definitions to scientific and medical ones. Behavior not considered typical

was redefined from possession by evil spirits or some outer force, to madness or insanity as an illness of the mind.

In Carolyn Merchant's book *The Death of Nature: Women, Ecology, and the Scientific Revolution* (1989), the philosophical basis of a mechanical view of nature as utilized by modern science is traced to many of the ideas of scholars around the Middle Ages. According to Merchant, the writings of Francis Bacon in particular were instrumental in constructing a view of nature as something from which to torture secrets. His descriptions of the scientific process closely resemble the method of acquiring confessions during the Inquisition. Thomas S. Szasz (1970) describes the foundation of modern psychiatric ideology as "an adaptation -- to a scientific age -- of the traditional ideology of Christian theology. Instead of being born into sin, man is born into sickness. Instead of life being a vale of tears, it is a vale of diseases." This new symbolic meaning led to a shift from ritual exile and public sacrifice, to ritualized confinement, but often what would now be considered torture was still used as medical scientific treatment.

In his work, *The Manufacture of Madness* (1970), Thomas Szasz, describes the progression of ideology that led to the development of the concept of madness. Science as ideology displaced theology, and in that change , the idea of madness became a viable replacement for the theological concept of heresy. "The Christian concept of man as a spiritual being was superseded by the positivistic concept of man as a biological machine." Concepts such as *good* and *evil* were replaced in ideology as *socially harmonious* and *deviant or socially disruptive* belief and behavior. Faith in God and his

priests became faith in reason and its priests -- medical doctors, lawyers, scientists and such.

The shift in symbolism had large effects on the social world such as the great rise of institutional hospitals originating in seventeenth century France and spreading throughout the modern western world. Such institutions became a major symbolic image of the age of reason. However, many of those incarcerated under the name of madness included political and religious deviants, as well as people with developmental disabilities (Foucault, 1965). The purposed treatments and causes for such deviant behavior and beliefs, resembled only new scientifically reformulated moral arguments based around the old assumptions of sin, rationalized and redefined in the terms of science (Szasz, 1974).

What had begun as described by Foucault as a confinement to the exterior had become a confinement to the interior (1965). What had been ritual exile in the practice of *the ship of fools* had become ritual confinement. He suggests that the rise in institutions was not so much a response to new developments in the ideas of treatment, as it was to the rationalization of nature, and the resulting ideas of there being a sickness that needed confinement as treatment. He points out the strange occurrence of institutions for the mentally ill being located in the same places that housed lepers only a century before. As leprosy began to disappear, society proceeded to rationalize people with mental illness and retardation into the role of societal scapegoats. People with mental disabilities began to serve the void function previously held by people with

leprosy. People with mental illness or disabilities were rationalized as an explanation for the problems in society, and thus confinement was utilized as treatment.

This shift of the scapegoat to a physical as well as symbolic interior position corresponds to the shift in ideas. That is in society changing its views from the cause of things such as mental illness and disabilities from being the work of the devil, to being a form of sickness in the individual, society also changed its method of dealing with such individual from exile or execution, to confinement and treatment. As the idealized problem shifted from esoteric outside forces to scientific internal forces, so did the rationalized solution. However, madness was still seen as a psychological effect of a moral fault. The treatment that occurred in these early asylums ranged from people being unexpectedly pushed backwards into a pool of water, to being strapped into a chair that spun at different speeds. These methods of therapy, quickly degenerated into forms of punishment. "Medicine was now content to regulate and punish, with methods which had once served to exorcise sin"(Foucalt. 1965).

This internalization of the scapegoat image is evident in many symbolic ways. One of Foucault's most striking examples is in his observation of the exceeding prevalence of a certain aspect of window design for early asylums. The interesting aspect is that the windows were not designed for resident's of the asylums to look out, but for those passing by on the streets outside to be able to look in.

Kuhn describes this apparent lag between the changes in accepted symbolic meanings and its actual translation into practice as the process of paradigm shift. In his book, *The Structure of Scientific Revolution* (1962), Kuhn discusses how scientific

thought evolves through revolutionary change. Utilizing examples focusing on the hard sciences in a modern context, Kuhn describes the process throughwhich new paradigms in science replace the older established ones.

The term paradigm suggests an encompassing way of viewing the world and how it operates with all its supporting arguments and assumptions. The process Kuhn describes begins with a reigning paradigm -- as more knowledge is accumulated, more and more of it produces anomalies which cannot be explained by the established paradigm, a crisis occurs. This crisis eventually leads to the development of a new paradigm that can explain the anomalies, and it thus replaces the old paradigm.

This process can easily be applied to the development of the positivistic scientific paradigm and the resulting ways of treating people with developmental disabilities which during the Enlightenment, began to replace the old theological paradigm. Kuhn describes there being a lag between the development of a new paradigm and the actual shift. The knowledge may be know and even accepted in the rhetoric of the time, but not yet effective in bringing about a true change in common understanding.

The ideas of many of the philosophers during the Enlightenment began to change attitudes toward the definition and method of dealing with people with developmental disabilities. One of the most influential was Jean Jacques Rousseau. His ideas influenced much in the way society tried to educate people with developmental disabilities. Thinkers and educators such as Seguin and Montessori were influenced by Rousseau's belief in the human capability to learn. Rousseau emphasized that educating

should be done in a fitting order utilizing the experience of physical properties such as sight, touch, listening, looking and feeling (Scheerenberger, 1983).

Inspired by Rousseau, as well as other thinkers and scientists, mental retardation became separated from mental illness, and treatments began to become more humane, and based more upon educating. However, treatment continued to take place mostly within the framework and social structure of the institutional setting.

Modern Special Education is considered to have developed in nineteenth century France from Jean-Marc-Gaspard Itard's efforts to educate a feral child named Victor. Over a period of five years, Itard attempted to teach Victor utilizing the techniques of operant conditioning and task analysis which became the basis of special education. " At the end of the period, however, Itard believed his famous experiment a failure, not because he could not teach Victor anything, but because he could not teach him enough"(Ferguson, 1987). Itard had worked intensively to teach Victor, and had acquired such insignificant results that he concluded Victor to be an incurable idiot. This led to the exclusion from schooling and education of many individuals with forms of retardation.

Scientific advances were moving the western world into the industrial age. The ideological focus of treatment of people with developmental disabilities began to be center more around ideas of economics. Much institutionalization for people with developmental disabilities still focused on the perceived need for containment. And as some reform began to take place, its basis reflected the idea of teaching and training of these individuals so as to produce people who could support themselves and no longer

burden society (Ferguson, 1987). Economics became the definition of success, and treatment continued to take place in institutions. The idea of reform was spurred by the idea that treatment could result in a supply of laborers as described by the developer of the IQ test, H.H. Goddard, as "...able and willing to do much of the drudgery of the world, which other people will not do"(Ibid.).

Institutions have been the major focus of treatment for many types of individuals, including those with developmental disabilities since modern times. Many sources give similar descriptions of problems these institutions have had, such as overcrowding, abusive treatment of resident, and dehumanizing conditions (Scheerenberger, 1983; Foucault, 1988; Blatt, 1970; Conroy, 1992). However, institutionalization continued to increase. "Institutional population increased till the late 1960s when corrective measures began to occur under the influence of the "normalization principle"(Meyers & Blacher, 1987, p. 11). This change in ideology has begun to dismantle centuries of tradition based around the institutional model.

**The Nature of the Total Institution**

Much of how people with developmental disabilities have been treated by modern western society has focused on the institutional model. The work of Erving Goffman is of interest in understanding the issue of residential treatment, specifically in regards to the effects of the modern institution.

Many of the fundamental ideas of Goffman developed out of the symbolic interactionist tradition, but where Mead's ideas focus on how actors create social reality, Goffman's approach focuses on how actors do this. Goffman metaphorically describes

the process actors take part in to create social reality, utilizing the dramaturgical perspective as a framework (Ritzer, 1992). Dramaturgy is a perspective within symbolic interactionism that uses the theatrical metaphor in creating a framework of understanding for social phenomenon. With this framework, Goffman stresses the act of presenting one's self to other members of society , as a performance (ibid.).

Goffman suggests that when an individual interacts with others, that individual is presenting a sense of self that will be accepted by others. This self is shaped by the individual and the expectations of the others. It is also influenced by the surroundings.

One's surroundings, or *the set*, is an important idea for the analysis of one's environment. Sets possess *props* which the individual utilizes to play the accepted role. Since both the actor and the audience want to observe a believable role, there is pressure against assuming roles that are not believable , or roles that do not correspond to the set and props (ibid.).

The ideas of Goffman concerning a specific type of setting called "the total institution" are especially relevant to the study of those with developmental disabilities and their residential environments. In his book, *Asylums* (1961), Goffman discusses the characteristics of the total institution and its effects on individuals in it. Goffman describes how the nature of the total institution limits, controls and attempts to direct the ways in which those residing in such institutions view themselves, and develop roles in which to interact with others.

He points out that the main characteristic of a total institution is that the residents perform all of their three spheres of life; sleep, play, and work in the same

setting. This is supported and inherent in the bureaucratic organization of large groups of people. First, all aspects of life are conducted in a single place under supervision of the same authority. Second, all aspects of life are conducted within a group whom are all treated alike. Third, all are tightly scheduled together by some formal rule or authority from above. Fourth and finally, the whole design is according to some plan inherent in the goal of the institution.

By the very nature of the institution, there is a gap between the residents and staff, resulting in interactions based on "narrow hostile stereotypes". These stereotypes center on common themes of the oppressed and the oppressor. According to Goffman this division is create and maintained in part through the mortification processes. These processes are utilized as a continuous method of control. Mortification processes include a wide variety of techniques such as role-stripping and various forms of regimented control over the everyday life of individuals.

Goffman describes how the staff of an institution use mortification processes as punitive forms of control that eventually lead to destructive effects on the resident's selves and often erodes the original intent of the institution. "The reason for such practices, if one looks beyond rationalizations provided by the staff, is a practical one: degraded and demoralised human beings are more pliant and easier to administer than those with a high degree of self-autonomy and initiative"(Mouzelis, 1971). However, this new focus on the strict control of the individual gradually replaces the original aim and goal of the institution. "Thus, according to Goffman, a sort of goal displacement

occurs: administrative efficiency becomes the central aim of the organisation and the officially prescribed goals are systematically discarded"(Ibid.).

Goffman's vivid and detailed description of the processes, structures and social interactions occurring in institutional settings has spawned much work in this area. In a review of studies utilizing this concept and other studies in the same area of concern, McEwen (1980) discusses the growth occurring from Goffman's original observations and descriptions, and specifically in what ways that growth has been stunted. McEwen states that much work in this area has failed to contribute to growth in a general theory, and often rely heavily on concepts that "...simultaneously overemphasized similarities among significantly different organizations of the same type and underemphasized continuities with organizations of different types"(1980).

In a critique of Goffman's concept of the Total Institution, Mouzelis(1971) suggests that differences occur between institutions in regards to the implementation of themortification processes. "The existence and degree of mortification processes in a total institution often depend on its power structure..."(ibid.). For example, institutions such as finishing schools for the children of wealthy individuals may tend not to use mortification processes in the same way or to the same extent as institutions such as a prison. McEwen(1980) also discusses various cases in which subtle differences in specific types of organizational settings, can effect the degree to which an organization reflects the described characteristics of a total institution. McEwen suggests that Goffman's original description, though vivid and evocative, is difficult to use other than in descriptions of the most isolated and total of institutions. This limitation is evident in

that many of the practices and characteristics of the total institution exist in different organizational settings in varied degrees and combinations. McEwen's insights are especially relevant to the study of settings that may have varying degrees of similarities and differences from that of the total institution.

## Theoretical Approach

This current study is concerned with comparing two different types of community placements for people with developmental disabilities that were developed in part as alternatives to the traditional institutional setting. In constructing a framework within which to discuss these two community placements, the goals and ideals of the Normalization Principle as demonstrated in various quality of life indicators and those descriptions of the social manifestations of the total institution are both to be utilized. As discussed in the previous section on the ideological history of society's treatment of individuals with developmental disabilities, often as ideology grows, there occurs a subsequent shedding of the old ideology.

This present study is directed at helping to indicate and describe how in relation to each other, these two community placements compare in increased quality of life. These two types of community placement will be compared by their Quality of life as defined by recent changes in ideology, and as opposed to the degree in which they retain or demonstrate aspects of the total institution, they are intended to replace. By comparing these two residential settings for people with developmental disabilities in this way, the present research hopes to better explore the nature of relative success or

comparative degree of advancement these two settings demonstrate as defined by the new paradigm of treatment and care.

The concept of the Total Institution and the Normalization Principle will both be utilized in the analysis and discussion of this research's qualitative portion. Though neither of the community placements observed in this study would be considered, in the traditional sense, a total institution, Goffman's insights are still useful. For example, both of these community settings differ from the classic "total institution" in that they serve as residences for a far fewer number of individuals than that of the typical state school or hospital, and are commonly located in normal neighborhoods. These same community settings however, still contain elements of the institution, such as bureaucratic structure and goals, as well as hierarchical authoritative divisions between the staff and residents.

Based on observations, Supported Living and Group Homes will be compared in relation to the degree and in what ways they retain aspects of the total institution, as well as to what degree they possess aspects of normality in relation to typical social environments.

McEwen's work, in developing a framework from organizational research in which to compare total and non-total institutions, is especially useful. In an effort to extend the practical use of Goffman's total institution concept, McEwen has developed a set of nine separate dimensions with which the organizational features of total and non-total institutions can be more systematically compared. The nine factors discussed by McEwen (1980) include organizational scope, voluntariness of membership,

hierarchical authority structures, staff consensus about goals and practices, social distance, organizationally sponsored surveillance, organization size, social characteristics of lower ranked members, and extra-organizational variables. Utilizing these nine dimensions as well as the nature and degree of mortification processes, Van de Poel-Knottnerus and Knottnerus (1993) analyzed an elite school system of early modern France. Through historical analysis the researchers discuss the ways in which the lycees of France resembled and perpetuated conditions associated with the concept of the total institution, yet at the same time demonstrated dynamics uniquely different from some of those typical to the total institution.

The first of McEwens(1980) dimensions is organizational scope. This is described as the degree to which an organization creates obstructions to social interactions with the outside. The less opportunity an individual has to quality social interactions outside an organization, the greater and more direct of an influence those interactions within the organization become. "The greater degree that lower associates are separated from the external social world, the greater the importance of the relationships within the total institution"(Van de Poel-Knottnerus et al, 1993).

The second factor considered is the voluntariness of membership. This refers to the nature of an individual's membership, and the relative division of power in conferring or terminating that membership. The degree of choice an individual has in being under the influences of an organization is directly related to the nature of that organization. Organizations in which the individual chooses to enter into and submit to

the institution goals are strikingly different from those organizations inwhich such decisions are conferred to the staff or higher authority.

The third factor is described as the degree to which the authority structure is arranged hierarchically. The nature of the division of power within an organization is very relevant to the nature of control that organization has on its members. The greater the power is concentrated into the upper parts of a hierarchical authoritative structure, the more that organization resembles Goffman's Total institution.

The amount of consensus among staff in the goals and practices of an institution is the fourth factor. This factor points to the relevance of cooperation and consensus amongst the staff in controlling its members and perpetuating its goals. The degree to which organizations differ in this respect is directly related to the nature of different organizations and institutions.

The fifth factor described by McEwen is referred to as social distance, and is concerned with the degree to which social interaction is permitted and fostered between the staff and residents of an institution. This factor is concerned with the relative degree of social distance between lower and higher participants within an organization, and is indicative of the nature and amount of limited and narrow social roles available in an institution.

The sixth area of analysis is the amount of organizationally sponsored surveillance an institution propagates over group interactions and individual privacy. This aspect of an organization is directly linked to the privacy and autonomy of those individuals associated with the organization.

The seventh factor has to do with the size of the organization or institution. This characteristic has received much attention throughout the movement toward deinstituionalization, and is often considered an indication of an institution's ability to create more normalized environments and individualized social interactions.

The eighth factor McEwen discusses is the characteristics of the individuals residing in an institution. This area of concern will be of special interest in relating how the limitations of those individuals with developmental disabilities residing in the community settings observed, may effect the nature of their settings in regards to the degree of normalization possible, as well as the degree to which these settings resemble the classic institutional model.

The ninth and last factor described is the degree of external influence the surrounding society has upon the community setting. Included within this dimension are the various ways and possible effects the outer society may have upon the nature of those settings observed.

In addition to detailed descriptions of these community settings in relation to characteristics of the institutional model, the concept of normalization will also be used in developing a broader understanding of the social nature of the observed living environments.

**Normalization and Deinstitutionalization**

The concept of normalization was first presented by Bengt Nirje (Nirje, 1969). Normalization is the belief that individuals with developmental disabilities should live in environments that are as culturally typical as possible. Others have added to the

concept of normalization having expanded it to include areas of life outside the idea of environment. Bercovici (1983) states that as a philosophy, Normalization has had a great influence on the deinstitutionalization movement. "The normalization principle," as described by Bercovici, "is based on a recognition of the humanity and potential of even the most severely handicapped persons; it requires that they be allowed to live and develop under conditions that are as culturally normal as possible, and that they be accorded the rights and dignities expected by any other citizen."

In MacEachron's study (1983) the development of the concept of Normalization is discussed from its ideological roots in Scandinavian countries to its utilization in the deinstitutionalization movement in the United States. The principles of Normalization originating in Scandinavia were based upon the ideological and somewhat moral implications of the nature of human life and individual dignity. The move toward more normalized environments in Scandinavian countries emphasized the right of people with developmental disabilities to live "normal" and productive lives. MacEachron states that the principles of Normalization when adopted in the United States as a working philosophy of reform, underwent an important change. "The Scandinavian perspective of normalizing the physical and social environment was attached to an American expectation that the behavior of residents would become more normalized"(ibid.).

This shift in the emphasis in Normalization has led to the concept changing from a simple moral argument, to a new form of treatment. From the American perspective, Normalization changes from the emphasis of people with developmental disabilities having the right to live more "normal" lives, to the use of "...means which

are as culturally normative as possible in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible"(Wolfensberger, 1972). This change in the idea of normalization emphasizes that it is not only the individual's right to live as normally as possible, but even beneficial in regards to development and treatment.

The principles of normalization have been a major influence in deinstitutionalization. Another large influence on the trend towards deinstitutionalization was that of the Kennedy family. In the 1962 report of the President's Panel on Mental Retardation (1962) a major concern was in the development of more community options.

The trend towards deinstitutionalization has also been spurred by litigation. Conroy (1994) presents the opposing arguments for the famous Willowbrook case (New York State Association for Retarded Citizens and Patricia Parisi, et al., v. Carey, 1972) showing that the case was decided on philosophical and ideological arguments supported on both sides by expert opinion. Similar court cases have been occurring throughout the United States.

This illustrates how, even in the present age, our treatment towards people with developmental disabilities is being shaped by the shifts and changes in the developing ideology, and the ways in which society gives meaning to this aspect of the social world. This research will draw from these theoretical perspectives in order to give a clearer understanding of these two different residential placement types for people with developmental disabilities.

## CHAPTER III

## RESEARCH DESIGN AND METHODOLOGY

This research will focus primarily on statistical analysis of quantitative data to better understand the differences and similarities in the "quality of life" for residents of both supported living arrangements and group-homes. In addition, qualitative analysis in the form of descriptive detailed observations made in both types of settings will be used to supplement and enhance the general understanding of this issue.

### The Sample

The subjects consist of twelve matched pairs resulting in twenty-four individuals total. Each individual is matched (within 5 points of the other member of their pair) on their baseline score on the adaptive development scale and by gender. The matching resulted in 7 pairs of males and 5 pairs of females. The mean baseline score on the adaptive development scale for those who moved from Hissom into supported living (group 1) is 63.5. The mean for those who moved from nursing facilities to group-homes (group 2) is 63.7. The adaptive development scale is a modified version of the adaptive behavior scale developed originally by Nirihi, and later modified by Conroy and Bradley(1985).

Due to the limitations in the number of individuals from which to choose, and the wide variation in ages, matching according to age was not possible. The average age of those moving from Hissom into supported living was 29 years old. The average age

for those transitioned from nursing facilities into group-homes was 56 years old. It could be argued that due to the age differences, these two groups are essentially different. However, it could also be argued that individuals with developmental disabilities do not necessarily develop according to age, and thus an indicator of development such as an adaptive behavior scale may give a clearer indication of a person developmental level than chronological age. It is however a limitation to consider in its possible effects on the results and interpretations of the results.

Other differences exist amongst the sample and should be considered . Various demographic features and factors related to the subjects in this study are presented in Table 1. These include the pair number, race, age, baseline adaptive development score, gender, level of verbal ability and the level of retardation as recorded in the data from 1992. Table 1 clearly indicates many of the differences between the members of each matched pair. The differences in age between the members of each pair is shown. Other areas which reflect possible differences between the matched pairs are the level of verbal ability, and the level of retardation. Though the level of retardation shows a considerable amount of difference between many of the matched pairs, in a study of reliability the level of retardation was shown to be the least reliable (r=.85) measure amongst demographic characteristics (Dodder, R., Foster, L., & Bolin, B., 1995). This is partially attributable to the information not always being known or available to the staff person being interviewed in the field.

**TABLE 1**

**Demographics of Matched Sample Pairs from 1992**

| Pair Number | Race | Age | AD Score | Gender | Verbal Ability | Level |
|---|---|---|---|---|---|---|
| 1S | White | 37 | 35.16 | Male | Verbal | Severe |
| 1G | White | 44 | 38.28 | Male | Partially V. | Severe |
| 2S | White | 24 | 67.19 | Male | Nonverbal | Profound |
| 2G | White | 44 | 65.63 | Male | Verbal | Mild |
| 3S | White | 26 | 71.09 | Male | Verbal | Severe |
| 3G | White | 44 | 70.31 | Male | Verbal | Moderate |
| 4S | White | 24 | 78.13 | Male | Verbal | Severe |
| 4G | White | 44 | 80.47 | Male | Verbal | Mild |
| 5S | White | 29 | 64.84 | Male | Verbal | Moderate |
| 5G | White | 59 | 65.63 | Male | Verbal | Severe |
| 6S | White | 22 | 82.03 | Male | Partially V. | Severe |
| 6G | Nat. Amer. | 60 | 82.81 | Male | Verbal | Mild |
| 7S | White | 32 | 36.72 | Male | Nonverbal | Profound |
| 7G | White | 63 | 37.5 | Male | Partially V. | Severe |
| 8S | White | 29 | 52.34 | Female | Partially V. | Severe |
| 8G | White | 39 | 51.56 | Female | Verbal | Moderate |
| 9S | White | 24 | 59.38 | Female | Nonverbal | Profound |
| 9G | Black | 53 | 62.5 | Female | Verbal | Severe |
| 10S | White | 22 | 83.59 | Female | Verbal | Mild |
| 10G | White | 57 | 78.13 | Female | Verbal | Mild |
| 11S | White | 35 | 71.88 | Female | Verbal | Severe |
| 11G | Black | 59 | 68.75 | Female | Verbal | Severe |
| 12S | White | 36 | 60.16 | Female | Verbal | Unknown |
| 12G | White | 61 | 62.5 | Female | Verbal | Mild |

Table 2 presents an overview of specific types of disabilities other than mental retardation that were recorded concerning this sample in 1994. This is intended to give a clearer indication of the similarities and differences that exist between these two populations. Though this information can help to indicate other areas of difference

between matched pairs, the degree of these differences is difficult to establish. For example the category of visual impairment included all varying degrees of impairment ranging from needing a perscription for glasses, to total blindness. Information on the exact nature of these disabilities is not readily available.

**TABLE 2**

**Specified Disabilities of Matched Sample from 1994**

| Pair Number | Visually Impaired | Hearing Impaired | Autistic like Behavior | Cerebral Palsy | Physical Disabilities | Mental Illness |
|---|---|---|---|---|---|---|
| 1S | X | . | . | . | X | . |
| 1G | . | X | . | . | . | . |
| 2S | . | . | X | . | . | . |
| 2G | . | . | . | . | . | . |
| 3S | X. | . | . | . | . | . |
| 3G | . | . | . | . | . | . |
| 4S | . | . | . | . | . | . |
| 4G | . | . | . | . | . | X |
| 5S | . | . | . | . | . | . |
| 5G | X | . | . | . | . | . |
| 6S | X | . | . | . | . | . |
| 6G | . | . | . | . | . | . |
| 7S | . | . | . | . | . | . |
| 7G | . | . | . | . | X | . |
| 8S | . | . | . | . | . | . |
| 8G | . | . | . | . | . | . |
| 9S | . | . | . | . | . | . |
| 9G | . | . | . | . | . | . |
| 10S | . | . | . | . | . | . |
| 10G | X | . | . | X | . | . |
| 11S | . | . | . | . | . | . |
| 11G | . | . | . | . | . | . |
| 12S | . | . | . | X | X | . |
| 12G | . | . | . | . | . | . |

## The Instrument

The data used for this study come from an annual independent assessment of consumer outcomes conducted by the Department of Sociology at Oklahoma State University. This assessment is conducted annually in compliance with the Consent Decree resulting from the Homeward Bound vs. The Hissom Memorial Center (1987) litigation. The assessment instrument is administered by a trained research staff consisting primarily of graduate students in the Department of Sociology. The instrument itself is an adaptation of an instrument used by Temple University Affiliated Program (Conroy and Bradley, 1985) in assessing the outcomes of the closure of Pennhurst State School and Hospital and the relocation of its residents into community programs.

The assessment instrument used in this study consists of various questions, some of which are used to develop scaled items. These are utilized in assessing consumer outcomes and quality of life in terms of independence, productivity, integration, and consumer satisfaction.

The conceptualization of outcomes and quality of life has been based on the general framework put forth in the 1987 amendments to the Developmental Disabilities Act. The four areas used to indicate the quality of life for individuals with developmental disabilities are independence, productivity, integration, and consumer satisfaction.

Level of independence is best described in the individual's ability to function in everyday life tasks and interact socially in a typical manner. It is roughly conceptualized in the idea of the individual's ability to independently care for themself, interact with others socially, and the perceived likelihood and intensity of behaviors occurring that would hinder that. Independence is operationalized into three different scaled items. A behavior development scale is used to measure changes in adaptive behaviors, such as body balance, comprehension, self-care skills, and communication. Challenging behavior scales are used to measure problematic behaviors in both the frequency of them occurring and severity of them when they occur. Challenging behaviors include such things as threatening or doing physical violence to others, destruction of property, inappropriate screaming, yelling or crying, and others. All three measurements are scaled from 1 to 100 where the higher the score the better.

A high score on the adaptive development scale represents more adaptive behaviors. Such behaviors include physical capabilities, cognitive abilities, and interaction skills. Information on the consumer's level and skills in these areas were obtained in a personal interview with the consumer's primary caretaker.

The severity and frequency of challenging behaviors were also obtained during a personal interview with the primary caretaker of the DDS consumer. The challenging behavior scale measures both frequency and severity across five dimensions. The five dimensions include inappropriate behaviors directed at others, inappropriate behaviors directed toward one's self, stereotypical behaviors, inappropriate sexual acts, and general listlessness (Murray p. 6). The higher the score on either the frequency or the

severity scale indicates the greater the ability to control either the frequency or severity of challenging behaviors.

Productivity can be indicated by the amount of time an individual participates in activities considered beneficial and achieving some goal such as work or school. Productivity is operationalized as the number of hours per month the consumer participates in productive activities like work or school. These are also obtained by interviewing the consumer's primary caretaker. Such activities include paid employment such as sheltered workshops, supported employment, competitive employment, and training such as prevocational programs. Also included are various types of educational services such as public schools (both regular and special classes), private schools, special schools and homebound education (Murray p. 6).

Integration is connected to an individual's opportunities to interact socially with other members of society. Due to the difficulty in assessing the quality of one's social interactions, integration is operationalized as the number of times the DDS consumers left their residence to participate in various social activities during the past year. In this way what is measured is the quantity of possible social interactions, it is assumed that the larger frequency of possible interaction would result in a greater chance for quality interactions. This could result either through the sheer number of outings and extended amount of time spent in the community, or through established habitual outings resulting in a qualitative difference in the interactions.

These data are acquired from the primary caretaker, and the results indicate the average number of times a week the consumer experiences potential social interactions

in the community. Examples of the various outside activities inquired about include visits to friends or relatives, church services, and visits to places such as supermarkets, retail stores and/or restaurants.

Lastly, consumer satisfaction is an individual's perception of their own quality of life. The consumer satisfaction scale is developed from the answers given by the primary consumer to questions about the facility and its programs. The scale measures two distinct areas, the level of satisfaction the consumer has for the residential setting, and the interactions they have available. The scale is scored from 1 to 100 where a score of 100 is the highest level of satisfaction.

**The Research Design**

The research design is quasi-experimental in that there are two groups that came from similar "total institution" settings, but received separate treatments. A matched comparison is one quasi-experimental design suggested by Campbell and Stanley (1966). As a research design, a matched comparison adds an additional measure of control by assuring that the two groups to be compared start with similar if not the same characteristics. After being matched, the two groups can be compared on a variety of measures. The changes from 1992 to 1994 between the two groups in terms of independence, integration, productivity, and satisfaction will be analyzed using the Wilcoxon Matched-Pairs Signed-Ranks Test. This statistical technique gives both the direction of differences in pairs as well as the magnitude of difference (Siegel, 1956).

## Qualitative Data

Statistical analysis of these previously mentions areas of quality of life will be supplemented with qualitative data in the form of detailed observations of the interactions and physical environments of six supported living arrangements and six group-home arrangements. These observations will take place on site during the administering of the quantitative instrument during 1995. The precise placements observed will not necessarily be those in which the individuals in this study reside, and are not intended to indicate specifics about those placements. Rather, the qualitative component is used in generating possible explanations for subsequent findings, and to give a general understanding of the nature of each of the two different types of placements.

The process of observation begins with thick detailed descriptions of what is observed. According the Emerson (1983) thick description serves to make connections between the events and individuals involved in the events, as well as the meanings and context in which they occur. He acknowledges however, that it can be problematic for the researcher in understanding the meanings of what is observed due to the fact that the researcher is an outsider. On the other extreme, the researcher can become so much a part of the group that objectivity is lost. In this study some of these problems are minimized due to the nature of the observations. Since each observation will take place in such a limited amount of time and contact the problem of losing objectivity is greatly reduced. In an attempt to circumvent the lack of perspective needed to develop an insider's understanding of the meaning of what is observed, observations of the physical

environment and social interactions will be utilized only in regards to the research question at hand. The interpretation of the observations will be limited to the possible influences in regards to the concept of normalization and other theoretical issues such as Goffman's (1961) description of institutional characteristics.

As Denzin(1989) explains, "...no single method ever adequately solves the problem of rival interpretive, causal factors." The findings utilizing the quantitative data and its analysis can give an indication of the differences that occur between these two placements and treatments, but is limited in the interpretation of those findings. Likewise, the limitations of observation and qualitative interpretation is that they can give very limited empirical findings and/or generalizability.

Denzin suggests the use of various methods in research, which he calls triangulation. The logic is that since no single method can give the social scientist what is needed, the use of different methods focused in upon the same research question, can give a clearer and more holistic picture of what is occurring in the area of interest. In this study, the empirical findings will result in very limited interpretative capabilities, thus observation will help in interpreting the statistical findings. By researching this question of the differences between Group Homes and Supported Living from two different methodological perspectives, a broader, more complete understanding can be developed.

**Ethical Considerations**

The protection of those individuals studied is of utmost importance in any research. To protect individual privacy and confidentiality, identifying characteristics

will not be included in the research findings. Those individuals selected as part of the matched pairs sample will be known during the research only be their individual identification code. Their actual residence will not be utilized in any of the analysis, or other aspects of this study.

Likewise, those involved in the observation section of this study will not be discussed in any way or by any characteristic that could potentially identify them.

On the issue of use of fieldnotes, the observations conducted for this research are considered implied in that the researcher is conducting a survey in the residence to assess quality of life, and utilize observations if deemed appropriate. In this way the observations are not "disguised" per say (ibid.) though they occur outside of the specified bounds of the current assessment instrument. As researcher, I will be observing what goes on within each residence, and those residing there and their staff will know that I am there to assess quality of life.

## Reliability

Reliability refers to the extent to which a measure is congruous in regards to the information it attains. This is indicated by the consistency in the results it obtains when used repeatedly. A measure is considered reliable by the similarity in the results of its measurement when used various times. The more similar the results when used many times in measuring the same thing, the more reliable that measure is considered to be (Babbie, 1979). The importance of establishing the reliability of an instrument helps to indicate the strengths and weaknesses inherent in the results of a study.

Interrater reliability is the degree to which more than one person using the same measure records the same information from the same subjects. Test-retest reliability refers to the consistency of information obtained from subjects when ask the same questions more than once.

The Adaptive Development Scale utilized in this study has been systematically examined for reliability in various past research. Such studies have consistently indicated high levels of correlation in both test-retest and interrater reliability (Dodder, Foster and Bolin, 1995).

In Isett and Spreat's research of test-retest reliability (1979) of an earlier measure called the Adaptive Behavior Scale high Spearman rank correlations were found ranging from r=.85 to r=.97 with 1.00 being a perfect correlation. This research consisted of choosing at random 28 individuals whom were tested and then re-tested after a period of two weeks. Interrater reliability was found to range from r=.42 to r=.93 on the Adaptive Behavior Scale.

For the Pennhurst Longitudinal Report conducted over a five year period, Conroy and Bradley (1985) found the test-retest reliability as well as interrater reliability to be very high on the measure of a modified Adaptive Behavior Scale. Test-retest reliability of r=.96 was found. An interrater reliability correlation of r=.94 was reported as well. Another study utilizing the data from the Pennhurst study (Devlin, 1989) found similar high correlations for both interrater reliability (r=.95) and test-retest reliability (r=.91).

Dodder, Foster and Bolin (1995) found similar levels of reliability for the Adaptive Development Scale, modified from the Adaptive Behavior Scale utilized by Conroy and

Bradley (1985). Researchers' analysis of the data collected by the Developmental Disabilities Quality Assurance Project at Oklahoma State University, and utilized for this research project, found the Adaptive Development Scale to be the most consistent scale used in this research. In 1991 , 49 interviews were accidentally scheduled for the same consumer with a different interviewer. In 1992, 86 such interviews were conducted. Often the interviews were not only conducted by different interviewers but a different caregiver as well. Using Pearson's Product Moment Correlations coefficients of .96 in 1992, and .58 in 1992 were reported.

The Challenging Behavior Scales showed reliability within an acceptable range, but less overall than the Adaptive Development Scale. The frequency of challenging behaviors showed correlations of .74 in 1991 and .69 in 1992. The severity of challenging behaviors was indicated to have a reliability of .69 in 1991 and .72 in 1992 (ibid.).

Other studies of reliability have indicated similar levels of reliability. Conroy and Bradley (1985) reported interrater reliability of r=.70, and a test-retest reliability of r=.90. Devlin (1989) reported a similar interrater reliability of r=.72, however, test-retest reliability was somewhat lower, being reported at r=.60.

A study of group homes size conducted by Helmig (1995) utilizing the same data base as used for this study, found an item-by-item overall scale correlation for the variable integration to be .90 with a significance level of .01. An item-by-item correlation for the variable productivity was found to be .77 at a .01 level. And the variable of consumer satisfaction showed an overall correlation of .96 at the .01 level.

The reliability of qualitative data is difficult to discern due to the fact that different researchers may observe the same thing but report different aspects or interpretations of what was observed. The researcher for this study has conducted interviews in the area of concern for over three years, which has included many informal observations of the settings in question. Also, to help insure reliability, detailed notes of the current observations were taken. Throughout the analysis the researcher has attempted to insure the reliability of the findings mentioned and discussed, though it is difficult to assess the extent of that reliability.

## Validity

Validity is considered to be the extent to which a measure actually measures what it is intended to. Construct validity is determined by the extent to which a measure corresponds to others designed to measure the same concept.

Factor Analysis was conducted on portions of the data used in this study to determine construct validity. Dunsmore and Dodder's (1993) findings indicate the Adaptive Development Scale, severity and frequency of challenging behaviors scales measured what was intended. They suggest there is confidence in the Behavior Development Scale. The results of consumer satisfaction scale are not as strong, however the researchers suggested that the individual items indicated enough cohesiveness to indicate the measurement of a common variable.

To help insure validity for the data used in this research project Bolin and Dodder (1993) conducted random checks between the data collected in the field and that loaded into the O.S.U. mainframe. No coding errors were found out of 1650 possible input errors.

The validity of the qualitative aspects of this study were difficult to control for completely. In general qualitative analysis can possess more valid results than quantitative, in that the researcher is observing the very things that make up the data (Denzin, 1989). To help enhance this the researcher avoided biased questions and comments. A professional attitude throughout the study has helped to control for this, but verification of a level of validity is difficult.

## Generalizability

This research is not intended to be generalized to a greater population, but to give a better understanding of the concepts and issues involved. The sample used is not a random sample of all individuals with developmental disabilities residing in Oklahoma group homes and supported living. Instead for purposes of the research design, individuals were consciously chosen with certain specific characteristics allowing for the development of a matched sample. Likewise, the research design does not allow for the analysis of cause and effect and should not be generalized to other populations. It can however, indicate areas of interest for future research and provide additional information to researchers interested in the differences between residential settings and those individuals who reside in them.

## Limitations

There are several limitations to consider in regards to both the instrument and the research design. These limitations should be taken into consideration when reviewing the findings of both the quantitative and qualitative portion of this study's findings.

One of the major limitations of the instrument used is that it was developed in response to and for the purpose of collecting data according to stipulation set by a court ordered mandate. By being developed to monitor a mandate based upon a class action suit, the instrument has a built in basis. Often times caretakers of people with developmental disabilities may present an image of their programs that is based on meeting the court ordered mandate. This research project functions as an outside audit, and many caretakers may present information based more on expectations and less on the surrounding realities of their programs. Seeing the link between important funding and the conducting of audits, some caretakers may give biased answers. Also, the wide variety of educational backgrounds and various employment positions of the caretakers may reflect how the questions are interpreted and answered.

Another inherent limitations in the instrument's consumer satisfaction portion is the nature of the population. Questions of consumer satisfaction were asked of the consumers themselves. This portion of the instrument was conducted under a variety of environmental conditions. Ideally the consumer satisfaction interview would take place with only the consumer and interviewer present, under other circumstances the caretaker or other consumers may have been present. With some consumers the caretaker was needed to interpreted and verbalize answers for the consumer due to the nature of the consumer's disability.

Other limitations to be considered are inherent in the research design. In developing the matched sample utilized in the quantitative portion of the study, the researcher was required to work within certain constraints of the research data. In pursuing

a quasi-experimental design, the researcher was limited in matching individuals with which to compare. The sample developed and analyzed, though matched on some criteria, remained essentially different in other ways. As previously discussed the pairs were matched by gender and scores on the Adaptive Development scale. However, other important demographics varied extremely. One such difference inherent in the sample was that of age. Those who moved into supported living had an average age of 29 years old as compared to those who moved into group homes with an average age of 56 years old. Do to the nature of these individuals being developmentally disabled, the relationship of chronological age to individual developmental is an area of interest and indicates some concern in the interpretations of this study. Seeing the nature of developmental disabilities as linked to obstacles in typical developmental processes, the scores of the Adaptive Development Scale may result in a closer criterion for comparison between individuals, but the fact of age difference and its possible effects on the outcomes of this research needs to be acknowledged and taken into consideration.

Another limitation to consider is the nature of the two different settings from which the sample population moved. Though it is argued for the purpose of this research that Hissom Memorial Center and the various nursing facilities from which this sample was drawn are similar in regards to the nature of the total institution as described by Goffman(1961), differences may still be inherent in the structure, purpose and design of these facilities. These possible differences are inherent and unavoidable in the constraints of this research, and should be considered in the results and subsequent discussion.

There are also limitations to consider in the collection and analysis of the qualitative data. The researcher being present for the purpose of a court mandated audit may have biased the occurrences and observations that took place in these settings. These observations were also limited by time constraints, a typical interview took approximately one half hour, and the length of observation at each setting was essentially tied to the number of residents at each setting.

# CHAPTER IV

## PRESENTATION AND ANALYSIS OF FINDINGS

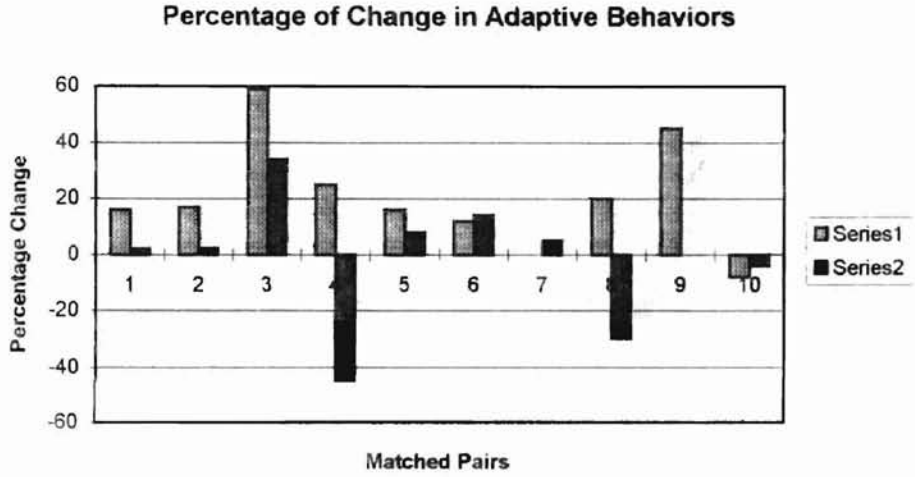
The purpose of this study was to develop a broader and more comprehensive understanding of the differences in quality of life that occur between two types of community residential setting for people with developmental disabilities. The quantitative portion of this study focused on four aspects related to the concept of quality of life. These aspects were originally developed from the 1987 amendments to the Developmental Disabilities Act (Murray, 1994). The four areas used to indicate the quality of life for individuals with developmental disabilities in this research are independence, productivity, integration, and consumer satisfaction.

The first area of independence is made up of three scales used to indicate the level of independence an individual has in regards to their personal ability to do things for themselves as well as the limitations of their living environment. The two sets of matched pairs were compared by the percentage of change shown in the base line scores of the three scaled items as recorded in 1992 and compared to data from 1994.

The first measure consisted of the percentage of change in the adaptive development scaled score from 1992 to 1994. This scale is made up of various questions concerning the individual's ability to do simple, everyday tasks as well as questions relating to such things as their level of comprehension and form of communication.

As shown in Figure 1, there are general percentage increases in scores on the adaptive development scale for both groups during the two year period between 1992 and 1994. Those who moved from nursing facilities into group homes (Series 1) show a significant (.03) percentage increase in adaptive behaviors as compared to those who moved from Hissom Memorial Center into supported living arrangements (Series 2). Of the twelve pairs, ten had sufficient data for analysis on adaptive behaviors.

**FIGURE 1**

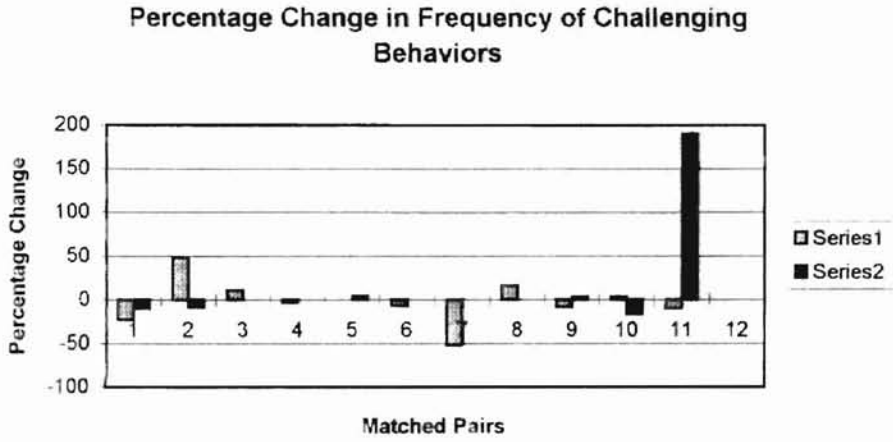



**(N= 10, significant at P < .03) Series 1= Group Homes, Series 2= Supported Living**

The other two scales used to indicate the level of independence are concerned with the frequency and severity of challenging behaviors. This is thought to help indicate the degree to which the staff of the living arrangement may see a need to limit the degree of independence an individual is allowed. It is assumed that the greater the degree of challenging behaviors in either severity of frequency, the greater would be the limit placed on that individual's ability to function independently of their staff.

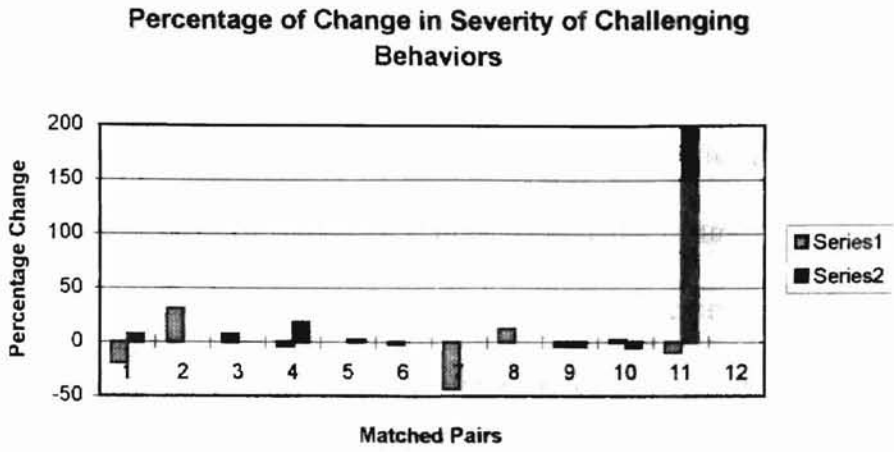
Percentage changes in both the frequency or severity of challenging behaviors were not found to be statistically significant (see Figures 2 and 3). This indicates that the amount of change in the pairs' scores on their ability to control the severity and the frequency of challenging behaviors did not significantly change over the indicated two year period. There was found to be no difference between the two placements types in this area.

**FIGURE 2**




**(N= 12) Series 1= Group Homes. Series 2= Supported Living**

**FIGURE 3**




**(N= 12) Series 1= Group Homes, Series 2= Supported Living**

The second area of Productivity consisted of comparing the percentage of change in the number of hours spent weekly in a productive activity relate to work skills or education. Results were lacking due to insufficient data.

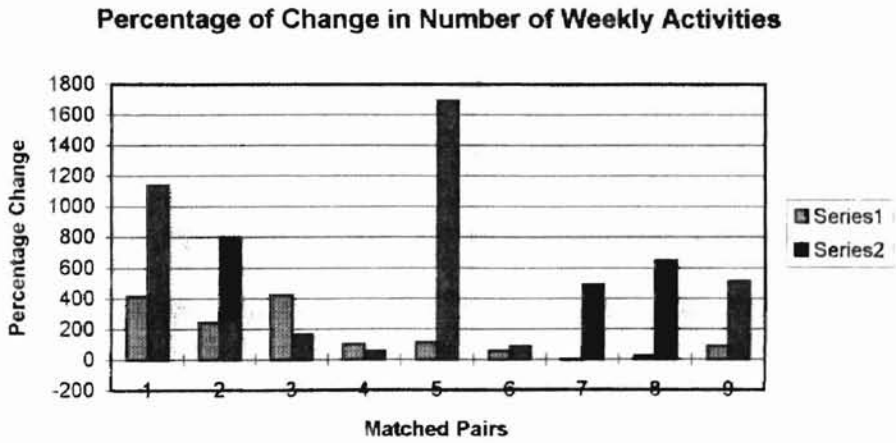
In computing the percent of change in the amount of time spent for productive activities such as school and employment over the two year period, insufficient data on one of either member of a pair left only one matched pair for analysis. Percentage of change in productive activities for this one pair was incidentally not significant. Due to the limitations of comparing the scores of only one pair, this study is unable to present any reliable results in the area of productivity.

The area of Integration is concerned with the individual's degree of integration in the community. Due to the nature of the study of human subjects the quality of social

interactions in that community is difficult to ascertain. This research compares the percentage change in the number of times an individual leaves their residence to participate in various social activities. The area of integration indicates the potential for social interactions and not necessarily the quality of those interactions. It is assumed though that the greater opportunity for social interaction would tend to allow for a greater chance of those interactions to be of a quality nature.

Data for 1994 consisted of nine of the twelve pairs with which to compare. In comparing the percentage of change in the number of weekly opportunities for social interaction in the community, those individuals who moved from Hissom Memorial Center into supported living placements (Series 2) showed significant (.04) increases over those transitioned into group homes (Series 1). This indicates that though all pair member's scores indicate an increase in community activities, those in supported living arrangements increased significantly more (See Figure 4).

**FIGURE 4**




**(N= 9, significant at P< .04) Series 1= Group Homes, Series 2= Supported Living**

Findings concerning the area of consumer satisfaction are limited due to the small number of pairs with both members having sufficient data for analysis. With only three pairs with which to compare, the analysis of the data is questionable. Findings in this area are not significant.

The Qualitative portion of this study was designed to give a thicker and more descriptive comparison of supported living placements and group homes for people with developmental disabilities. The analysis consists of detailed observations of six supported living arrangements and six group homes during 1995. The placements selected for the quantitative analysis and those utilized for the qualitative analysis are not necessarily the same placements. The following discussion of the observations of this study is divided into two areas of interest. The first section discusses the ways in which the observed placement types correspond to the ideals of the normalization principle. The second section compares these settings in regards to their unique combinations of total and non-total institutional characteristics that could hinder the goal of normalization.

**The Goal of Normalization**

The group home arrangements observed in this study functioned as homes for an average six to eight people each. The supported living arrangements typically served as residence for two individuals, with none having more than three. These small sizes in the number of residents compared to a typical institutional setting had obvious effects on the level of normalization possible. Not only are these sizes similar to what could be called a typical household, they allow for a more typical residence in many other ways. Of both

types of placements observed, the majority were located in typical housing in normal neighborhoods. All of the six supported living arrangements were located in either a suburban housing addition or an apartment complex. The group homes were typically in similar suburban housing editions. The group homes differed somewhat from the supported living arrangements due to the larger number of individuals living in them. Whereas the supported living arrangements were either a two to three bedroom house or apartment, the typical group home was almost twice as large. Two of the homes observed were older large houses. Another two were duplexes modified into one home. There was one exception among the group homes which was located in an almost rural and much more isolated area with few and scattered neighbors.

An interesting feature of this one exception was that it had been designed as a placement for individuals with developmental disabilities whereas the others had not. The structure of the home itself suggested its function in small details. Some of these differences made it seem less like a typical home, for example many of the floors and hallways had what could be described as industrial tiling similar to that of an office building or school. Also, structural features such as wider doors and ramps for those with physical disabilities were present. Some of these features though less typical, were actually positive in creating a more accessible environment for some of its residents. Many of the other settings had also modified their environments to better suit those individuals with physical disabilities residing there.

The difference between those group homes that had made modifications on an existing structure and the one built with its intended purpose in mind, seemed a difference

in aesthetics versus utility. The structure built specifically to function as a group home seemed somewhat sterile compared to the others.

Though the residences observed were similar in their locations and structural design there were striking contrast in the decorating of the interiors of the home. The effort placed on making these places homes for the individuals residing in them was partly observable in the degree of personalization apparent. These differences were most apparent in the personalization of individual's private rooms. One supported living placement had nothing on the walls for decoration in one of the individual's room, and a mirror, some charts on safety and a calendar in the other individual's room. This was, however, in stark contrast to other supported living arrangements in which the individual's rooms had many posters of various musicians and athletes they admired, family photos, and other personal possessions. Most had personalized rooms to varying degrees and the differences did not seem to relate to whether the placement was a group home or supported living. Of all those that were either not personalized at all or had very meager personalization, the individuals residing there were of lower levels of functioning. This also indicated that the staff had not put the effort into doing it for them. However, in some of the residences observed with low functioning individuals, there was a large degree of personalization and/or decorating of individual's rooms. Those environments that had been personalized had a pleasent atmosphere and seemed more typical of a home.

There was some degree of decorating of the common parts of all the homes observed. However, the content differed along the same distinction as did that of the personalization of individual rooms. Though there was a wide variety of styles displayed

throughout these homes ranging from folk crafts, to modern abstract pieces, some of the residences observed seemed to have simply put more effort in designing a comfortable and pleasing environment. For example the supported living arrangement mentioned early for having very little personalization of individual rooms, was almost equally sparse throughout the rest of the home. There was nothing on the walls in the hallway, and the wall decorations in the living room were beige and tan abstract textile collages. Such an environment was quite different than others that contained a complex color scheme, and/or interesting detailed pictures. Some of the homes even had resident's art work hanging on the refrigerator. At one supported living arrangement the staff was observed engaging the residents in helping to decide the color of new carpet for the living room. Again, rather then the type of placement, the differences observed in the amount of normalization, or degree to which an environment resembled that of a typical home seemed to be more influenced by the degree to which the resident's were able to display and communicate their interests and the staffs' own level of motivation in this area. Though there were extreme difference in a few of the cases observed, the majority were pleasant and often times reflected the interests of its residents. This observation seemed to indicate an effort towards normalization on the part of the staff, as well as a normal opportunity for an indiviual to create their own personal space.

One of the most common elements in the central living area of all the homes observed was a dominating feature of the television. In all of the homes, the television was the central point of interest in at least one room. Some of the group homes, however, had a separate room without a television, devoted usually to art, games or reading. Some of the

resident's of the homes observed also had personal televisions and sometimes video games or VCR players in their own rooms. Watching television was observed to be a very popular pastime. This aspect seemed rather typical of normal society.

**Characteristics of the Institutional Model**

In many ways the placements observed were quite different from typical institutional settings. However, some characteristics of institutional type placements remain in the bureaucratic authoritative structure and treatment goals of the agencies providing service to those individuals in supported living and group homes.

In considering the ways and degree inwhich these settings may develop characteristics similar to different types of total and non-total institutions, nine dimensions developed by McEwen were utilized. These nine dimensions were developed to give a clearier indication of ways inwhich organization differ in their degree of similarity to the Goffman's concept of the total institution.

The first dimension is organizational scope, which refers to the degree inwhich the organization hinders social interactions with the outer society. Though this was difficult to ascertain through observations, it was apparent that there existed a clear division between these residential placements and the outer society. This was not necessarily due to the goals of the service providers, but more likely due to the nature of the individual's disabilities. Many individuals observed had difficulties acting in socially appropriate and/or typical ways. And though they were interacting in the community on a regular basis, this interaction was most commonly buffered by the presence of staff. However, any degree of social isolation from the outer society these placements might possess was quite

different then that described for the total institution. During observations at one group home there was an opportunity to ride in a van with a staff person and four residents to get a fifth resident finishing their shift at their place of employment. On the way, incidential teaching on the part of the staff was observed. The staff person engaged the residents in asking them question about various aspects of the surrounding environments. Much of the focus was placed upon the identification of traffic signs and various places such as stores and restaurants the individuals had been with the staff. The residents of the group home seemed to look forward to and enjoy such outings. Often while conducting the instrument at supported living arrangements, one of the residents and one of the staff would either arrive from being somewhere, or leave to go somewhere. This was usually going to work, therapy or such, but on occasion they were merely visiting a friend. Interaction with the outer society and residents were usually in the presence of staff. But while observing at one group home, three residents by themselves arrived from having been to visit another group home.

The second and third dimensions described by McEwen have to do with voluntariness of membership, and the degree of heirarchical power structure that exists in the regulating of these placements. In many ways the degree of voluntariness the individuals possessed in choosing to reside in these placements was very limited. This often had to do with the degree to which the individual could advocate on their own behalf, or depended on an outside individual to advocate for them.

All of those observed at supported living arrangements had been institutionalized at Hissom Memorial Center. They had been transitioned into the community according a

consent decree (Homeward Bound vs. Hissom Memorial Center, 1987). The amount of voluntariness of membership relied mainly on there being other residential and care options such as family with whom they could live. At one supported living arrangement the parents of both individuals residing there had chose to be there during the interviews. Due to the advocacy on the part of the parents and the ability of the residents to communicate their wants, the two individuals living there had had a large degree of input in the decision making process. They had chosen each other as roommates and helped in picking the house they were renting. This seemed to indicate a large degree of power available in the decision making aspects of placement. This similar potential seemed to be available for some in group homes as well. One individual residing in a group home had made visits with their parents before moving in, and seemed to indicate choosing to move into the group home over staying at their parents as a means to gain more independence.

There was observed other individuals in both supported living arrangements and group homes who indicated they did not like the specifics of their placements, and seemed frustrated in not being able to change them. They did not have active family members and/or were typically more difficult to communicate with, some had few choices merely due to economic reasons. Much of the power in these decisions tended to rest in decisions made by professionals in the field and the upper part of the hierarchical authoritative structure. This area of interest was difficult to analyse due to the limitations of the observations.

The fourth area of interest relates to the degree of consensus between staff on the goals and practices of staff. From observations there seemed to be a high degree of

consensus between staff in both types of settings, however, this could have been influenced by the presence of a researcher. For example, at one supported living arrangement, staff that were finishing their shift were observed giving a summary of the days events and what was generally going on that day to the arriving staff. They also discussed various ongoing things and how they had been dealing with them. This seemed to show an effort on the part of those particular staff to develop an ongoing consensus and consistance in their practices. The extent to which this occurred in all the settings was difficult to observe, but occasions of well informed staff at both types of settings was observed. Whether the degree of consensus observed was typical of everyday life in these placements is difficult to say when considering the presence of a researcher.

There was the opportunity to observe one supported living arrangement twice over a period of weeks. Between the first visit to the residence and the second visit, there had occurred a total change of staff. The previous staff had been let go, and this indicated some idea of acceptable behavior and agreed upon ideas of treatment in the higher levels of administration for that service provider agency.

The fifth dimension is decribed as the amount of social distance that exists between the staff and the residents. Differences were observed between and amongst both types of community setting. Many of the placements observed seemed to have very close relationships between the staff and the residents. Mutual joking and pleasent constructive interactions between the staff and residents were observed at both types of settings. However, some settings demonstrated a larger division between staff and residents. There was a degree of dislike between certain individuals in some of the homes observed. This

division seemed more apparent in supported living arrangements perhaps due in part to the closer one on one ratio of caregivers to residents. If problems existed, there seemed to develop a resident versus staff type dynamic. In group homes settings this was not as clearly visible because the staff often times employed the help of other residents in social sanctioning, making the distinction of staff to residents less obvious and defined. However, in supported living arrangements in which there were close relationships between the caregivers and the residents, this distinction was also less defined or apparent.

The sixth area of interest is the amount of organizational sponsored surveillance. This was difficult to observe in the limited time and nature of the observation in this research. However, due to the typical home like structure of these residential settings, true privacy could only be obtained by an individual when in their private rooms. The degree to which the residents could retire to their rooms was not readily observed. At a few of the settings during a personal interview with the individual residents, there seemed a reluctance on the part of the staff in giving the resident privacy in which to interact. This reluctance seemed to occur in settings where there existed personal differences between the staff and residents. The presence of a researcher.may have had an influence as well.

The seventh factor has to do with the size of these placements. Both supported living arrangements and group homes housed far fewer individuals then the typical institution. The difference in size between these two types of settings seemed to effect some of the social dynamics observed. For example, in one supported living placement, the two residents who lived there had developed a dislike for each other. This had resulted in both individuals portraying a high amount of social isolation and alienation, in that they had no

one but each of their personal staff members with which to interact while in their home environment. There was also present a general environment of unease and tension. This was a single placement and not necessarily like the social dynamics of those other supported living arrangements observed. However, it does indicate a unique dynamic that can form in a placement of such size.

A similar dynamic was observed in one of the group home settings. However, due to the difference in size the social dynamics were also different. One individual out of the six living at this home was very isolated, and tended to stay in his room. The difference observed was that at the supported living arrangement the two residents disliked each other, and thus tended to avoid oneanother. In the group home arrangement, however, this one individual was singled out and seemed to undergo a large amount of social pressure from the other five residents. This is a classic example of the difference described by Simmel (1950 ) that can occur between a social dyad and groups that number three or more.

The differences in size between these two settings seemed to also have effects on the degree of social integration outside the facilities. For example, it was quite obvious that the larger number of individuals living in group homes created a greater challenge in scheduling both individual and group outside activities. However, this difference seemed to work both ways in some instances. For example, at one group home it was observed that the larger number of individuals allowed for a greater degree of social independence and integration. It was observed that the residents of this particular group home could go places together without being accompanied by staff members, because some of the

residents were higher functioning. These higher functioning individuals were given the responsibility of making sure they all returned by time for dinner. In that they could tell time and knew their way around the community, they could keep track of the others and make sure that they were back at the group home at specific times. This dynamic seems to be related to both a lesser distinction between staff and residents, and the formation of heirarchial structure within the residents. This dynamic was not observed in the supported living arrangement.

The eighth factor is concerned with the characteristics of individuals residing in a setting. Between the two types of setting in general there was little substantial differences amongst the residents. Both types of setting had individuals within a large range of levels of functioning. However, there was a higher degree of diversity amongst those in group homes. The residents of supported living arrangements tended to be much more similar to one another within each supported living arrangement. Supported living arrangements observed tended to house two individuals with similar specific needs. Group homes tended to have a wider diversity ranging from individuals who could do many things for themselves, to individuals who needed a much greater degree of care and help from their staff. In many ways the charasteristics of the individuals residing at a setting had effects on many of the other factors mentioned.

The ninth factor considered is the degree of external influence the surrounding society may have upon the community setting. By their very locations it was clear that the external influence would tend to be greater for both settings than is typical of a large institution. For example, many of the residences observed were located in a typical

neighborhood and the windows of the homes gave clear view of the surroundings. Some were located near convenience stores and schools. Some of the individuals claimed to have close friends in the neighborhood whom they would visit.

Much of the influence of the greater society could be observed coming from viewing television. There appeared to be little difference between the two types of settings, and the degree and nature of the outer societies influence was difficult to observe.

Both types of settings seemed quite different in appearance than the typical image of the total institution. Yet, in some ways due to the nature of their bureaucratic structure on administrative and staffing levels, as well as their inherent purpose and goals, there existed dynamics similar in structure rather then degree, to some of the dynamics associated with the total institution. In many of the settings observed there seemed some degree of normalization and a concerted effort at integration. Most of the differences observed were related to the differences in sizes and the different makeups of the individuals residing there.

# CHAPTER V

## SUMMARY AND CONCLUSIONS

Findings in this study support previous research that indicates increased adaptive behaviors for individuals who are deinstitutionalized and move into community settings. Those who moved into group homes showed a significant increase in adaptive behaviors compared to those who moved into supported living arrangements.

Of the other two measures of independence, control of severity of challenging behaviors, and control of frequency of challenging behaviors, no significant differences were found.

Findings in the areas of productivity and consumer satisfaction are difficult to assess in any useful way due to the limitations of the data used for this study. After removing those pairs with insufficient data, those left for analysis were too few for any meaningful analysis or discussion.

In the area of integration which is measured by the number of weekly activities, those in supported living had a significantly greater increase than those in group homes. This means that those individuals residing in supported living went out into the greater community significantly more times weekly.

In assessing the overall "quality of life" for the individuals in supported living compared to the individuals in group homes, the findings of this study suggest that there are differences between them. It is indicated that in the area of independence,

specifically adaptive behaviors, the individuals in group homes showed the largest overall increase. Likewise, in the area of integration, the individuals in supported living show an overall increase in opportunities for social interaction in the community. Observations of supported living arrangements and group homes indicated that on the surface these residential settings are very similar. However, there were some apparent differences. The increase in adaptive behaviors for those in group homes could range from the increased dynamics of the group home due to the different consumer to staff ratios. The general increase in number of consumers to number of staff, could decrease the amount of individual attention and force some consumers to do things for themselves that could done by the staff. Another effect the differences in staff to consumer ratios may have is that in supported living where the ratio is closer to one on one, there could form a clearer division between the staff and consumers, resulting in some of the same dynamics described by Goffman in his definition of the "Total Institution"(1961). Though these settings in many ways are vastly different than the typical institution, certain aspects may help to create an isolated and oppressive environment similar in some ways to that of an institution.

These placement types serve as our society's current answer to the problems of the institution. This goal of moving away from the institutional type settings, coupled with moral and ideological implications of the normalization principle has influenced the development of these types of community placements. Observations of these two types of placement seemed to reflect the attempt to transition not only physically but ideologically as well, from the institutional setting to settings of a higher degree of

integration into the wider society. However, there were some degree of the institutional type framework residing still within these placements.

When considering the findings in the area of integration, the increased number of potential social interactions for those individuals in supported living could indicate a number of differences. A potential influence as described from observation is in how the dynamics of increased size can limit the scheduling capabilities in group homes.

The factor of a large age difference between the two groups compared in this research should also be considered. This difference in the number of weekly activities may have less to due with whether the residential setting was supported living or a group home, and more to due with the differences in age. Those individuals selected for the group home sample were generally much older than those selected from supported living arrangements. The difference here may be that those individuals who are older simply do not wish to go out as often. Those in group homes who are considerably older may not get out into the community as much by the mere nature of their age.

Another issue that might be helpful in understanding these results is the fact that all of the individuals in this sample who reside in supported living arrangements are Hissom class members who by the very nature of the court ruling, may have economic and service opportunities that are unavailable to others who never resided in Hissom Memorial Center.

Further research is needed to assess various explanations for these differences between setting types, as well as possible ways of improving either one of these setting types in the areas of integration or independence.

Areas that may be of potential help in explaining this finding could range from differences accounted for in the dynamics of scheduling, to different economic realities faced by the providers of these two different groups, due to differences in funding. Further research could look at the differing types and levels of care in regards to these different settings. Another area of interest may be the differing number of consumers to staff ratios, and their effects on individual consumer's abilities and/or opportunities to have things done for them by the staff.

More qualitative research into differences between the types of care practices at the two different settings could be beneficial. Other areas of importance revolve around a better understanding of the ties that exist between ideology and practise, as well as ways in which these settings could be better freed from dynamics similar to those associated with the institutional model.

Though the generalizablility of these findings is limited, they could still indicate a general trend in the differences between group homes and supported living. Further research is encouraged and would benefit understanding the dynamics of this area of interest.

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VITA

Mark D. Green

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Master of Science

Thesis: DIFFERENCES IN QUALITY OF LIFE BETWEEN SUPPORTED LIVING AND GROUP HOMES: A LONGITUDINAL COMPARISION

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**OKLAHOMA STATE UNIVERSITY**
**INSTITUTIONAL REVIEW BOARD**
**HUMAN SUBJECTS REVIEW**

**Date:** 07-26-95 **IRB#:** AS-96-005

**Proposal Title:** DIFFERENCES IN QUALITY OF LIFE BETWEEN SUPPORTED LIVING AND GROUP HOMES: A LONGITUDINAL COMPARISON OF A MATCHED SAMPLE

**Principal Investigator(s):** Robert L. Maril, Mark D. Green

**Reviewed and Processed as:** Exempt

**Approval Status Recommended by Reviewer(s):** Approved

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ANY MODIFICATIONS TO APPROVED PROJECT MUST ALSO BE SUBMITTED FOR APPROVAL.

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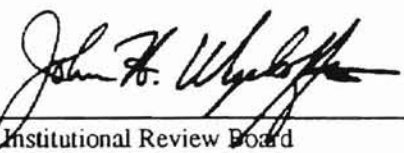
Signature:  Date: July 31, 1995

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