DEINSTITUTIONALIZATION AND ACCOMPANYING CHANGES AMONG PEOPLE WITH DEVELOPMENTAL DISABILITIES

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Chapter I

INTRODUCTION

"The primary motive of community homes is to help people with developmental disabilities to achieve a daily life experience that approximates that of members of mainstream culture. The underlying goals are improved quality of life resulting from integration and independence" (MacEahcen, & Munby, 1996, p.71). As well, Landesman-Dwyer (1981) suggested that people with developmental disabilities show differences in behaviors when moving amongst living environments. The purpose of this thesis was to examine changes in people with developmental disabilities after deinstitutionalization The philosophy of normalization as well as perspectives of socialization were used to interpret the data. In order to bridge the gap between theory and method, available caregivers assisted in the interpretation of the calculated data. Some of these caregivers were currently employed in community settings, but had experience in institutional settings.

The data were gathered through personal interviews with people with developmental disabilities receiving services from the Oklahoma Department of Human Services Developmental Disabilities Services Division. The caregivers of the consumers of Department of Human Services Developmental Disabilities Services Division were interviewed by the Developmental Disabilities Quality Assurance Project at Oklahoma State University. The first cohort (referred to as

Group 1) were living in an institutional setting in 1991, moved into a community setting by 1993. The measures of normalization consisting of adaptive skills, challenging behavior, consumer satisfaction, productivity, and integration, were followed over the subsequent two years. This process was replicated with a second cohort beginning in 1993 then followed through 1995 to 1997 and compared to the first group in regard to the measures of normalization. The cohorts were analyzed for differences in the measures of normalization between three different categories. The groups were analyzed in order to determine if there were differences in the measures of normalization between an institutional setting and a community setting. The groups were then analyzed to see if there were differences between different community living environments, specifically supported and non-supported. The final analysis was to determine if there were differences in measures of normalization in community settings over time.

There were significant differences in the measures of normalization for persons moving out of an institutional setting to a community setting, however these differences were not uniform across the two different cohorts. There were very few differences between the two different community living environments. There were also significant differences between those that had resided in a community setting for an extended period of time. Again, however, these were not consistent between the two different cohorts. There were also significant differences in the measures of normalization for the length of time that a person with developmental disabilities had resided in a community setting. Yet again, these differences were not consistent between the different cohorts.

The results of the data were presented to available caregivers to assist in the analysis. Their insight into the meanings of the measures of normalization and the inconsistencies of the data proved to be invaluable for the inclusion of the theoretical perspective and this study.

CHAPTER II

THEORETICAL PERSPECTIVE AND LITERATURE REVIEW

Theoretical Perspective

This section deals with the explanation of the two main concepts that are used throughout this study. The ideas of normalization and socialization are essential in regards to persons with developmental disabilities. These basic premises parallel the deinstituationalization movement and its ideals. These two concepts also work in conjunction with the five scaled scores that are measured in the study. Normalization and socialization are seen as undercurrents, pro or con, throughout the history of persons with developmental disabilities and their struggle for basic civil liberties.

Normalization

The concept of normalization was first developed in Sweden by Bengt Nirje in 1969. Then Wolf Wolfensberger, a Syracuse University professor, later refined this position. The normalization principle is based on the realization of the humanity and potential of people with even the most severe of disabilities (Bercovici, 1983). This philosophy entertains the idea that people with disabilities have the right to live and develop under conditions that are as culturally normal as possible as well as being afforded the same rights as other citizens (Bercovici, 1983). The normalization philosophy became a catalyst for the movement of

people with developmental disabilities from institutional settings to community placements.

Wolfensberger, as cited in Rumelhart (1983), proposed that persons with developmental disabilities can "live normally" only if they are taught to "maintain behaviors and appearances that come as close to being normative as circumstances and that person's behavioral potential permit" (Rumelhart 1983, p 149). In other words, the chances for a person with developmental disabilities to live a normal life "vary directly with the extent to which he or she is perceived as normal by other people" (Rumelhart 1983, p. 152). This perception of normalcy is often predicated upon appearances and behavior during social interaction. Therefore, complex processes of social interaction based on endless assumptions and interpretations of the situation can make interacting with others very complicated for people with developmental disabilities who are being integrated into the community.

In basic social interaction there are unlimited assumptions made in regard to social knowledge, acquired through primary and secondary socialization, that is necessary for mutual understanding (Berger & Luckmann, 1966; Rumelhart, 1983). The notion of socialization will be discussed in more detail in the following section. It has been suggested that people who have been institutionalized have had some sort of atypical socialization which contributed to a different social knowledge base than those outside of that environment (Rumelhart, 1983). As well, positive social interactions for individuals with developmental disabilities, in many cases, rarely happened especially for those who were institutionalized

(Tjosvold & Tjosvold, 1983). Subsequently, when interaction occurs between individuals who have been socialized differently, there is the potential for a breakdown in mutual understanding and eventually the interaction. In other words, there is a potential for "interactional breakdown" between someone who was socialized in an institutional setting and someone who was socialized outside of an institutional setting. This in part would be due to the dissimilarities in the respective social knowledge base and assumptions, which were more than likely derived at differently in some way, on behalf of the actors involved. An example of this could be certain behaviors such as screaming, self-injury, or talking incessantly about "inappropriate" subjects that may have been ignored in an institutional setting are not most often tolerated in a community placement. Therefore under normalization there is an attempt for re-socialization in order to promote behaviors that make community integration more successful (Rumelhart, 1983).

Socialization

Measures of normalization, which will be discussed in more depth in the following section, have been created in order to examine integration of people with developmental disabilities into community settings. All of the measures examined in this study involve, in some fashion, social interaction and enacting different roles on the part of people with developmental disabilities.

People are not merely passive beings but rather active participants in social life. In society we are dependent upon agreement of meaning in many aspects of social life. Agreement of meaning can involve change in the initial meaning by an individual during the interaction. As an example, consensus of meaning must be attained between two people involved in a conversation in order for the conversation to be successful. This consensus is derived from mutual agreement of symbols and norms acquired through socialization (Clausen, 1968) "Socialization focuses on the development of the individual as a social being and participant in society" (Clausen, 1968, p. 3). Socialization is a process of interaction with persons that are influential to an individual. Throughout an individual's life, the influences of others upon the individual will be subject to many changes and phases by factors such as marriage and maturity.

There are many different perspectives of socialization across the social sciences. Anthropology, Psychology, and Sociology each have their own perspectives on socialization, and in some cases alternative terms to refer to socialization. Anthropology addresses socialization or enculturation as the processes within a given cultural context. They focus on agents of enculturation which transmit the culture explicitly or implicitly (Clausen, 1968). Psychology explicates socialization in regard to theories of learning. It tends to focus specifically on the relationship between teacher and learner particularly at a young age (Clausen, 1968). Sociology has four characteristics in regard to socialization:

1.) *Concern with modes of social control (and more recently with the sociology of deviant behavior)*

2.) *The significance of social interaction in the attainment of human nature, with particular emphasis on the development of the social self and the self-other patterns.*
3.) *The influence of social structure and value orientations on child-rearing practices and emphases*
4.) *The significance of social roles, role recruitment, and role training for the understanding of behavior.*

(Clausen, 1968, p. 48)

For this study, the sociological perspective on socialization is employed to examine the measurements of normalization of people with developmental disabilities.

One of the earliest and most influential individuals in Sociology was George Herbert Mead (Reynolds, 1993). Among his many contributions was to symbolic interactionism, the most important was his notion that society was comprised of people with selves (Reynolds, 1993). Mead devised one of the first theories of socialization in his model concerning the development of the "social self". The first of this development involves the *preparatory stage* which occurs at a very young age. This is fairly meaningless imitation with no real understanding of the action on the part of the actor. The second part of the development is the *play stage*. Also occurring at a young age, the actor begins to take on roles, usually only one role at a time (Mead, 1934). In other words, the actor plays the role of single others and directs attention towards himself/herself. Those who are significant others to the young actor are important models for patterns of behavior or conduct in which the child emulates. The third portion of the development of the social self is the *game stage*. This process involves the taking on of several roles simultaneously (Mead, 1934). The actor becomes capable of responding to the expectations of others at one time. The child begins

to understand the *generalized other* which is a group perspective, generalized role, or standpoint from which the actor views the self and thus allows coordination of his/her behavior or actions according to expectations of society (others) (Mead, 1934). The social self is not completely shaped, however, by the internalized expectations of others. "All meaningful human behavior consists of selves addressing action toward objects, including the self as that which can be an object to itself" (Reynolds 1993, p. 127). One can not precisely predict how someone will respond to every situation. The view that an individual becomes an object to himself or herself by adopting the attitudes of others towards himself or herself in the social environment in which both are involved lays the foundation for one's self-concept. In other words, a person's self concept is largely based upon how it is treated by significant others (Johoda, Markova, & Cattermole, 1988) Mead developed a model of what he considered to be the three elements of the social self which he defines as the "I", "me" and mind

The "I" represents the impulsive tendency of the individual (Mead, 1934). The "I" is regarded as spontaneous, undirected, creative or in other words, a "free self". It has also been suggested that the "I" is a combination of both natural needs (e.g. biological nature) and impulses (Mead, 1934). The "me" portion of the social self is considered to be the conventional part of the self The internalized social order which can involve attitudes and definitions of the self gives direction for action. The last part of the social self is the mind. Mead suggests that it is through communication by way of significant symbols that mind results (Mead, 1934). In other words, the mind is socially derived. However, it

also needs to be noted that Mead saw the mind as process. As presented in Reynolds (1993), Mead suggests:

> *[First]...there is an actual process of living together on the part of all members of the community which takes place by means of gestures. The gestures are certain stages in the cooperative activities which mediate the whole process...Given such social process, there is a possibility of human intelligence when this social process, in terms of the conversation of gestures, is taken over into the conduct of the individual...The mind is simply the interplay of such gestures in the form of significant symbols...It is such significant symbols, in the sense of a sub-set of social stimuli initiating a cooperative response, that do in a certain sense constitute our mind, provided that not only the symbol but also the responses are in our natures.*
>
> *(p. 126)*

Another influential individual on socialization is Herbert Blumer. Blumer, who was a student of Mead, actually coined the term *symbolic interactionism* and has remained true to the "Meadian" view of interaction (Reynolds, 1993). Blumer's interpretation of the social world relies heavily on his premises of meaning. According to Blumer, human beings act toward things on the basis of meanings that the things have for them. In other words, actions are given meanings (different sometimes depending upon the situation) and decisions are made from judgments made about those actions. As well, Blumer suggests that the meaning of things arises out of this social interaction with fellow human beings. This presumes that meaning is a social product coming out of interaction with others. Finally, meanings of things are handled in and modified through an interpretive process used by the person when dealing with things he/she encounters, according to Blumer. This process is more or less "talking to one's self" and the individual creates the interpretation as the interaction continues. It should also be noted that interpretive processes are always occurring. A simple notion one must recognize about social interaction is that interaction is between

actors and not between factors attributed to them (Blumer,1969). According to Blumer, "this importance lies in the fact that social interaction is a process that *forms* human conduct instead of being merely a means or a setting for the expression or release of human conduct" (Blumer 1969, p. 10).

To delineate further on Blumer's notion of meaning, it is important to discuss 'objects' which comprise the world of reality for individuals and their groups. Objects are anything to which an individual or group indicates, observes, or refers (Blumer, 1969). According to Blumer (1969), there are three types of objects that exist in the social world of interaction. Categories for these objects are: physical objects, such as chairs, cars and doors; social objects, such as mothers, friends, and teachers; and abstract objects, such as morality, civil rights and religious doctrine (Blumer, 1969). Any and all objects consist of meanings for whom it is an object in their reality. The meaning of an object influences the way an individual will observe the object, talk about the object, and act toward the object (Blumer, 1969). For example, a grasshopper will be a different object to an entomologist than to a farmer. Meanings of objects for an individual are basically developed out of the manner in which the object is defined to the individual by others in their group. In other words, the means by which the meanings of objects within an individual's world are established are through the processes of socialization.

According to Berger and Luckmann (1967), primary socialization begins when an individual is born into an objective social structure within which he or she encounters the significant others who are in charge of his or her socialization.

Interestingly, those who are socializing the child modify the reality as they are imparting it upon the child. In this way primary socialization agents filter the world for the child. As should be apparent, primary socialization is the first socialization that an individual goes through in childhood as he or she becomes a member of society.

"Secondary socialization is any subsequent process that inducts an already socialized individual into new sectors of the objective world of his or her society" (Berger & Luckmann 1967, p. 130). The purpose of secondary socialization is to pass along role-specific knowledge. Berger and Luckmann (1967) note that primary socialization is characterized by emotionally charged relationship between child and significant others. While on the contrary, "most forms of secondary socialization dispense with this kind of relationship and precede effectively with only the amount of mutual identification that encounters into any communication between human beings" (Berger & Luckmann 1967, p. 141)

History

Institutionalization

Over a century ago in America, facilities were created for the care of people with mental retardation. The animating principle of the time generated an outpouring of compassion to help all people in need which in turn brought about professions in education, medicine, nursing and social services (Zigler & Hodapp,

1986). The notion of "physiological education" developed by Frenchman Edouard Seguin in the 19th century entertained the idea that the functioning of people with mental retardation could be increased through stimulation of the senses and muscles. As presented in Zigler & Hodapp (1986), Kraft presented another idea of Seguin referred as "moral education" which suggested " the effort to reestablish the equilibrium of the desires or drives of the disturbed individual, to change the conditions of the environment, and in a careful manner to replace the sick personality of the patient with the total consciousness of the therapist by a strong act of will". The facilities established in America employing Seguin's "moral education" essentially became "training schools" believing that teaching people with mental retardation would "reawaken" them into a normal human existence (Zigler & Hodapp, 1986). However, some people did not accept the idea of teaching individuals with mental retardation. Administrators of these teaching facilities felt pressured to give results to legislatures. This spawned a practice of only admitting people with mental retardation who were already high functioning individuals that gave the facility a facade of success and ultimately impressed legislators (Zigler & Hodapp, 1986). Over time, the enthusiasm of actually teaching people with mental retardation faded and the facilities that were created as schools for people with developmental disabilities shifted emphasis to long-term custodial care (Zigler & Hodapp, 1986).

In the late 19th and early 20th centuries, changes in attitudes towards people with mental retardation began to occur. Works such as the studies of genius throughout generations by Francis Galton and the studies of multi-

> *"The feebleminded are a parasitic, predatory class, never capable of self-support or of managing their own affairs. The great majority ultimately become public charges in some form....Feebleminded women are almost invariably immoral and if at large become carriers of venereal disease or give birth to children who are as defective as themselves....Every feebleminded person, especially the high-grade imbecile, is a potential criminal, needing only the proper environment and opportunity for the development and expression of his criminal tendencies."*
>
> *(P. 274)*

Consequently, adherence to views such as Fernald's and/or similar views had an effect on the care and treatment for people with mental retardation. One such practice stemming from such beliefs was sterilization.

Some sources claim that the sterilization of people with developmental disabilities started around the late 1800s while other sources suggest that it began in the early 20th century. Nevertheless, this practice brought about much debate between proponents of its use and those who felt there were ethical issues that were not being addressed. As cited in Tyor and Bell (1984), fifteen states had created some form of eugenic sterilization law by 1917: Indiana (1907); California, Connecticut, and Washington (1909); Iowa, Nevada, and New Jersey (1911): New York (1912); Kansas, Michigan, North Dakota, Oregon, and Wisconsin (1913); Nebraska (1915); and South Dakota (1917). Although these laws varied greatly from state to state on content and purpose, all were predicated on the verification of "feeblemindedness (or insane, epileptic, or criminal) by a board of examiners" (Tyor & Bell, 1984). As debates continued over ethical issues regarding sterilization, so did debates concerning the constitutionality of the laws enacted in the various states. However, even though some of the laws were deemed "unconstitutional as class legislation and/or a denial of due process", 3,233 sterilizations were performed across all classes in 1921 (Tyor & Bell, 1984).

Views and beliefs about developmental disabilities began to change by the mid-1920s due to new discoveries that debunked the theory that developmental disabilities were hereditary (Zigler & Hodapp, 1986). According to Tyor and Bell (1984), medical discoveries during the 1920s and 1930s suggested that mental retardation was caused by brain damage and/ or the individual having some "unusual pathology", not by genetics. This shift in medical ideology of developmental disabilities also perpetuated a change in social beliefs. Developmental disabilities were no longer associated with societal problems. As well, enthusiasm about the potential of treatment and care of people with developmental disabilities came from those who worked so closely with them. This period in history marked the beginning of community care for people with developmental disabilities, although the majority of people with developmental disabilities living under residential care were in large state institutions (Zigler & Hodapp, 1986).

Erving Goffman (1961) offered his characterization of what he termed the "total institution" in his book Asylums. First of all, Goffman (1961) suggests that unlike in a typical social arrangement, certain social "spheres" are clustered together under a single authority and some sort of rational plan fulfilling a goal of the institution. In other words, everything that was done in a single day was done so generally in the same place and the same time everyday with little to no variation. As well, almost all activities were done with large groups of people (Goffman, 1961). It has been suggested by proponents against institutions that large residences "dehumanize by voiding relationships of feelings, excitement,

and compassion" (Tjosvold & Tjosvold, 1983). Although this is a different slant on Goffman, it is still in accordance with his observations. Needs of these large groups of people were managed in a very bureaucratic organization of what Goffman referred to as "blocks" watched over by a staff member whose primary job was "surveillance" (Goffman, 1961). There is a distinct stratification between those that are residents or "inmates" and the staff of the institution. A basic difference between residents and staff is that residents have very restricted contact with the outside world, whereas the staff were generally well integrated into society (Goffman, 1961). Social interaction between residents and staff was, as a rule, kept to a minimum. Usually basic needs were met and that was also maintained at or below standard. Interestingly, Goffman mentioned that each group devises "narrow stereotypes" of each other. For example, residents are seen as feeble minded or childish by the staff, and staff members are seen as mean or overbearing by the residents (Goffman, 1961). This in part can be attributed to the kind of social interaction that occurs between residents and staff members. Of Goffman's delineation of several "total institution" typifications, the characterizations offered particularly apply to the types of institutional settings housing people with developmental disabilities. These types of living conditions and treatment of residents with developmental disabilities sparked the advocation for codified rights and reform.

Reformation

Political changes in regard to people with developmental disabilities began in the 1950s and 1960s. Originally formed as the Association of Retarded Children in 1950, the "Association for Retarded Citizens" was influential in forefronting the motion for institutional reform, eventually leading to deinstitutionalization, and the formation of community living alternatives (Developmental Disabilities Services training manual, Oklahoma State University, 1997). As long-time supporters of research and treatment of developmental disabilities, the Kennedy family brought about national attention to mental retardation (Tyor & Bell, 1984).

In the 1960's, the election of John F. Kennedy as president brought about involvement of the federal government in programs concerning people with developmental disabilities (Tyor & Bell, 1984). According to Tyor and Bell (1984), President Kennedy had a "special interest" in people with developmental disabilities because his sister, Rosemary, had mental retardation. Soon after his election, Kennedy created a task force to obtain information about needs in regard to developmental disabilities. In 1963, Kennedy suggested in his address to Congress that the care for not only people with developmental disabilities but also mental illness demanded a new approach specifically in the areas of programs and facilities that would be community based (Tyor & Bell, 1984). The Kennedy Administration was successful in passing the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 which

allocated money for training of teachers and building research centers as well as clinical facilities for people with developmental disabilities (Tyor & Bell, 1984). However, reformation of the lives of persons with developmental disabilities went far beyond merely adjusting living conditions.

A philosophy of "normalization" regarding the personal and social lives of people with developmental disabilities was adopted. The idea of normalization was first developed in Sweden by Bengt Nirje in 1969. Wolf Wolfensberger, a Syracuse University professor, later refined this position. He observed the living conditions and treatment of persons with disabilities in North American institutions and concluded that "deviant groups", labeled so by society, are negatively valued (Braddock, 1977). The "principle of normalization", according to Wolfensberger as presented by Tjosvold & Tjosvold (1983), entertained that people with mental retardation deserve to share the "cultural patterns and have advantages offered to others". Under normalization, it has been suggested that there are ways to apply practically the abstract concept of values that encompasses all of us to the world in which we exist (Braddock, 1977). The term *practical* infers that the actual application of those abstract concepts of values can be taught to someone. Wolfensberger, as presented by Rumelhart (1983), proposed that people with developmental disabilities can "live normally" only if they are taught to uphold behaviors and appearances that come as close to being normative as circumstances and behavioral potential allows. First, the seemingly negative value system that has shadowed persons with developmental disabilities had to be reconstructed. Most often, certain attempts are made to be politically correct

when referring to either a minority or gender types. The same principle holds true for people with developmental or physical disabilities. The premise of this reconstruction is to think "people first" and the disability later (D.D.S. training manual, Oklahoma State University, 1997). Revamping the value system in terms of more politically correct references applied to not only how others viewed disabilities but also how people *with* disabilities saw themselves. People with disabilities, either developmental or physical, were no longer to consider themselves as "cripples" or "idiots" but rather, by right, as typical members of society.

The principles of normalization acknowledges the power of "environment" over people (Braddock, 1977). Accepting the view that all behavior is purposeful, actions on the part of people are influenced by the milieu in which they exist. The term "environment" includes all of the things that people come into contact with that influence behavior. This includes the physical environment (e.g. involving the senses) and interaction with other human beings such as communication, affection, and love, to name a few. The main premise of normalization promotes the notion that people with disabilities should live as "normally" as possible (Braddock, 1977). The reconstruction eventually turned toward living environments and social interaction.

Civil Rights and Deinstitutionalization

Awareness of the problems and efforts made by those to change these situations became widespread. Eventually, federal lawsuits filed on behalf of persons with developmental disabilities were fundamental in extensive future change. One such lawsuit, filed in 1979, was on behalf of residents of the Pennhurst State School and Hospital in Pennsylvania (Conroy, Lemanowicz & Feinstein, 1987). The outcome of this lawsuit was a federal court order mandating the movement of the residents of Pennhurst to less restrictive living arrangements outside of the facility. This resulted in the transition into the general community. To track the progress and the well-being of those who were deinstitutionalized, Temple University in conjunction with the Human Services Institute of Boston developed an inquiry called the Pennhurst Study (Conroy, Lemanowicz & Feinstein, 1987).

Another important lawsuit was filed in 1987 on behalf of persons with developmental disabilities living in the Hissom Memorial Center in Sand Springs, Oklahoma. This lawsuit essentially made Oklahoma a testing ground for the rights of those with developmental disabilities. In July of 1987, the Northern District Court of Oklahoma ordered the Department of Human Services to "phase out" services to Hissom. The court order also called for the State of Oklahoma to place Hissom residents in appropriate alternative living environments. Like the Penhurst Study, Oklahoma State University and the Oklahoma Department of Human Services conduct independent assessments of outcomes and services

provided to those with developmental disabilities (Homeward Bound v. Hissom Memorial Center, 1987).

These landmark lawsuits sparked an increase in interest regarding civil rights of people with disabilities. It is suggested that persons with disabilities are the fastest growing minority (Gadacz, 1994). Moreover, the Congressional Research Service reports that there are 43 million people with one or more disabilities in the United States (D.D.S. training manual, Oklahoma State University, 1997). Estimations by the US Census Bureau indicate that there will be a ratio of one out of every two Americans having some disabling condition. Fueled by predictions like this as well as increased awareness of the need for formalized rights for persons with disabilities, The Americans with Disabilities Act was signed into law in 1990 (Helmig, 1994). The intended purpose of this Act is to: 1) provide a clear and comprehensive national mandate to end discrimination against individuals with disabilities; 2) provide enforceable standards addressing discrimination against individuals with disabilities; and 3) ensure that the federal government plays a central role in enforcing these standards on behalf of individuals with disabilities. Of course this spurred even further actions for deinstitutionalization. This is not to say that there are no longer any institutions operating. With the American Disabilities Act in place, many institutions have complied and some are trying to implement a similar ideology as community living environments specifically in terms of personal and interpersonal growth of residents.

Deinstitutionalization and the Community

With the deinstitutionalization of people with developmental disabilities, gradual movement into the community took place. There are various types of community settings for people with developmental disabilities to reside. This study places focus on six different placement types in the community. The community placement types include supported living, group homes, independent living, assisted living, adult companion, and adult foster care.

For those who moved from Hissom Memorial Center in Sand Springs, Oklahoma, it was court mandated that they move to supported living environments. Supported living environments are of a residential program that provides state payment for some living expenses in addition to staff support. Supported living allows people to live in their homes, usually with one or two roommates of their choice.

Another type of community placement is the group home. A group home is a residential type that furnishes a home-like setting for six or fewer people in which the residence is owned or leased by the service provider rather than by the residents. In order to become familiar with the areas that will enable them to care for a home and access their community for work and recreation, increased independence among residents is encouraged.

Independent/assisted living environments allows for a person to live in his or her own home and receive support services from others. Depending on the needs of the individual, the amount of support may vary from occasional (several

hours in a week) to extensive (several days a week). The person may choose to live alone or have roommates.

Adult companion involves an individual who shares his/her home with an adult with developmental disabilities and receives compensation. The support services the companion provides is based on recommendations of the team of the resident with developmental disabilities.

The residential setting of foster care is a "superimposition on an existing household" (Heal, Haney,& Amado 1988, p. 99). This arrangement provides the opportunity for a person/s with developmental disabilities to live in a family environment. Those who are foster care providers furnish services to one or more people with developmental disabilities who are not family members and also receive compensation for their services.

The importance of regular social interaction with valued significant others should not be underestimated (Abery & Fahnestock, 1994). Under the rubric of normalization and deinstitutionalization exists multifaceted opportunities for social interaction. The facets most important to this study are the areas of interaction in that behaviors can be labeled as being "challenging", having adaptive skills, being satisfied in a community setting, being productive, and being integrated into the community.

There are many issues involved in deinstitutionalization and the integration into community life. One of these issues focuses on the displaying of behaviors that "escalate into an ineffective interaction between the individual and his or her family members, peers, or service providers" (University Affiliated Program of

Oklahoma, 1993). According to the University Affiliated Program of Oklahoma (UAP), people who exhibit "challenging behaviors" are struggling to communicate a message to others. The other party's ability to understand what is being communicated by the behavior is just part of the problem of trying to develop an appropriate and effective response to the individual. Challenging behaviors, as defined by the UAP, refers to

> *those behaviors by an individual that (1) appear inappropriate to the environmental setting, (2) limit or interfere with the expression of adaptive behaviors, and (3) may be harmful to the individual (self-injurious) or (4) potentially harmful to others (i.e., biting, hitting, etc.). Certain behaviors are considered "inappropriate" because they are perceived (generally by staff) to interfere with the ability to continue or complete tasks until the behavior is diminished or stopped.*

As indicated by Hill & Bruininks (1984), the relative basis by which society determines what behaviors are considered unacceptable makes it difficult to judge its prevalence. In most cases that involved behavior problems, it has been observed that certain behaviors would be considered inapplicable if a person without developmental disabilities had performed the behaviors (e.g., a person without developmental disabilities would not be institutionalized for missing work) (Hill & Bruininks, 1984). However, studies by Eyman & Call (1977) and Hill & Bruininks (1984) have reported a relatively high frequency of challenging behaviors among people with developmental disabilities in residential settings. In spite of the fact, it was suggested that these findings be elaborated upon because many types of challenging behaviors are accepted, ignored, or tolerated in populations of people without developmental disabilities (Hill & Bruininks, 1984).

Perception and interpretation play key roles in the reporting of challenging behaviors. Blumer (1969) suggests that humans act on the grounds of meaning. Meanings, then, are products of collective situations, which is to say that they arise out of interaction with others as the interactive process itself is mediated by language (Blumer, 1969). The lack of mutual understanding in social interaction may contribute to a behavior being labeled as "challenging" in regard to people with developmental disabilities. Caregivers most times are handed the role of "re-socializers" for people who were atypically socialized so as to teach behaviors which would be more appropriate for successful integration into the community. However, according to Rumelhart (1983), caregivers as re-socializers sometimes failed because they did not suspend their normal assumptions and assess the actual perspective of the consumer before responding to them. Even though exposure is an important factor in acquiring social knowledge, it cannot be assumed that a person with mental retardation will derive the same meaning within the context of interaction from the exposure as do most members of our society due to their atypical life experiences and socialization (Rumelhart, 1983).

Skills that increase or enhance a person's ability to live independently are called adaptive behavior skills and are thought to be very important to the success of integration into the community. As stated in the Homeward Bound Inc. v. Hissom Memorial Center case:

> *The normalization principle requires that retarded persons be treated alike and permitted experiences like other persons of the same age in their own community to the greatest possible extent. Their similarity to normal persons is to be emphasized and their deviant aspects de-emphasized and diminished through appropriate habilitative programming. They are to be enabled to live in a culturally normative community setting, in typical housing, to communicate and socialize in age- and culturally-appropriate ways, and to utilize community resources as other citizens do. Normalization requires that habilitation occur in the settings in which acquired skills will*

be utilized and that habilitation be attained by the use of generic services in the community.

Adaptive behavior skills include cognitive skills, self care skills, community living skills and other skills that aid in the integration into the community (Abery and Fahnestock, 1994). Cognitive skills involve having basic knowledge of reading, writing, and mathematical computation. These abilities are used in everyday life experiences such as ordering off of a menu, writing a letter, or managing money. Self care skills are any abilities related to an individual taking responsibility for their own needs. Behaviors such as bathing, dressing, and cooking meals for one's self are regarded as self care skills. Some of the most basic skills fall under societal expectations, which are probably different than the expectations within an institutional setting, of individuals who are living independently or at least attempting to integrate into the community. Community living skills are any skills that allow an individual to live outside of an institutional placement and in the least restrictive environment in the community. Holding a job, eating at a restaurant, or even shopping would be considered as community living skills. Being involved in the community, such as having a job, can give not only self- actualization to the individual, but also the perception of normalcy to others. It is imperative to recognize the importance of the perception of normalcy in that, according to Blumer (1969), participants in interaction judge each other and guide their own acts by that judgment.

The degree of satisfaction on behalf of people with developmental disabilities who live in a community setting is also important to the ideology of

normalization. Consumer satisfaction, which is based on the right to choose and the availability of choices, carries strong meaning in our society and is considered both a privilege and a right afforded to most in society. The extent to which a person can make his or her own decisions has a strong impact on that individual's self-esteem and self-efficacy (Abery & Fahnestock, 1994). Through deinstitutionalization and normalization this, too, is afforded to people with developmental disabilities.

Being a productive member of society is yet another expectation placed on us by others whom we are in contact. From a societal perspective, work has become a measure of both worth and status and unemployed individuals are viewed as less socially acceptable (Oberman, 1965) Given a chance to hold a job not only enables a person with developmental disabilities to earn money but also to interact with others in the community. This can lead to more opportunities for integration within the community. However, opportunities to go out into the community do not always ensure that people with developmental disabilities are treated with respect or with kindness. No matter the potential outcome of interactions within the community, it is still a right for people with developmental disabilities to not only maintain a job. but also to take advantage of social opportunities outside of their homes (Johnson & Lewis, 1994)

Research Questions

1. Does the type of residential environment have an impact on challenging behavior frequencies, adaptive skills, consumer satisfaction, productivity, and integration?

2. Is there a difference of challenging behavior frequencies, adaptive skills, consumer satisfaction, productivity, and integration among people who live in different community residential environments?

3. Does length of time in community living environments have an impact on challenging behavior frequency, adaptive behavior, consumer satisfaction, productivity, and integration?

CHAPTER III

METHODOLOGY

Sample Subjects

The survey population for this research is comprised of all known individuals receiving services from the Oklahoma Department of Human Services/Developmental Disabilities Service Division. These persons were determined by the Department of Human Services/Developmental Disabilities Division to be residing within the state of Oklahoma in the years between 1991 and 1997. The selected sample consisted of all persons with developmental disabilities that were in an institutional setting in 1991, moved into a community setting by 1993 (N=155), then followed over the subsequent two years (this will be referred to as 'group 1'). This process is replicated (referred to as 'replication group') with a selected sample of all persons with developmental disabilities residing in an institutional setting in 1993, deinstitutionalized, then followed through 1995 to 1997 (N=228) and compared to the first group. The purpose for the replication group is that the first group utilized for this thesis yielded a relatively small sample size. Therefore a replication group is used to compare for similar results if patterns are found in the first group. Measures of normalization are compared between groups for each corresponding year.

Data Collection

The instrument used to gather the data is an adaptation of a model from Temple University that typified a similar court-ordered monitoring of the deinstitutionalization of people with developmental disabilities from the Pennhurst State School and Hospital (Conroy and Bradley, 1985). The use of this instrument by the Developmental Disabilities Quality Assurance Project was included in a court order by the State of Oklahoma as a result of the Hissom class action-suit in 1989. Beginning in January of 1990, the project has collected data on the quality of care provided to persons with developmental disabilities residing in institutions and community settings across the state. Interviewers gathered data including demographics, residential history, family and advocate contact, adaptive equipment needs, adaptive development, abilities to control the frequency and severity of challenging behavior, needs for medical services, drug usage, weekly contact information, civil involvement, citizenship activities, service planning, consumer perceptions of their living situation, and interviewer perceptions of the facility's physical quality (Helmig, 1994).

Procedure

Each year, the project conducts a three-day workshop providing training to those who will be conducting interviews in the field. Experienced interviewers as well as directors of the project thoroughly explain the instrument question by

question. The interviewers are not only taught terminology but also skills to address potential situations that could occur in the field. The newly trained interviewers are then paired with an experienced interviewer in the field for first observation then to conduct the interview in the presence of an experienced interviewer (Dodder, Foster, & Bolin, 1999). Sociology graduate research assistants consist approximately half of those employed as interviewers, and the other half employed are professional independent interviewers.

The interviews take roughly 45 minutes to conduct with a caregiver and then an additional 15-20 minutes to interview the consumer.

Variables

The independent variable for this research is type of residential environment and the dependent variable is the measurement of normalization. In group 1 and in the replication group , the primary year which occurred in the institutional setting is used as a baseline for comparison of measures of normalization within each group. The measures of normalization that are examined include challenging behavior frequency, adaptive skills, consumer satisfaction, productivity, and integration.

Challenging behaviors are measured on the basis of frequency and severity. The severity of behaviors was of no interest to this research and are not examined due to its subjective nature. Items involved with the Challenging Behavior Scale include inappropriate behavior directed toward others or the self,

stereotyped behaviors (e.g. rocking the body), inappropriate sexual behavior, and general listlessness. A higher score on this scale indicates greater ability to control the frequency of these behaviors. Scores obtained for the challenging behavior scale were from interviews with the primary caregiver.

Adaptive behaviors are measured on the basis of the attainment of life skills that enable one to be more independent. This could include, but by no means exclusive, skills such as bathing oneself, preparing meals, use of money and sense of direction. The higher the score, the better an individual demonstrates adaptive behaviors. These scores are also obtained through interviews with the primary caregiver.

Consumer satisfaction is based on likes and choices of the person with developmental disabilities. These scores are obtained through interviews with the consumer. This is measured by questions involving how he/she likes/dislikes where they live, likes/dislikes their caregivers, likes/dislikes the food they eat, and so on. This scale also provides an open-ended qualitative question of telling what they would wish for if they could have only one wish.

Productivity is measured by the total hours of employment by the consumer per month. The consumer could be working in a competitive working environment with or without a job-coach, a workshop environment, or vocational environment. Competitive work environments pay at least minimum wage or more, while the other working environments pay much less or not at all.

Integration is measured by the number of opportunities to go out into the community per week. This can include visits with friends, family or neighbors,

trips to the store, religious services, and other social activities. The information gathered by the two previous scales are obtained by the primary caregiver.

After deinstitutionalization of both groups, the community placement types are divided into two categories: supported living environments and non-supported living environments. The supported living environment is a community placement type that has 24 hour staffed care provided to a consumer in his or her own home. The non-supported living environments include placement types such as group homes, independent living, assisted living, adult companion, and adult foster care. All of the placement types are represented on the survey instrument. This distinction is made to examine differences between placement types for the second research question.

Generalizability and Limitations

According to Babbie (1989), generalizability refers to the "quality of a research finding that justifies the inference that it represents something more than the specific observations on which it was based." Basically, generalizability is the degree to which research findings are applicable outside of the research situation. The sample used for this study are all known people with developmental disabilities receiving services in the State of Oklahoma. To the extent that these persons resemble other people with developmental disabilities receiving services in other states is generalizable. Characteristics of this sample are broken down into the categories of sex, race and level of mental retardation. For group 1 there

were 74 males and 51 females. In regards to race, 107 were Caucasian, 11 were African-American, 1 was Hispanic, 5 were Native-American, and 1 was in the 'other' category. In the category of level of mental retardation, 1 had none, 11 were mild, 17 were moderate, 30 were severe, 60 were profound, and 6 were unknown (See Table 1).

As for the characteristics of the replication group, 131 were male and 97 were female. In the category of race, 177 were Caucasian, 32 were African-American, 1 was Hispanic, and 18 were Native-American. In regards to level of mental retardation, 6 had none, 14 were mild, 29 were moderate, 34 were severe, 132 were profound, and 13 were unknown (See Table 1).

There are limitations to this research. The sample is taken from a basic census of all people with developmental disabilities receiving services from The State of Oklahoma. Although the attempt is made, it is not always possible to reach everyone receiving services for various reasons. There are some refusals on the part of both consumer and caregiver, even though caregivers are court ordered to comply. Lists from which those receiving services are taken are not updated, still having people who have died or moved. Another problem is that a consumer may not have the cognitive capabilities to respond to the questions asked.

It should be recognized that some of the data collected that was utilized was court ordered from the Homeward Bound v.Hissom Memorial Center lawsuit in 1987. This may lead to certain biases on behalf of respondents, especially caregivers. As well, another potential problem to be noted is that of

acquiescence which is the tendency of either consumer or caregiver to answer in a positive manner to all of the items of the survey for a variety of reasons (Voelker, 1990).

Reliability

Reliability concerns the extent to which an experiment, test, or any measuring procedure yields the same results on repeated trials (Carmines & Zeller, 1979). The degree of interrater reliability, which is the consistency of various raters recording the same data from the same subjects, was analyzed by Dodder, Foster, & Bolin (1999). The findings showed high interrater reliability for demographics, adaptive development, challenging behavior (both severity and frequency), and consumer satisfaction variables. Test-retest reliability is the extent of consistency of responses to the same questions asked more than once. Dodder, Foster, & Bolin (1999) found high test-retest reliability for consumers in regards to the food quality variable, a question asked twice in the survey.

Validity

Validity is a descriptive term used of a measure that accurately reflects the concept that it is intended to be measured (Babbie, 1989). Construct validity is the degree to which measures agree with other measures of the same concept (Carmines & Zeller, 1979) The instrument employed by the Developmental

Disabilities Quality Assurance Project was first created by experts for the Pennhurst Study in 1985. In regard to content validity, the instrument has undergone numerous modifications, made by experts, to fit the Oklahoma population of people with developmental disabilities.

CHAPTER IV

RESULTS AND FINDINGS

The purpose of this study was to examine changes among people with developmental disabilities after changing living environments. The results and findings were calculated by the use of t-tests as the statistical measure to make conclusions about the research questions outlined earlier in the thesis. The t-tests were used to compare different living environments, different community placement types as well as differences in length of time in a community placement type in regard to measurements of normalization. All of the conclusions were done at the .05 level. The dependent variables are the scales representing the measurement of normalization. The independent variables will change according to the research question. After the calculations for each group were performed, available caregivers were asked for their assistance in interpreting the outcome of the data. Their remarks will be discussed further in the next section.

Research Question 1

Does the type of residential environment have an impact on challenging behavior frequencies, adaptive skills, consumer satisfaction, productivity, and integration? This question was calculated using the measures of normalization

by the movement of individuals in an institutional setting to the community. In group 1, the sample was in an institutional setting in 1991 and then deinstitutionalized by 1993 (See Table 2). In the replication group, the sample was in an institution in 1993 and in the community by 1995 (See Table 3).

For the challenging behavior frequency scale, the higher the mean indicates better ability on behalf of the person with developmental disabilities to control challenging behavior. In 1991, the mean was 86.35 for challenging behaviors in the institutional settings. In 1993, the mean was 90.70 for challenging behaviors in the community settings. The calculated t was 3.53 which was considered to be significant at the .05 level with a probability of < .0005. This implies that after leaving the institution, individuals had a greater ability to control challenging behaviors. The replication group, however, offered the opposite trend with a mean of 92.88 in 1993 and 88.19 in 1995. The calculated t was 4.81 with a probability of < .0005.

Adaptive behaviors for group 1 had a significant increase with the means of 43.71 in 1991 and 46.99 in 1993. The calculated t was 3 92 with a probability of <.0005. This signifies that those in the community setting demonstrated greater adaptive behaviors. The replication group showed a similar trend with the means of 35.75 in 1993 and 41.97 in 1995. The calculated t was 8.28 with a probability of < .0001.

In regard to consumer satisfaction, there was a significant increase from 1991 to 1993 with means of 86.04 and 92.32. the calculated t was 2.24 with a probability of < .016. The replication group similarly displayed an increase with

means of 74.19 in 1993 and 88.07 in 1995. The calculated t was 5.42 with a probability of < .0001. This insinuates that after moving to the community, consumers showed higher consumer satisfaction.

Productivity demonstrated a significant decrease after deinstitutionalization with means of 117.43 in 1991 and 105.76 in 1993. The calculated t was 1.82 with a probability of < .035. The replication group echoed this trend between 1993 and 1995 with means of 112.60 and 95.75. the calculated t was 3.61 with a probability of < .0001. This would lead one to believe that employment opportunities were not as prevalent at the initial years of community living for people with developmental disabilities.

There was no measurement of integration on the instrument in 1991, therefore this cannot be compared to 1993. However, the replication group suggested a substantial increase in opportunities for integration after deinstitutionalization with means of 1.75 in 1993 and 7.21 in 1995. The calculated t was 21.47 with a probability of < .0001.

Research Question 2

Is there a difference of challenging behavior frequencies, adaptive skills, consumer satisfaction, productivity, and integration among people who live in different community residential environments? For this question, the community placements were divided into two categories: supported living environments and non-supported living environments. T-tests were conducted with both categories

for group1 within the years 1993 and 1995 (see Table 4 and Table 5). Since there is basically a 'replication' being done within each year, there was no comparison to the actual replication group of 1995 and 1997. All calculations were conducted at the .05 level.

Challenging behavior frequencies between supported and non-supported living environments showed a significant difference in 1993 with the supported living environment mean of 90.16 and non-supported environment mean of 94 40. The calculated t was 3.21 with a probability of < .005. In 1995, the comparison of the two categories is not similar. The supported living environment had a mean of 88.32 while the non-supported living environment had a mean of 88.28. The calculated t was .015 which is statistically considered insignificant.

Adaptive behavior displayed a significant difference between supported and non-supported living environments. In 1993, supported living had a mean of 46.24 and non-supported living had a mean of 60.58 with a t calculation of 6.22 and a probability of < .0005. Similarly, in 1995, supported living had a mean of 42.29 and the non-supported living environment group had a mean of 36.79 with a t calculation of 2.16 and a probability of < .025.

In regard to consumer satisfaction, there was a significant difference between the supported living mean of 89.54, and the non-supported living environments in 1993 had a mean of 92.86 with a t calculation of 2.49 and a probability of < .01. In 1995, there was a insignificant difference with supported living having a mean of 88.64 and non-supported having a mean of 88.18.

There was a significant difference in productivity between supported and no-supported living environments in 1993. Supported living yielded a mean of 104.95 and non-supported living had a mean of 119.50. The t calculation was 7.12 and had a probability of < .0005. As well, there was a significant difference between supported and non-supported living in 1995. Supported living gave a mean of 115.33 and non-supported gave a mean of 90.68 with a t calculation of 7.15 and a probability of < .0005.

Integration into the community were very similar for both years. There were significant differences between supported and non-supported living. Supported living had a mean of 6.13 in 1993 and a mean of 8.52 in 1995. Non-supported living had a mean of 8.37 in 1993 and 7.11 in 1995. 1993 had a t calculation of 2.06 and a probability of < .025, and 1995 had a 4.39 t calculation and a probability of <.0005. The supported living had an increase in integration between the two years, whereas the non-supported living environments experienced a decrease in integration.

Research Question 3

Does length of time in community living environments have an impact on challenging behavior frequency, adaptive skills, consumer satisfaction, productivity, and integration? This question is addressed by examining the category of supported living environments between the years of 1993 and 1995 (group 1) using t-tests (See Table 6). The purpose for only exploring trends

within supported living environments is that the majority of the samples in both group 1 and the replication group reside in supported living environments. The replication group years of 1995 and 1997 are utilized for this section in order to substantiate findings (See Table 7). All calculations were done at the .05 level.

The ability to control challenging behavior showed a significant increase among the supported living environment having a mean of 90.16 in 1993 and 91.05 in 1995. The t calculation was 2.09 with a probability of < .025. The replication group yielded different results. The supported living environment displayed a slight, yet significant, decrease in ability to control challenging behaviors with a mean of 88.32 in 1995 and a mean of 87.48 in 1997. The calculated t was 3.01 having a probability of < .005.

Adaptive behavior skills for people in supported living did not significantly increase from 1993 to 1995 (group 1) with means of 46.24 in 1993 and 46.79 in 1995. The replication group showed a similar trend with significant difference among supported living settings in 1995 to 1997. The t calculation was 2.54 with a probability of < .01.

Consumer satisfaction significantly decreased for supported living in group 1. The supported living had a mean of 89.54 in 1993 and 85.21 in 1995. The t calculation was 5.52 with a probability of < .0005. The replication group did not yield similar results. There was a slight decrease but it was not significant at the 05 level. The mean score for consumer satisfaction was 88.64 in 1995 and 88.57 in 1997.

Productivity showed a significant decrease among supported living in group1. Supported living gave a mean of 104.95 in 1993 and 96.75 in 1995. The t calculation was 9.14 with a probability of < .0005. The replication group increased in productivity, having means of 90.68 in 1995 and 99.70 in 1997, with a t calculation of 10.90 and a probability of < .0005.

Finally, opportunities for integration in group 1 slightly but significantly increased, yielding means of 6.13 in 1993 and 6.89 in 1995. The t calculation was 3.51 with a probability of < .0005. The replication group gave similar results. The means showed a significant increase in integration having means of 7.11 in 1995 and 7.35 in 1997 with a t calculation of 1.17 and a probability of < .05.

For the persons in the study that moved from institutions to a community setting, there were significant differences in a majority of the measures of normalization. The data shows that in for some of the measures of normalization, there were positive outcomes. For the comparison between different placement settings in the community, there seemed to be little difference between the supported and non-supported living environments. There were significant differences for four of the five measures of normalization for persons living in the community for an extended period of time. There was little difference in consumer satisfaction for this group. Each of the research questions and their implications will be discussed in next section.

CHAPTER V

DISCUSSION AND CONCLUSION

Each of the research questions analyzed will be discussed more in depth. Caregivers who work with people with developmental disabilities were utilized in the interpretation of the findings. The accounts given by the caregivers are often in reference to personal experiences with whom they have worked.

Research Question 1

According to the data concerning the measures of normalization, there were significant changes in the scaled scores depending on the residential living environment. The five individual scaled scores have implications for community living for persons with developmental disabilities. Each of the five scaled scores will be discussed, and their effect concerning the sample.

Challenging behavior frequencies decreased for persons moving from an institutional placement to a community placement setting for the first experimental group. In the replication group, there was an increase in challenging behavior. The reasons for this discrepancy were examined by caregivers that work with people with developmental disabilities.

There were also historical aspects concerning the closure of the Hissom Memorial Center that could assist in the explanation of the difference. Several

caregivers stated that the reason that there was a difference in the scores of challenging behavior was because of the manner in which the residents of Hissom were released. "They let the easiest people to place in the community out first" stated a caregiver. These individuals were considered to be higher functioning mentally, physically and socially. "Those that were in chairs were harder to place", commented a caregiver.

The adaptive skills for group 1 and the replication group changed significantly. In each group there was an increase in mean scores for adaptive skills. There were numerous comments by caregivers concerning the increase in adaptive skills after leaving the institution. The most prevalent remarks were that in the institution, there were less opportunities for performing some of the skills that were used to comprise the adaptive scales. Cooking and sometimes laundry were done by paid staff in the institution. "He didn't even know how to turn on the stove when he first moved in to this house. Now he cooks with supervision from a staff member". Another staff member relayed a story about her consumer ending up with shrunken clothes soon after learning how to wash her own clothing. "She turned the dryer up too high, but she hasn't done it since. Luckily, there wasn't much in the dryer!"

Consumer satisfaction increased significantly for both groups. A majority of the caregivers expressed that the consumers were able to have more choices regarding their own lives in a community placement setting. One caregiver conveyed the excitement that a consumer in his care had for being able to soon test for a learner's permit to drive a car. "He has carried that book (the driver's

manual) around with him for a month now, he can't wait to take his test." There were other comments about the freedom that the consumers felt living in the community. "He doesn't like to eat green beans, and now he doesn't have to." Another caregiver told of a situation where the consumer wanted to move. "We are getting ready to move her to a new apartment; she says that her upstairs neighbors are too noisy at night."

For the productivity scale, there was a decrease in both groups. This was unlike what was expected, but there were care givers that addressed this issue. A caregiver explained that in some institutions, there were internal workshops that were considered to be a work environment. "They put them into workshop classes and considered them work, but the main concern was to keep them in the room. They probably weren't doing anything," said a caregiver. There were also concerns by caregivers to the lack of work positions that consumers were able to obtain. "She was tired of working in the kitchen washing dishes; she wanted to spend more time with people. She quit to find another job, but it took a really long time to get something she wanted to do".

A coordinator of an agency stated that institutions are contracted out to do piecework for different companies around the state. She said that they take people into the work area to work that do not have the ability to do the work. They sit in the workshop all day, but it is considered work. "Some in the community that were 'working' in the institution, can't work in the community."

The integration scale was not on the 1991 survey, therefore it can not be compared to the 1993 data on integration. The information for this scale comes

from the replication group. The 1993 to 1995 data on integration showed a significant increase from institution to community. When caregivers were shown this information, they were not surprised. "They didn't go out into the community very often, maybe to see family on weekends, but that's all." One caregiver said that "in the community there are more opportunities to go out. They can go do their own shopping, go to see a movie, go to church, and go out to visit with their friends. They can just go out more." Another caregiver noted that there were scheduled outings for the consumer, and that there were at least three a week. Opportunity to go out into the community has been made possible by the decreased number of persons in a single living environment. "It was hard to take 30 residents out to do something when there were only 3 of us to watch out for them. People were scared to see thirty people walking towards them. It is easier with a smaller number, now I have only one" mentioned a caregiver that said he used to work at Hissom.

Research Question 2

Group 1 and the replication group were divided into supported and non-supported community living environments. The purpose of looking at these different settings was to allow for analysis of the difference in staffing for the two living environments. The interaction between consumers and staff could have an effect on the scaled score, as staff members see themselves as "re-socializers"

for consumers. "We're helping them to be better members of society", stated a caregiver.

The outcomes for each of the each of the groups analyzed were inconsistent for both living environments. Between the group 1 and the replication group, the scores alternated as to which was higher for each year. For group 1, the non-supported living environments had a significantly higher ability to control challenging behavior, however for the replication group, the supported living environment had a higher mean score, but it was not significant. The trend for inconsistencies for adaptive behavior was just the opposite. The replication group had a significantly lower mean adaptive score, and in group 1, the non-supported group had a significantly higher mean score. This trend continued throughout the remainder of the scaled scores, with consumer satisfaction being higher in the non-supported living setting in group 1 and being higher in the replication group in the supported living environment. The productivity score was higher in the non-supported category in group 1, and higher in the supported category in the replication group. Both of these scores were statistically significant. Integration also had the difference between both groups and placement settings. The measure of integration was higher for the non-supported living setting for the first group, and higher in the replication group for supported living settings.

These inconsistencies were addressed by the caregivers in both living settings. "His situation is non-supported because we aren't here while he is at work and sleeping." Another caregiver stated "aren't both living in the

community?" According to the comments that followed, the caregiver believed that since both settings are in the community in their own homes that there should be little difference between the two environments. Perhaps some of the inconsistencies discovered could be attributed to the smaller sample in a non-supported living environments. The smaller number of consumers living in non-supported settings could have been affected more drastically with a higher or lower score than in the supported living groups.

Research Question 3

The length of time in the community was the focus of this question. There were significant differences in most of the categories, yet there were some inconsistencies between the groups. The inconsistencies came in the challenging behavior scores and the consumer satisfaction scores. The remaining three scales showed positive increases, though some not significantly

The ability to control challenging behavior scale had an increase during the first group, that is that the consumers were demonstrating less challenging behavior. This decrease in behavior was significant, however there was an increase in behaviors for the replication group. A caregiver commented on this discrepancy saying, "They have good days and bad days, and some bad days are worse than others." Another caregiver stated that there were more things to trigger a "behavior". "He gets into a situation that he's never been in before. and he doesn't know how to handle it. He had to return a broken radio, one that he

had just bought, and he was so stressed out that he began to break things around the house." The caregiver said that, "after he had taken the radio back, with my help, that he didn't have anymore problems."

The adaptive behavior scores showed increases for both groups. The first group did not have a significant increase, but an overall mean increase. The replication group had a significant increase in adaptive scores for the length of time in the community. "He is cooking his own meals now, and planning out a menu for the week. He is able to go to the store and buy the things for the whole week that he needs, and what he wants to eat." Another caregiver mentioned that with the help of a physical therapist, "she now puts on her own clothes and can tie her shoes. This meant a lot to her that she can dress in private and put on her own shoes."

Consumer satisfaction for both years tended to go down in total mean scores for both years. The replication group scores were calculated as not being statistically significant. This was not what was initially expected, but after discussing this phenomenon with caregivers, the reason seemed to come into focus. "He doesn't like to have to go to work everyday. He misses his favorite t.v. shows and doesn't have a v.c.r. yet." Another caregiver relayed a story about the consumer not liking his landlord and the problems that he was having with his house. "He says that the landlord is not taking care of the house and there are things that need to be fixed, so he's pretty unhappy, and is looking for a new place to live." Still another caregiver said "She doesn't think she is making enough money, and she thinks that she should get more. She is still in a

workshop and she wants to get a "real" job." In this particular instance, the consumer knew from friends that she was not getting paid the same amount, which was minimum wage, and she felt it was unfair. Another caregiver said that once they see what they can have with the money that they make, they want what everyone else has. "He wants a red pickup, but he can't get a driver's license. He really wants it, the neighbor has one like the one he wants, and I can't convince him that he had to get his driver's license and save his money to get one."

Although this scale would seem to have a relationship with the previous discussion, this scale measures number of hours worked a month and does not include the wages earned as a factor of productivity. There was a difference in the productivity scores for the groups. In group 1, there was a decrease in the levels of productivity, which was calculated to be significant. In the replication group, however, there was an significant increase in the levels of productivity. This seemed to not be consistent with what was expected, but was clarified by a caregiver when she said, "When you guys came, she (the consumer) was not working, but she was able to get a job within a couple weeks after you left." The scale does not seem to actively reflect the actual productivity, in so far as what would be considered a job. The inconstancies seem to originate with the 'snapshot' time frame that exists at the time of the interview. If the person is not currently working at the time of the assessment, they are marked as not currently employed, but this does not take into account that they could have had a job directly before or after the assessment.

There were consistent increases for integration for both groups for being in the community longer. For both groups this increase was significant. One caregiver stated that the consumer was spending time with friends more often, and that most of his friends were from his work. "He has been working there for a few years and goes with his co-workers to the movies at least once a week." Another caregiver mentioned that "she had dinner pretty frequently with some of the neighbors, especially during the summer when they cooked out." One of the caregivers said that the consumer liked to go to the mall for exercise, and to talk with some of the other walkers. "She loves to go to the mall! She likes the other walkers and talks about them when we leave. Some of the other walkers usually make a round with her and talk with her, she loves it."

Conclusion

In regard to changes in people with developmental disabilities when living in different environments, this study supports the conclusion of the reviewed literature that deinstitutionalization does promote the development of adaptive skills, increases consumer satisfaction (at least to some degree) and provides better opportunity for integration. This study also coincides with Landesman-Dwyer's(1981) conclusion that even though most agree that community living is a better environment for people with developmental disabilities. There are some tendencies for inconsistent results based on scaled scores representing the normalization process. Some findings and trends are consistent with the ideals

surrounding normalization, but sometimes they do not tend to carry over into different living environments or across time. An alternative explanation is that living environments have less to do with the changes in normalization among people with developmental disabilities than do the people with whom the consumer interacts. A caregiver stated that "We (the staff) are teachers of normalization. We teach the rules and norms and rights and responsibilities, rewards and consequences. We moved them from big institutions to small living environments. Their daily activities should not be regimented, they should be able to chose what they want to do. Houses should not be run uniformly, which is what agencies want to do, but they shouldn't. The people living inside are different in so many ways that they each need special consideration. They should be run as to the needs of the resident." The inconsistencies between years and living environments could be because of what the previous caregiver termed "the mechanistic way of service providing".

It has been suggested by a caregiver that integrating people with developmental disabilities in the community has changed the way the community views people with developmental disabilities through interaction with them at work, school, and church. A caregiver mentioned "because people with developmental disabilities are working in the community and being seen in the community, people have been able to get used to them." It has also been demonstrated by the accounts given by caregivers that social interaction and social inclusion play substantial roles in the successful implementation of normalization. As presented earlier in this thesis, there is a strong adherence to

the idea of re-socializing a person who has been atypically socialized, such as a person with developmental disabilities who was socialized in an institutional setting. The concept of re-socializing is a misnomer. Berger (1969) and Clausen (1968), suggest that socialization is a continuous process that occurs throughout an individual's life. In the same regard, individuals learn their behavior through socialization by observing others. Once there is an acceptance of others, we are then enveloped into a process of modeling our roles in accordance to how we see ourselves in others (Helmig, 1994). Through new experiences and interactions with others, we learn, define, re-define, and adjust meanings of objects in our social reality to constant socialization. It has been suggested that regular social contact with valued significant others and other such ties are crucial for the successful community adjustment of persons both with and without disabilities (Abery &Fahnestock, 1994). One point that seems to have been lost in the literature is that socialization is a reciprocal process. A person cannot be involved with interaction and not be influenced in some way (Goffman, 1959; Blumer, 1969). For example, you cannot interact without being interacted with or teach without simultaneously being taught. Individuals with developmental disabilities tend to have "physical, functional, and organizational integration in the way their lives are structured, but lack social, personal and societal integration" (Lord & Pedlar, 1991, p.217). With these deficiencies in social, personal and societal integration, persons with developmental disabilities are not being provided with opportunities for adequate socialization into a community setting.

Another possible reason for inconsistencies in scores is that there are many problems in the community such as an inaccessibility to long-term staff. The transitory nature of staff for people with developmental disabilities could be considered when looking at meaning. For example, certain behaviors that a staff member may label as challenging, may not be viewed as such by another, or that some adaptive abilities may be regarded as exemplary by one and mediocre by another. As suggested by Blumer (1969), meaning is a product of interaction and meaning is given to something in accordance with interpretation. With this in mind, it is understandable why there are inconsistencies in scores that pertain to the measures of normalization. "If service providers are to provide the best services possible, they must be able to fully understand situations and needs as perceived by their clients" (MacEachen & Munby, 1996 p. 72).

The data that were analyzed for this thesis shows the quantification of measures of normalization; however, the deeper meaning that was obtained through the caregivers allowed for a more comprehensive interpretation. There were inconsistencies in the scaled scores for the different groups. This could be because of the differences in interpretation of the meanings that are associated with the scaled scores of normalization. These differences in meanings could be between different care providers or different placement settings in terms of the interpretation of particular situations. The instrument did not address some of the issues that not only were found through talking with caregivers, but also found in the literature.

Suggestions for Further Research

There is a need for more qualitative research in the area of developmental disabilities. Assessment of successful social inclusion may indeed need to be the next step in research of people with developmental disabilities. Taylor and Bogdan (1994) suggests that within the past decade there has been a growing interest and visibility of qualitative research in the field of developmental disabilities. There was a noticeable lack of this type of research in the study of developmental disabilities. Different types of qualitative research could be conducted in this area. Perhaps exploring such experiential levels as liking one's job or disliking to pay bills would give greater insight to the actual lives of people with developmental disabilities. As mentioned before, it is apparent that community living has benefits for people with developmental disabilities with regard to normalization. However, to understand fully the degree of favorable processes of normalization, outcomes should be sought at the level of the individual experiencing the social inclusion or exclusion, whatever the case may be.

There also seems to be a need for new ways of understanding the world of people with developmental disabilities. The concepts that are currently in use seem to be outdated and irrelevant to many areas of their lives in the community. More qualitative research, specifically a grounded theory approach would be helpful in the development of the necessary concepts that are relevant to the worlds of persons with developmental disabilities.

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APPENDIX A

Table 1
Demographics for group 1 and group 2

	Frequency		Percent	
	Group 1	Repl group	Group 1	Repl group
Sex				
Male	74	131	47.5	57.5
Female	51	97	32.9	42.5
Race				
Caucasian	107	177	69.0	77 6
African-American	11	32	7 1	14.0
Hispanic	1	1	6	4
Native-American	5	18	3.2	7 9
Other	1	n/a	.6	n/a
Level of mental retardation				
None	1	6	.6	2 6
Mild	11	14	7 1	6.1
Moderate	17	29	11.0	12 7
Severe	30	34	19.4	14 9
Profound	60	132	38 7	57 9
Unknown	6	13	3.9	5.7

Table 2

Changes in mean scaled score for measurements of normalization for persons with developmental disabilities living in an institution in 1991 and in the community in 1993

Measurements of Normalization	Mean Scaled Scores			
	1991	1993	t calc.	p<
Challenging Behavior	86.35	90.70	3.53	<.0001
Adaptive Skills	43.71	47.00	3.92	<.0001
Consumer Satisfaction	86.04	92.33	2.24	<.0001
Productivity	117.44	105.77	1.82	.035
Integration *	n/a	n/a	n/a	n/a

*no measure of intergration on the 1991 intstrument

Table 3

Changes in mean scaled score for measurements of normalization for persons with developmental disabilities living in an institution in 1993 and in the community in 1995

Measurements of Normalization	Mean Scaled Scores			
	1993	1995	t calc.	p<
Challenging Behavior	92.89	88.20	4 81	<.0001
Adaptive Skills	35.75	41.97	8.28	<.0001
Consumer Satisfaction	74.20	88.07	5.42	<.0001
Productivity	112.61	95.75	3 61	< 0001
Integration	1.76	7.21	21 47	<.0001

Table 4

Differences in mean scaled scores for measurements of normalization for persons with developmental disabilities living in a supported and non-supported environment in 1993

Measurements of Normalization	Mean Scaled Scores			
	Supported	Non-supported	t calc.	p<
Challenging Behavior	90.16	94.40	3.21	< 005
Adaptive Skills	46.24	60.58	6.22	<.0005
Consumer Satisfaction	89.54	92.86	2 49	<.01
Productivity	104.95	119.50	7 12	< 0005
Integration	6 13	8.37	2 06	<.025

Table 5

Differences in mean scaled scores for measurements of normalization for persons with developmental disabilities living in a supported and non-supported environment in 1995

Measurements of Normalization	Mean Scaled Scores			
	Supported	Non-supported	t calc	p<
Challenging Behavior	88.32	88.28	.02	N/S
Adaptive Skills	42.29	36.79	2.16	<.025
Consumer Satisfaction	88.64	88.18	.23	N/S
Productivity	115.33	90.68	7 15	<.0005
Integration	8.52	7 11	4 39	< 0005

Table 6

Changes in mean scaled scores for measurements of normalization for persons with developmental disabilities living in a supported environment in 1993 and in 1995

Measurements of Normalization	Mean Scaled Scores			
	1993	1995	t calc.	p<
Challenging Behavior	90.16	91.05	2.09	<.025
Adaptive Skills	46.24	46.79	.85	N/S
Consumer Satisfaction	89.54	85.21	5.52	<.0005
Productivity	104.95	96.75	9.14	<.0005
Integration	6.13	6.89	3.51	<.0005

Table 7

Changes in mean scaled scores for measurements of normalization for persons with developmental disabilities living in a supported environment in 1995 and in 1997

Measurements of Normalization	Mean Scaled Scores			
	1995	1997	t calc.	p<
Challenging Behavior	88.32	87 48	3.01	<.005
Adaptive Skills	42.29	43 70	2 54	<.01
Consumer Satisfaction	88.64	88.57	09	N/S
Productivity	90.68	99 70	10 90	<.0005
Integration	7 11	7 35	1 17	<.05

APPENDIX B

OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD

Date: June 2, 1999 IRB #: AS-99-072

Proposal Title: "DEINSTITUTIONALIZATION AND ACCOMPANYING CHANGES AMONG PEOPLE WITH DEVELOPMENTAL DISABILITIES"

Principal Investigator(s): Dr. Richard Dodder
Shana Porteen

Reviewed and Processed as: Exempt

Approval Status Recommended by Reviewer(s): Approved

Signature:

Carol Olson, Director of University Research Compliance

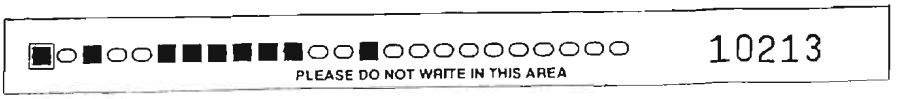
June 2, 1999
Date

Approvals are valid for one calendar year, after which time a request for continuation must be submitted. Any modification to the research project approved by the IRB must be submitted for approval. Approved projects are subject to monitoring by the IRB. Expedited and exempt projects may be reviewed by the full Institutional Review Board.

OKLAHOMA STATE UNIVERSITY
DEPARTMENT OF SOCIOLOGY
STILLWATER, OKLAHOMA

DEVELOPMENTAL DISABILITIES QUALITY ASSURANCE QUESTIONNAIRE 1996/97 - 1997/98

Revised 8-8-96



OKLAHOMA STATE UNIVERSITY
DEPARTMENT OF SOCIOLOGY
STILLWATER, OKLAHOMA

DEVELOPMENTAL DISABILITIES QUALITY ASSURANCE QUESTIONNAIRE

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

SECTION I: DEMOGRAPHICS, RESIDENTIAL HISTORY, FAMILY/ADVOCATE CONTACT and CIVIC INVOLVEMENT

*Interviewer -- code this page from ADDENDUM sheet.

Interviewer

Interview Date

M M D D Y Y

ID Number

○ No ID

Class Status

○ Focus
○ Balance
○ Non Member
○ Don't Know

○ OBRA Member

Sex

○ Male
○ Female

Race

○ White
○ African American
○ Asian
○ Hispanic
○ Native American
○ Other: _____

D.O.B.

M M D D Y Y

Site Code

Level of Retardation

○ Not MR
○ Mild
○ Moderate
○ Severe
○ Profound
○ Unknown

Residential Setting

○ Public ICF/MR
○ Private ICF/MR
○ Private Home
○ Group Home
○ Nursing Facility
○ Community Placement

10213

5. Is the residence private or public?

- ○ Private nonprofit
- ○ Private proprietary
- ○ Public
- ○ Private home (includes FC, SIL, ASL, IL, SUP, AC)
- ○ Other: _____

2. When did s/he move here?

M M D D Y Y

- ○ Unknown
- ○ Life-long resident

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

- ○ ESS = Northern Oklahoma Resource Center - Enid
- ○ FC = Foster Care (under 18)
- ○ OBGH = OBRA Group Home
- ○ GH = Other Group Home
- ○ GRE = Greer Center
- ○ HMC = Hissom Memorial Center
- ○ NF = Nursing Facility
- ○ IL = Independent Living
- ○ INC = Incarcerated (JAIL or PRISON)
- ○ MHF = Mental Health Facility
- ○ MR = ICF/MR Placement
- ○ OS = Out of State
- ○ OSD = Oklahoma School for the Deaf
- ○ PVS = Southern Oklahoma Resource Center - P.V.
- ○ RH = Parent's or Relative's Home
- ○ ASL = Assisted Living (own home, less than 24 hour support)
- ○ SUP = Supported Living (own home, 24 hour shift staff)
- ○ AC = Adult Companion (private home, live-in companion)
- ○ OT = Other
- ○ AFC = Adult Foster Care
- ○ Life Long Resident
- ○ Unknown

92. How many individuals receiving residential supports reside in this setting (if multiple living units, indicate the number of individuals residing in the person's living unit).

92A. How many direct care staff are on the living unit at any given time during waking hours?

- ○ Unknown ○ None

92B. If direct care staff, do they:

- ○ work shifts
- ○ reside at facility
- ○ some of both

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

- ○ Unknown/unavailable
- ○ Pays Nothing

6. Has s/he ever lived in an institution? *(MARK ALL THAT APPLY)* If no, skip to #3.

- ○ NO
- ○ UNKNOWN
- ○ State School
- ○ Private ICF-MR
- ○ Nursing Home
- ○ Mental Health
- ○ Other: _____

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

- ○ Currently institutionalized
- ○ Unknown

M M Y Y

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

- ○ Unknown

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

- ○ A family member
- ○ A non-relative guardian
- ○ A friend
- ○ A direct contact staff person (paraprofessional/adult companion)
- ○ Case Manager/Social Worker/QMRP
- ○ Other professional or administrator
- ○ Foster Parent
- ○ Other (define): _____

1A. What is this person's principal mode of communication?

- ○ Verbal communication
- ○ Sign Language
- ○ Communication Device
- ○ Alerting Device
- ○ Gestures
- ○ Other: _____

100. Is s/he an adult who has a guardian (not conservatorship) appointed by a court?

- ○ Person is an adult with a guardian
- ○ Person has had a guardian recommended but not yet appointed
- ○ Person does not have a guardian but may need one. (Skip 101)
- ○ Person is an adult who does not need a guardian. (Skip 101)
- ○ Person is under 18 years of age. (Skip 101)
- ○ Don't Know (Skip 101)

101. What kind of guardianship has been ordered? *(MARK ALL THAT APPLY).*

- ○ General guardian of property
- ○ Limited guardian of property
- ○ General guardian of person
- ○ Limited guardian of person
- ○ Don't know

Other Disabilities (Mark all that apply)

- ○ Visually Impaired
- ○ Hearing Impaired
- ○ Physical disabilities
- ○ Autistic like behavior
- ○ Other: _____
- ○ Mental illness
- ○ Feeding Tube
- ○ Cerebral palsy
- ○ Tracheostomy

What is this person's average monthly income:

93. from employment?

- ○ None
- ○ Unknown/unavailable

93A. From entitlements:

- ○ None
- ○ Unknown/unavailable

Now, I'd like to ask some questions about the amount of contacts s/he has with family, case managers and advocates in the past year.

	Lives with family	About once a week or more	About 2-3 times a month	About once a month	About every 3 months	Twice a year or less	Never in the past year	No family, or no DDS case manager or No Advocate (does not apply)	Unknown
7. In the past year, how often has there been contact by phone/mail/letters with the consumer's family?	○	○	○	○	○	○	○	○	○
8. How often did family member(s) (biological/adoptive) visit him/her in the consumer's home in the past year?	○	○	○	○	○	○	○	○	○
9. How often did s/he visit the family (biological/adoptive) home or go on outings in the past year?	○	○	○	○	○	○	○	○	○
10. How often did the DDS case manager make contact with consumer by phone in the last year?	○	○	○	○	○	○	○	○	○
11. How often did the DDS case manager make contact with the consumer in person in the past year?	○	○	○	○	○	○	○	○	○
11A. How many times do neighbors visit this person in their place of residence?	○	○	○	○	○	○	○	○	○
11B. How many times do other people visit this person in their place of residence?	○	○	○	○	○	○	○	○	○
14. How often did other advocates visit him/her or their family in the past year?	○	○	○	○	○	○	○	○	○

Now some questions about how often s/he left the facility for various social interactions in the past year?

	More than twice a week	Twice a week	Once a week	2-3 times a month	Once a month	Less than once a month	Not sure or refused	Never
95. Go out to visit with friends, relatives, or neighbors.	○	○	○	○	○	○	○	○
96. Go out to visit a supermarket or food store.	○	○	○	○	○	○	○	○
97. Go out to a restaurant.	○	○	○	○	○	○	○	○
98. Go out to church or synagogue.	○	○	○	○	○	○	○	○
99. Go out to a shopping center, mall, or other retail store to shop.	○	○	○	○	○	○	○	○
99A. Go out to recreational activities (movies, arcades, etc.)	○	○	○	○	○	○	○	○
99B. Go out to the bank.	○	○	○	○	○	○	○	○

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

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

104 How often does s/he typically participate in a civic organization (Lions Club, Kiwanis, Zonta, Scouts) or Social Club (Garden Club, Church Group, etc)? (*CHOOSE ONE*).

○ Daily ○ Every other week ○ Quarterly ○ Annually
○ Weekly ○ Monthly ○ Semi-Annually ○ Not in the past year

105. **Is s/he registered to vote?** ○ Yes ○ No ○ Don't Know ○ Underage

106. **Has s/he voted in the past two years?** ○ Yes ○ No ○ Don't Know ○ Underage

	Yes (may be assisted)	Sometimes	No (Paid staff makes these decisions)	No (Family/Friends makes these decisions)	Don't know	Not Applicable
111A. Does s/he choose their activities or does someone else choose their activities?	○	○	○	○	○	○
111B. Does s/he choose their friends or does someone else choose their friends?	○	○	○	○	○	○
111C. Does s/he choose what food to eat at home or does someone else choose what food they eat?	○	○	○	○	○	○
111D. Does s/he choose what food to order in a restaurant or does someone else choose for them?	○	○	○	○	○	○
111E. Does s/he choose how to spend their money or does someone else choose for them?	○	○	○	○	○	○

112-113. In the past year, has this person experienced discrimination in:
(*MARK ALL THAT APPLY*)

- ○ Physical access to buildings
- ○ Access to employment services
- ○ Access to educational services
- ○ Access to other human services
- ○ Access to transportation
- ○ Interaction with non-handicapped neighbors and friends
- ○ Participation in civic events (with non-handicapped individuals)
- ○ Participation in recreation/leisure
- ○ Other (Describe): _____

☐ ⓪①②③④⑤⑥⑦⑧⑨
☐ ⓪①②③④⑤⑥⑦⑧⑨

SECTION II: ADAPTIVE EQUIPMENT NEEDS

What adaptive equipment does s/he have or need?

No Needs ○

	Does not need	NEEDS but does not have	HAS	Has but needs REPAIR
17. Glasses	○	○	○	○
18. Hearing Aid	○	○	○	○
19. Wheelchair/Geri Chair	○	○	○	○
20. Helmet	○	○	○	○
21. Communication Device	○	○	○	○
21A. Dentures	○	○	○	○
21B. Walker/Cane	○	○	○	○
21C. Braces/Splints	○	○	○	○
21D. Aids For Toileting/Bathing	○	○	○	○
21E. Aids for Eating	○	○	○	○
21F. Transportation Aids	○	○	○	○
22. Other: _____	○	○	○	○

_____ ☐ ⓪①②③④⑤⑥⑦⑧⑨
☐ ⓪①②③④⑤⑥⑦⑧⑨

SECTION III: ADAPTIVE SKILLS (ADAPTIVE DEVELOPMENT SCALE)

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

23. How is his/her body balance? Does s/he: *(MARK HIGHEST NUMBER THAT APPLIES).*
    - ⑤ Stand on "tiptoe" for ten seconds
    - ④ Stand on one foot for two seconds
    - ④ Stand without support
    - ③ Stand with support
    - ② Sit without support
    - ① Can do none of the above
    - ⓪ Unknown

24. Does s/he use silverware? *(MARK HIGHEST NUMBER THAT APPLIES).*
    - ⑦ Use knife and fork correctly and neatly
    - ⑥ Use table knife for cutting or spreading
    - ⑤ Feed self with spoon and fork - neatly
    - ④ Feed self with spoon and fork - considerable spilling
    - ③ Feed self with spoon - neatly
    - ② Feed self with spoon - considerable spilling
    - ① Feed self with fingers or must be fed
    - ⓪ Unknown

25. Does s/he: (VISUAL AIDS ARE ACCEPTABLE) *(MARK HIGHEST NUMBER THAT APPLIES)*
    - ④ Order complete meals in restaurants
    - ③ Order simple meals like hamburgers or hot dogs
    - ② Order soft drinks at soda fountain or canteen
    - ① Does not order food at public eating places
    - ⓪ Unknown

26. Does s/he: *(MARK HIGHEST NUMBER THAT APPLIES).*
    - ④ Drink without spilling, holds glass in one hand
    - ③ Drink from cup or glass unassisted - neatly
    - ② Drink from cup or glass - considerable spilling
    - ① Does not drink from cup or glass
    - ⓪ Unknown

27. Does s/he ever have toilet accidents? *(MARK HIGHEST NUMBER THAT APPLIES).*
    - ④ Never has toilet accidents
    - ④ Seldom has toilet accidents during the day (but may have problems at night)
    - ③ Occasionally has toilet accidents (less than 1 a day)
    - ② Frequently has toilet accidents (more than 1 a day)
    - ① Is not toilet trained at all
    - ⓪ Unknown

28. Does s/he: *(MARK HIGHEST NUMBER THAT APPLIES).*
    - ⑦ Prepare and completely bathe unaided
    - ⑥ Wash and dry self completely
    - ⑤ Wash and dry reasonably well with prompting
    - ④ Wash and dry self with help
    - ④ Attempt to soap and wash self
    - ② Actively cooperate when being washed and dried by others
    - ① Makes no attempt to wash or dry self
    - ⓪ Unknown

29. **Does s/he:** *(MARK HIGHEST NUMBER THAT APPLIES).*
- ⑥ Completely dress self
- ⑤ Completely dress self with verbal prompting only
- ④ Dress self by pulling or putting on all clothes with verbal prompting and by fastening (zipping, buttoning, snapping) them with help
- ③ Dress self with help in pulling or putting on most clothes and fastening them
- ② Cooperate when dressed, e.g., by extending arms or legs
- ① Must be dressed completely
- ⓪ Unknown

30. **How is his/her sense of direction? Does s/he:** *(MARK HIGHEST NUMBER THAT APPLIES).*
- ④ Go several blocks from grounds, or from home, without getting lost
- ③ Go around grounds or a couple of blocks from home without getting lost
- ② Go around cottage, ward, yard, or home without getting lost
- ① Demonstrates no sense of direction
- ⓪ Unknown

31. **Does s/he:** *(MARK HIGHEST NUMBER THAT APPLIES).*
- ⑤ Use money with little or no assistance (e.g., assistance with budgeting is OK)
- ④ Use money with minor assistance (e.g., checking for correct change, etc.)
- ③ Use money with some assistance (e.g., being told the correct bills or coins)
- ② Use money with complete assistance of staff
- ① Does not use money
- ⓪ Unknown

32. **Does s/he:** *(MARK HIGHEST NUMBER THAT APPLIES).*
- ⑥ Choose and buy all own clothing without help
- ⑤ Choose and buy some clothing without help
- ④ Make minor purchases without help (e.g., snacks, drinks)
- ③ Do some shopping with slight supervision
- ② Do some shopping with close supervision
- ① Does no shopping
- ⓪ Unknown

33. **Does s/he:** *(MARK HIGHEST NUMBER THAT APPLIES).*
- ⑥ Write complete lists, memos or letters
- ⑤ Write short sentences
- ④ Write or print more than ten words without copying or tracing
- ③ Write or print own name or other words without copying or tracing
- ② Trace or copy own name or other words
- ① Does not write, print, copy, or trace any words
- ⓪ Unknown

34. **Does s/he:** *(MARK HIGHEST NUMBER THAT APPLIES).*
- ④ Sometimes use complex sentences containing "because," "but," etc.
- ③ Ask questions using words such as "why," "how," "what," etc.
- ② Communicates in few words, short phrases or simple sentences that make sense
- ① Does not communicate verbally, with sign language or with communication device.
- ⓪ Unknown

35. **Does s/he:** *(MARK HIGHEST NUMBER THAT APPLIES).*
- ⑥ Read books or other materials suitable for 4th grade level or above
- ⑤ Read books or other materials suitable for 2nd or 3rd grade level
- ④ Read simple stories or comics suitable for kindergarten or first grade level
- ③ Recognize 10 or more words
- ② Recognize various signs, such as "EXIT" or "STOP" or "WOMEN" or "MEN" or Street Signs.
- ① Recognize no words or signs.
- ⓪ Unknown

36. **Does s/he:** *(MARK HIGHEST NUMBER THAT APPLIES).*
    - ⑤ Do simple addition and/or subtraction
    - ⑤ Count 10 or more objects
    - ④ Mechanically count aloud from one to ten
    - ③ Count two objects by saying "one, two"
    - ② Discriminate between "one" and "many"
    - ① Has no understanding of numbers
    - ⓪ Unknown

37. **Does s/he clean his/her room?** *(MARK HIGHEST NUMBER THAT APPLIES).*
    - ③ Cleans room well, e.g., sweeping, vacuuming, tidying
    - ② Cleans room but not thoroughly
    - ① Does not clean room at all
    - ⓪ Unknown

38. **Does s/he:** *(MARK HIGHEST NUMBER THAT APPLIES).*
    - ④ Prepare an adequate complete meal
    - ③ Mix and cook simple foods
    - ② Prepare simple foods requiring no mixing or cooking
    - ① Does not prepare food at all
    - ⓪ Unknown

39. **Does s/he:** *(MARK HIGHEST NUMBER THAT APPLIES).*
    - ③ Clear table of breakable dishes and glassware
    - ② Clear table of unbreakable dishes and silverware
    - ① Does not clear table at all
    - ⓪ Unknown

40. **Does s/he go to:** *(MARK HIGHEST NUMBER THAT APPLIES)*
    - ④ Any type of paid employment
    - ③ Workshop
    - ② Prevocational training, in school, or retired
    - ① Performs no outside work
    - ⓪ Unknown

41. **Does s/he:** *(MARK HIGHEST NUMBER THAT APPLIES).*
    - ④ Initiate most of own activities
    - ③ Initiate some of own activities
    - ② Will engage in activities only if assigned or directed
    - ① Will not engage in assigned activities
    - ⓪ Unknown

42. **Does s/he:** *(MARK HIGHEST NUMBER THAT APPLIES).*
    - ⑤ Pay attention to purposeful activities for more than 20 minutes
    - ④ Pay attention to purposeful activities for about 15 minutes
    - ③ Pay attention to purposeful activities for about 10 minutes
    - ② Pay attention to purposeful activities for about 5 minutes
    - ① Will not pay attention to purposeful activities for as long as 5 minutes
    - ⓪ Unknown

43. **How is s/he at taking care of his/her personal belongings?** *(MARK HIGHEST NUMBER THAT APPLIES).*
    - ④ Very dependable, always takes care of belongings
    - ③ Usually dependable, usually takes care of belongings
    - ② Unreliable, seldom takes care of belongings
    - ① Not responsible at all, does not take care of belongings
    - ⓪ Unknown

44. Does s/he: *(MARK HIGHEST NUMBER THAT APPLIES).*
    - ④ Interact with others for more than five minutes
    - ③ Interact with others for up to five minutes
    - ② Interact with others in limited ways, e.g., eye contact, handshakes, responsive to touch
    - ① Does not interact with others
    - ⓪ Unknown

45. Does s/he: *(MARK HIGHEST NUMBER THAT APPLIES).*
    - ④ Initiate group activities at least some of the time (leader and/or organizer)
    - ③ Participate in group activities spontaneously and eagerly (active participant)
    - ② Participate in group activities if encouraged to do so (passive participant)
    - ① Does not participate in group activities (unless physically guided)
    - ⓪ Unknown

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

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

48. Does s/he: *(MARK ALL THAT APPLY)*
    - ○ Wash hands with soap
    - ○ Wash face with soap
    - ○ Wash hands and face with water
    - ○ Dry hands and face
    - ○ None of the above
    - ○ All of the above
    - ○ Unknown

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

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

51. **Does s/he:** *(MARK ALL THAT APPLY)*
- ○ Say a few words
- ○ Sign a few words
- ○ Nod head or smile to express happiness
- ○ Indicate hunger
- ○ Indicate wants by pointing or vocal noises
- ○ Express pleasure or anger by vocal noises
- ○ Chuckle or laugh when happy
- ○ None of the above
- ○ All of the above
- ○ Unknown

52. **Does s/he:** *(MARK ALL THAT APPLY)*
- ○ Understand instructions containing prepositions, e.g., "on," "in," "behind"
- ○ Understand instructions referring to the order in which things must be done, e.g., "first do this, and afterward, do that"
- ○ Understand instructions requiring a decision, e.g., "Put on your shorts, but if they're dirty, put on your jeans"
- ○ None of the above
- ○ All of the above
- ○ Unknown

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

54. **Does s/he:** *(MARK ALL THAT APPLY)*
- ○ Recognize significant others
- ○ Recognize others
- ○ Have information about others, e.g., relation to self, job, address
- ○ Know the names of people close to him/her, e.g., in neighborhood, at home or day program
- ○ Know the names of people not regularly encountered
- ○ None of the above
- ○ All of the above
- ○ Unknown

Would you say Adaptive Behavior information is:
- ○ Generally reliable/respondent seems to know individual
- ○ Not reliable/respondent does not seem to know individual well

SECTION IV: CHALLENGING BEHAVIORS

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

FREQUENCY CODING

Not observed in the past month, but has occurred in the past year
Less than or equal to five times a week in past four weeks
More than five times a week in past four weeks

RESPONSE CODING

No response from staff
Verbal response from staff
Organized effort to ignore
Physical/medical response
Additional help needed
Unknown

BEHAVIORAL PLAN or GOAL ON CARE PLAN IN PLACE?

Yes
No
Don't Know
Not Applicable

○ No challenging behaviors

55. Threaten or do physical violence to others (on purpose) ○○○ ○○○○○○ ○○○○
Describe: _____
_____
☐☐ ⓪①②③④⑤⑥⑦⑧⑨

56. Damage own or others' property (on purpose) ○○○ ○○○○○○ ○○○○
57. Disrupt others' activities ○○○ ○○○○○○ ○○○○
58. Use profane or hostile language ○○○ ○○○○○○ ○○○○
59. Is rebellious, e.g., ignore regulations, resist following instructions ○○○ ○○○○○○ ○○○○
60. Run away or attempt to run away ○○○ ○○○○○○ ○○○○
61. Is untrustworthy, e.g., take others' property, lie, or cheat ○○○ ○○○○○○ ○○○○
62. Display stereotyped behavior, e.g., rock body, hands constantly moving in repetitive pattern ○○○ ○○○○○○ ○○○○
63. Remove or tear off own clothing inappropriately ○○○ ○○○○○○ ○○○○
64. Injure self ○○○ ○○○○○○ ○○○○
65. Is hyperactive, e.g., will not sit still for any length of time ○○○ ○○○○○○ ○○○○
66. Inappropriate sexual behavior inside the home ○○○ ○○○○○○ ○○○○
Describe: _____
_____
☐☐ ⓪①②③④⑤⑥⑦⑧⑨

67. Inappropriate sexual behavior outside the home ○○○ ○○○○○○ ○○○○
Describe: _____
_____
☐☐ ⓪①②③④⑤⑥⑦⑧⑨

68. Listless, sluggish, inactive, unresponsive to activities ○○○ ○○○○○○ ○○○○
69. Scream, yell or cry inappropriately ○○○ ○○○○○○ ○○○○
70. Repeat a word or phrase over and over ○○○ ○○○○○○ ○○○○
71. Did s/he display any other challenging behavior?
○ Yes
○ No
Describe: _____
_____
☐ ⓪①②③④⑤⑥⑦⑧⑨

SECTION V: MEDICAL NEEDS/SERVICES

HEALTH INFORMATION

Please rate the individual's overall health, and the quality of the health care they are receiving. If a service is not needed and not being used, mark Not Applicable. (Ask for all consumers)

	Very Good	Good	OK	Poor	Very Poor	Not Applicable	Unknown
71A. Does this person receive medical services through a managed care organization? ○ Yes ○ No ○ Unknown							
71B. General Health: In general, how is this person's health?	○	○	○	○	○	○	○
Please rate the quality of the following services:							
71C. Primary Physician	○	○	○	○	○	○	○
71D. Nursing Services	○	○	○	○	○	○	○
71E. Emergency care (First aid, ER)	○	○	○	○	○	○	○
71F. Dental care	○	○	○	○	○	○	○
71G. Psychiatrist(s)	○	○	○	○	○	○	○
71H. Inpatient hospital care	○	○	○	○	○	○	○
71I. Neurologist(s)	○	○	○	○	○	○	○
71J. Medical management of Seizures	○	○	○	○	○	○	○
71K. Nutrition Services	○	○	○	○	○	○	○
71L. Other specialties (Surgery, Allergy, Skin, etc.)	○	○	○	○	○	○	○
71M. General Health Care: Overall, how good is the health care this person is receiving?	○	○	○	○	○	○	○

72. In general, how urgent is his/her need for medical care? *(MARK ONLY ONE)*
- ○ Generally has no serious medical needs
- ○ Needs visiting nurse and/or regular visits to the doctor
- ○ Has life-threatening condition that requires very rapid access to medical care
- ○ Unknown

73. How often does s/he receive care for a specific medical need from a doctor or a nurse (OTHER THAN MEDICATION ADMINISTRATION)?
- ○ Not in last year
- ○ Once a year
- ○ Twice a year
- ○ Three to six times a year
- ○ Once a month
- ○ Once a week
- ○ Once a day
- ○ More than once a day
- ○ Unknown

73A. How many times in the past year has this person received treatment at a hospital emergency room?
- ☐☐ ⓪①②③④⑤⑥⑦⑧⑨
- ○ Never
- ○ Unknown

73B. How many times in the past year has this individual been admitted to a hospital for any reason?
- ☐☐ ⓪①②③④⑤⑥⑦⑧⑨
- ○ Never
- ○ Unknown

74. To your knowledge, has s/he had difficulty receiving medical services in the past year?
- ○ No problem
- ○ One to three times
- ○ Four to six times
- ○ Seven to nine times
- ○ Over nine times
- ○ Don't know

What type of problem? _____ ☐☐ ⓪①②③④⑤⑥⑦⑧⑨

76. What was the date of the last dental examination?

M ☐ ⓪①
M ☐ ⓪①②③④⑤⑥⑦⑧⑨
Y ☐ ⓪①②③④⑤⑥⑦⑧⑨
Y ☐ ⓪①②③④⑤⑥⑦⑧⑨

○ never
○ unknown

77. What was the date of the last eye exam?

M ☐ ⓪①
M ☐ ⓪①②③④⑤⑥⑦⑧⑨
Y ☐ ⓪①②③④⑤⑥⑦⑧⑨
Y ☐ ⓪①②③④⑤⑥⑦⑧⑨

○ never
○ unknown

79. How often does s/he experience seizures (INCLUDE ALL TYPES AND OCCURRENCES)? *(MARK ONLY ONE)*

○ Daily
○ Weekly
○ Monthly
○ Yearly
○ One to six during the past year
○ Seven to 11 per year during the past year
○ Has documented history of seizures but no seizures in past year
○ No seizures in past five years (Skip 79A)
○ No history of seizures (Skip 79A)
○ Unknown (Skip 79A)

79A. Does this represent a change from the previous year?

○ Same
○ More
○ Less
○ Don't know

SECTION VI: MEDICATIONS USED

DRUG USAGE (QUESTIONS 80-85)

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

FREQuency of Administration

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

Drug: A

Frequency
- ○ TD
- ○ PRN
- ○ QID
- ○ TID
- ○ BID
- ○ HS
- ○ AVG
- ○ Other

drug code

Dosage

Units
- ○ Milligram
- ○ Gram
- ○ Milliliters
- ○ CC's

Purpose
- ○ behavioral control
- ○ seizure control
- ○ other ○ unknown

Drug: B

Frequency
- ○ TD
- ○ PRN
- ○ QID
- ○ TID
- ○ BID
- ○ HS
- ○ AVG
- ○ Other

drug code

Dosage

Units
- ○ Milligram
- ○ Gram
- ○ Milliliters
- ○ CC's

Purpose
- ○ behavioral control
- ○ seizure control
- ○ other ○ unknown

Drug: C

Frequency
- ○ TD
- ○ PRN
- ○ QID
- ○ TID
- ○ BID
- ○ HS
- ○ AVG
- ○ Other

drug code

Dosage

Units
- ○ Milligram
- ○ Gram
- ○ Milliliters
- ○ CC's

Purpose
- ○ behavioral control
- ○ seizure control
- ○ other ○ unknown

Drug: D

Frequency
- ○ TD
- ○ PRN
- ○ QID
- ○ TID
- ○ BID
- ○ HS
- ○ AVG
- ○ Other

drug code

Dosage

Units
- ○ Milligram
- ○ Gram
- ○ Milliliters
- ○ CC's

Purpose
- ○ behavioral control
- ○ seizure control
- ○ other ○ unknown

Drug: E

Frequency
- ○ TD
- ○ PRN
- ○ QID
- ○ TID
- ○ BID
- ○ HS
- ○ AVG
- ○ Other

drug code

Dosage

Units
- ○ Milligram
- ○ Gram
- ○ Milliliters
- ○ CC's

Purpose
- ○ behavioral control
- ○ seizure control
- ○ other ○ unknown

Drug: F

Frequency
- ○ TD
- ○ PRN
- ○ QID
- ○ TID
- ○ BID
- ○ HS
- ○ AVG
- ○ Other

drug code

Dosage

Units
- ○ Milligram
- ○ Gram
- ○ Milliliters
- ○ CC's

Purpose
- ○ behavioral control
- ○ seizure control
- ○ other ○ unknown

MEDICATIONS TABLE

001 acetophenazine
020 Adapin (R)
002 alprazolam
003 amantadine
100 Ambien (R)
004 amitriptyline
006 amoxapine
007 amphetamine sulfate
090 Anafranil (R)
026 Anxanil (R)
087 Artane (R)
006 Asendin (R)
026 Atarax (R)
030 Ativan (R)
040 Aventyl (R)
066 Barbita (R)
096 Beldin (R)
096 Benadryl (R)
096 Benylin (R)
008 benzatropine
007 Benzedrine (R)
007 Biphetamine (R)
091 bupropion
009 Buspar (R)
009 buspirone
059 Calan (R)
060 carbamazepine
014 Catapres (R)
065 Celontin (R)
047 Centrax (R)
010 chloral hydrate
011 chlordiazepoxide
012 *chlorpromazine
081 *chlorprothixene
029 Cibalith-S (R)
090 clomipramine
013 clonazepam
014 clonidine
013 Clonopin (R)
035 Clopra (R)
015 clorazepate
095 *clozapine
095 *Clozaril (R)
008 Cogentin (R)
108 Cognex (R)
048 *Compazine (R)
096 Compoz (R)
061 Corgard (R)
042 Cylert (R)
024 Delmane (R)
064 Depakene (R)
080 Depakote (R)
033 Deprol (R)
017 desipramine
036 Desoxyn (R)
054 Desyrel (R)
018 Dexedrine (R)
018 dextroamphetamine
062 diazepam
067 Dilantin (R)
096 Diphen (R)
096 Diphenhist (R)
096 diphenhydramine
080 divalproex sodium
101 Doral (R)
020 doxepin
104 Effexor (R)
004 Elavil (R)
004 Endep (R)
060 Epitol (R)
033 Equagesic (R)
033 Equanil (R)
029 Eskalith (R)
102 estazolam
079 ethosuximide
043 *Etrafon (R)
076 felbamate
076 Felbatol (R)
021 fenfluramine
022 fluoxetine
023 *fluphenazine
024 flurazepam
107 gabapentin
096 Genahist (R)
055 Halcion (R)
025 *Haldol (R)
025 *haloperidol
026 hydroxyzine
027 Iamimine (R)
027 imipramine
063 Inderal (R)
063 Ipran (R)
028 isocarboxazid
059 Isoptin (R)
027 Janimine (R)
013 Klonopin (R)
106 Lamictal (R)
106 lamotrigine
011 Libritabs (R)
011 Librium (R)
098 Limbitrol DS (R)
029 Lithane (R)
029 lithium
029 Lithobid (R)
029 Lithonate (R)
029 Lithotabs (R)
030 lorazepam
031 *loxapine
031 *Loxitane (R)
032 Ludiomil (R)
066 Luminal (R)
032 maprotiline
028 Marplan (R)
035 *Mäxolon (R)
069 Mebaral (R)
051 *Mellaril (R)
070 mephenytoin
069 mephobarbital
033 meprobamate
033 Meprospan (R)
070 Mesantoin (R)
034 *mesoridazine
036 methamphetamine
065 methsuximide
037 methylphenidate
035 *metoclopramide
033 Miltown (R)
011 Mitran (R)
038 *Moban (R)
038 *molindone HCl
072 Mysoline (R)
061 nadolol
039 naloxone
039 naltrexone
039 Narcan (R)
044 Nardil (R)
052 *Navane (R)
105 nefazodone
107 Neurontin (R)
096 Nidryl (R)
010 Noctec (R)
027 Norfranil (R)
017 Norpramin (R)
040 nortriptyline
096 Nytol (R)
035 *Octamide (R)
045 *Orap (R)
041 oxazepam
018 Oxydess (R)
040 Pamelor (R)
073 paramethadione
073 Paradione (R)
053 Parnate (R)
082 paroxetine
082 Paxil (R)
042 pemoline
023 *Permitil (R)
043 *perphenazine
017 Pertofrane (R)
075 phenacemide
044 phenelzine sulphate
066 phenobarbital
075 Phenurone (R)
067 phenytoin
045 *pimozide
046 piperactazine
021 Pondimin (R)
047 prazepam
072 primidone
048 *prochlorperazine
023 *Prolixin (R)
063 propranolol
102 Prosom (R)
049 protriptyline
022 Prozac (R)
101 quazepam
046 Quide (R)
035 *Reclomide (R)
035 *Reglan (R)
011 Reposana-10 (R)
050 Restoril (R)
039 Revia (R)
039 Revia (R)
103 *Risperdal (R)
103 risperidone
037 Ritalin (R)
041 Serax (R)
034 *Serentil (R)
083 sertraline
105 Serzone (R)
020 Sinequan (R)
066 Solfoton (R)
018 Spancab (R)
056 *Stelazine (R)
058 Surmontil (R)
003 Symmetrel (R)
108 tacrine
081 *Taractan (R)
060 Tegretol (R)
050 temazepam
051 *thioridazine
052 *thiothixene HCl
012 *Thorazine (R)
001 Tindal (R)
027 Tipramine (R)
027 Tofranil (R)
053 tranylcypromine
015 Tranxene (R)
054 trazodone
039 Trexan (R)
043 *Triavil (R)
055 triazolam
077 Tridione (R)
056 *trifluoperazine
086 *trifluopromazine
087 trihexiphenidyl
043 *Trilafon (R)
077 trimethadione
058 trimipramine maleate
062 Valium (R)
080 valproate sodium
064 valproic acid
062 Valrelease (R)
104 venlafaxine
059 Verelan (R)
059 verapamil
047 Verstran (R)
086 *Vesprin (R)
026 Vistaril (R)
049 Vivactil (R)
091 Wellbutrin (R)
002 Xanax (R)
079 Zarontin (R)
062 Zetran (R)
083 Zoloft (R)
100 zolpidum tartrate

CONVERSIONS:
1 ml = 1 cc
5 ml = 1 teasp
15 ml = 1 tablesp
30 ml = 1 fl oz

* = neuroleptic, major tranquilizer, or potential cause of drug-induced movement disorder

	Yes	No	Don't Know	Not applicable
86. If s/he receives a medication for behavior control, has a written behavior management plan been developed and implemented? (if not YES skip to #90)	○	○	○	
87a. What does the plan authorize you to do? *(MARK ALL THAT APPLY)*				
Ignore	○	○	○	
Verbal Reinforcement (positive or negative)	○	○	○	
Redirection/Alternative Behaviors	○	○	○	
Time Out	○	○	○	
Withdrawal of Privileges	○	○	○	
Restraint	○	○	○	
89. Have behaviors of concern improved since the behavior management plan started?	○	○	○	
90. If the individual received a drug identified with an asterisk has the individual received a screening for Tardive Dyskensia (an AIMS/DISCUS test) in the past year?	○	○	○	○
91 Have screening results been positive for Tardive Dyskensia in the past year?	○	○	○	○

SECTION VII: OBRA INFORMATION

91A. Have any of the following conditions occurred during the last year: **(ASK FOR OBRA CLIENTS ONLY)** *(MARK ALL THAT APPLY)*

HEALTH CONDITIONS	HEALTH CONDITIONS
○ Allergies	○ GI Problems
○ Drug	○ Colostomy
○ Skin	○ Reflux
○ Other	○ Ulcers
○ Anemia	○ Hearing Problems
○ Arthritis	○ Wax build up
○ Bed Sores	○ Other
○ Broken Bones	○ Heart Problems
○ Bladder/Kidney Problems	○ Congestive Heart Failure
○ UTI	○ Myocardial Infarction
○ Other	○ Shortness of Breath
○ Cancer	○ Hypertension
○ Breast	○ HIV (AIDS)
○ Cervix	○ Liver Problems
○ Lung	○ Cirrhosis
○ Prostate	○ Hepatitis
○ Uterus	○ Other
○ Other	○ Mental Health Problems
○ Chronic Constipation/Diarrhea	○ Osteoporosis
○ Dementia	○ Paralysis
○ Depression	○ Seizures
○ Diabetes	○ Sleep Disorders
○ Dizziness	○ Stroke
○ Electrolyte Imbalance	○ Thyroid Problems
○ Sodium	○ Graves
○ Potassium	○ Myxedema
○ Falls	○ Vision Problems
○ Gallbladder Problems	○ Cataracts
○ Gallstones	○ Glaucoma
○ Other	○ Other

OBRA Specialized Services - (Ask the following only for OBRA people living in Nursing Facilities)
Is this person receiving Specialized Services? ○ Yes ○ No ○ Unknown (If no, or unknown, skip to question #114)

If Yes, describe the 3 most important or most comprehensive services and *indicate which of the seven major life areas each service addresses?*

1. **Self Care Activities**
2. **Receptive/expressive language**
3. **Learning**
4. **Mobility**
5. **Self Direction**
6. **Capacity for independent living**
7. **Economic Self-sufficiency**

Specialized Service #1 _____ ☐☐ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨

_____

_____

Area addressed: ①②③④⑤⑥⑦

Specialized Service #2 _____ ☐☐ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨

_____

_____

Area addressed: ①②③④⑤⑥⑦

Specialized Service #3 _____ ☐☐ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨

_____

_____

Area addressed: ①②③④⑤⑥⑦

SECTION VIII: SERVICE PLANNING/DELIVERY

114. Does s/he have an individual habilitation plan (IHP) or individual program plan (IPP) or (IEP) or (IDP) or plan of care?

○ Yes, and it is under one year old
○ Yes, but over 1 year old (Skip to question #128)
○ Yes, but not on site or can not find (Skip to question #128)
○ No written plan (Skip to question #128)

115. What was the date the most recent written plan was developed?

○ Date Unknown

M ☐ ⓪①
M ☐ ⓪①②③④⑤⑥⑦⑧⑨
Y ☐ ⓪①②③④⑤⑥⑦⑧⑨
Y ☐ ⓪①②③④⑤⑥⑦⑧⑨

Are paid supports addressing the following goal/skill areas?	Yes	No
116. Work skills?	○	○
117. Recreational skills?	○	○
118. Self-care skills?	○	○
119. Domestic skills (including food preparation)?	○	○
120. Community living skills?	○	○
121. Sensory, motor skills (ambulation; arm use and hand-eye coordination; sensory awareness)?	○	○
121A. Health issues?	○	○
121B. Money management skills? Use of money?	○	○
122. Communication skills? (vision, hearing, use of verbal language; use of nonverbal communication; use of written language; use of numbers and numeric concepts)?	○	○
123. Reductions of challenging behavior?	○	○
124. Development of social skills?	○	○
125. Citizenship instruction?	○	○
126. Other goal directed activities?	○	○
127. Other educational goals?	○	○

For the following, what is the total number of hours spent per MONTH for him/her by:	Prescribed but not received. Why not received?
128. Hours spent on habilitation objectives identified in the IHP ☐ ☐ ☐ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ ☐ ⓪①②③④⑤⑥⑦⑧⑨
129. Homemaker Services by certified homemaker: ☐ ☐ ☐ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ ☐ ⓪①②③④⑤⑥⑦⑧⑨
130. Occupational Therapy Services: ☐ ☐ ☐ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ ☐ ⓪①②③④⑤⑥⑦⑧⑨
131. Physical Therapy Services: ☐ ☐ ☐ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ ☐ ⓪①②③④⑤⑥⑦⑧⑨
132. Psychological Services by licensed psychologist or psychological assistant: ☐ ☐ ☐ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ ☐ ⓪①②③④⑤⑥⑦⑧⑨
133. Psychiatric Services: ☐ ☐ ☐ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ ☐ ⓪①②③④⑤⑥⑦⑧⑨

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For the following, what is the total number of hours spent per MONTH for him/her by:	Prescribed but not received. Why not received?
146. Formal infant stimulation or preschool development training program outside of home: ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ _____ ⓪①②③④⑤⑥⑦⑧⑨
147. Homebound Education: ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ _____ ⓪①②③④⑤⑥⑦⑧⑨
148. Respite Services: ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ _____ ⓪①②③④⑤⑥⑦⑧⑨
148A. How many hours of HTS are prescribed on the IHP? ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨	
149. Any other services received: ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ If yes, what service: _____	⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨
150. Any transportation services prescribed: ○ Yes ○ No If Yes, from: ○ DDSD ○ Agency ○ Facility ○ Other	
151. Any other services needed? ○ Yes ○ No If Yes, what service: _____	⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨

PART II: CONSUMER INTERVIEW (COPYRIGHT COA 1986)

Interviewers: Gather this information prior to consumer interview to personalize conversation.

Family _____ Case Manager _____ Advocate _____ Favorite Thing _____

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

Hi! My name is _____. How are you today? Can I ask you a few questions? (*Note: OBRA responses are not confidential and respondents should be aware of that*) OBRA respondents informed? ○ Yes ○ No

○ Willing — Why unwilling _____ _____ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨

○ Unwilling _____

○ Unable (If unwilling, or unable, skip to Question # 26) — Why unable _____ _____ _____ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨

Is your favorite (food/toy/hobby) _____? I'm going to ask you some silly questions now. Just tell me yes or no, even though they are silly, OK? Do cats fly? Ⓨ Ⓝ Do dogs bark? Ⓨ Ⓝ Now I've got some questions that aren't so silly.

Which person is SMILING? ○ CORRECT ○ INCORRECT
Which person is STANDING? ○ CORRECT ○ INCORRECT

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For the following, what is the total number of hours spent per MONTH for him/her by:	Prescribed but not received. Why not received?
134. Speech and Communication Therapy: ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ _____ ⓪①②③④⑤⑥⑦⑧⑨
135. Audiology Services: ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ _____ ⓪①②③④⑤⑥⑦⑧⑨
136. Nursing Services by RN or LPN: ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ _____ ⓪①②③④⑤⑥⑦⑧⑨
137. Pre-Vocational Services: (non paid employment) ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ _____ ⓪①②③④⑤⑥⑦⑧⑨
138. Sheltered Employment/ Sheltered Workshop: (provided by workshop but receive less than minimum wage). ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ _____ ⓪①②③④⑤⑥⑦⑧⑨
139. Supported Employment: (Paid & supervised by job coach, mobile work crews, job enclave). ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ _____ ⓪①②③④⑤⑥⑦⑧⑨
140. Competitive Employment: ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ _____ ⓪①②③④⑤⑥⑦⑧⑨
141. Public School (regular classes): ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ _____ ⓪①②③④⑤⑥⑦⑧⑨
142. Public School (special classes): ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ _____ ⓪①②③④⑤⑥⑦⑧⑨
143. Special School: ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ _____ ⓪①②③④⑤⑥⑦⑧⑨
144. Private School: (Paid for by school system) ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ _____ ⓪①②③④⑤⑥⑦⑧⑨
145. Private School: (other than above) ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨ ⓪①②③④⑤⑥⑦⑧⑨	Reason: _____ _____ ⓪①②③④⑤⑥⑦⑧⑨

	Yes (nice, like, good, always, frequently)	Sometimes (occasionally)	No (mean, bad, never, don't like)	Did not answer	Not applicable
1. Do you like living here or not like living here?	○	○	○	○	○
2. Do you like _____ (the people who work with you) or not like them?	○	○	○	○	○
3. Is the food here good or bad?	○	○	○	○	○
4. Do you have enough clothes to wear or not enough?	○	○	○	○	○
5. Do you have any really good friends? Who?	○	○	○	○	○
5A. Do you have any other good friends?	○	○	○	○	○
6. Are _____ (the people who work with you) mean or nice?	○	○	○	○	○
7. (What do you do during the day?) Do you like _____ (these things you do in the day) or not like them?	○	○	○	○	○
8. (Do you work? If so:) Do you earn money?	○	○	○	○	○
9. Please let me check - is the food here bad or good?	○	○	○	○	○
15. Do you choose how you spend your money or does someone choose for you?	○	○	○	○	○
11. Do you choose the clothes you will buy or does someone choose for you?	○	○	○	○	○
10A. In a restaurant, do you choose the food you will eat or does someone choose for you?	○	○	○	○	○
10. At home, do you choose the food you will eat or does someone choose for you?	○	○	○	○	○
12. Do you choose the clothes you will wear or does someone choose for you?	○	○	○	○	○
13. Do you choose what you will do or does someone choose for you?	○	○	○	○	○
14. Do you choose your own friends or partners or does someone choose for you?	○	○	○	○	○
18. How often do you visit with your family?	○	○	○	○	○
16. How often do you visit with your friends? If never, skip #17.	○	○	○	○	○
17. Can you visit your friends in privacy?	○	○	○	○	○
20. How often do you visit with your advocates?	○	○	○	○	○
20A. How often do you visit with your case manager?	○	○	○	○	○
21. Do you go places for recreation or stay at home?	○	○	○	○	○

23. How do you feel about living here?
○ Likes a lot ○ Likes ○ OK ○ Dislikes ○ Dislikes a lot ○ Unable to assess

What is the best thing about living here? _____ ☐☐ ⓪①②③④⑤⑥⑦⑧⑨

What is the worst thing about living here? _____ ☐☐ ⓪①②③④⑤⑥⑦⑧⑨

If you could live anywhere you wanted, where would you live? _____ ☐☐ ⓪①②③④⑤⑥⑦⑧⑨

24. Is there something you would like to do someday? ○ Yes ○ No, skip to #25

If yes, What? _____

_____

Is someone working with you to do that? ○ Yes ○ No

25. If you had one wish, what would you wish for?

_____

_____

25A. Generally, does this person seem happy? ○ Yes ○ No ○ Unable to assess

Do you believe these answers are: ○ Reliable ○ Not reliable

Did you use our Adaptive Communication Device? ○ Yes ○ No

Did you work with a facilitator? ○ Yes ○ No

PART III: OBSERVATIONS

26. Is s/he dressed appropriately?
○ Yes Explain 'No' answer:
○ No _____

27 Is s/he clean and groomed appropriately?
○ Yes Explain 'No' answer:
○ No _____

28. Is s/he free of visible bruises, rashes, sores, cuts, or other signs of ill health?
○ Yes Explain 'No' answer:
○ No _____

PART IV: PHYSICAL QUALITY

1. Do you have any concerns about the neighborhood?
○ Yes Explain 'Yes' answer:
○ No _____

2. Do you have any concerns about the exterior of the residence?
○ Yes Explain 'Yes' answer:
○ No _____

3. Do you have any concerns about the interior of the residence?
○ Yes Explain 'Yes' answer:
○ No _____

4. Do you have any concerns about the health or welfare of the consumer(s) living here?
○ Yes Explain 'Yes' answer:
○ No _____

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VITA

Shana L. Porteen

Candidate for the Degree of

Master of Science

Thesis: DEINSTITUTIONALIZATION AND ACCOMPANYING CHANGES AMONG PEOPLE WITH DEVELOPMENTAL DISABILITIES

Major Field: Sociology

Biographical:

Personal Data: Born in Havre, Montana, December 5,1972, daughter of Marvin Porteen and Linda Porteen-Gottfried.

Education: Graduated from Perkins-Tryon High School in May 1991; received Bachelors of Arts in Sociology from Oklahoma State University. Completed requirements for the Master of Science Degree with a major in Sociology at Oklahoma State University in May, 2000.

Professional Organizations: Member of Alpha Kappa Delta since 1996. Member of Southwest Sociological Association since 1995. Member of Mid-South Sociological Association since 1996. Member od Mid-West Sociological Association since 1997.

Professional Experience: Employed as a teaching assistant for Kenneth Kiser at Oklahoma State University 1997-1999. Employed as an interviewer for United Way community needs assessment project for Stillwater, Oklahoma, 1999.