THE SOCIAL PSYCHOLOGICAL EFFECTS OF DEINSTITUTIONALIZATION ON THE WISHES OF PEOPLE WITH DEVELOPMENTAL DISABILITIES, A FIVE YEAR STUDY

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Introduction

Across the United States there is a movement toward deinstitutionalization for individuals with mental retardation. In Oklahoma this began with the judgment from the *Homeward Bound, Inc. v. Hissom Memorial Center* lawsuit. In this landmark decision, the court found that:

> Oklahoma together with other states built retardation institutions with public funds in faraway places, hired staff, and then pressured people to put their retarded children there for the welfare of the community . . . Hissom was built for a different time, for different needs, for different priorities, and different perceptions (Homeward Bound, Findings and Conclusions, supra at 19).

The court feels segregation causes serious problems, such as "reduced learning, reduced freedom, and reduced growth" (ibid. at 33). In communities around the state and country, this form of isolationism creates, perpetuates and internalizes prejudice against those with developmental disabilities. The result is the commitment to shut down Hissom Memorial Center and to reintroduce those with developmental disabilities into the community. This movement has created an interest around the country as to the outcomes those with developmental disabilities will endure.

Institutionalization for those with developmental disabilities not only isolates 'typical' people from interaction with, but also excludes behavioral and social scientists from easy access or knowledge of these people. There has been a movement toward empirical research in this field.

There are several studies regarding the effects of deinstitutionalization on such issues as the family (Conroy 1985), mortality (Heller 1984), regimentation (Howard 1990), behavior (Walsh and Walsh 1982), human rights (Hudson 1988), housing (May, Dobush, Endres, Getto, Patterson, Zipkin, and Kundert 1992), and neighborhood attitudes (Pittock and Potts 1988; Graham and Hogan 1990). Studies on deinstitutionalization have been mixed in their reviews. Some have found improvements of those deinstitutionalized claiming more integration with mainstream society and an overall better quality of life (Conroy, Ervin and Murray 1993; Hayden, Lakin, Bruininks, Copher and Hill 1992; and Horner, Stoner and Fergusen; 1988). Others (Crapps, Langione and Swaim 1985; Bercovici 1983) claim that deinstitutionalization can lead to social isolation.

Typically the research done outside of case studies focuses on physical behavior or ability without regard to the meanings placed on activity by those with the disability. Quality of life issues tend to focus on quantitative aspects of living in a community. How many times an individual goes out into the community helps in determining a better quality of life (Conroy, Ervin and Murray 1993; Hayden, Lakin, Bruininks, Copher and Hill 1992; Parker and Boles 1990; Oswald, Gliner and Spencer 1991). Others use similar methods, however, finding community living leading to more social isolation (Crapps, Langione and Swaim 1985: Howard 1990; Rhoades and Browning 1982; Bercovici 1983).

There are studies that shed some light on the perceptions of people with developmental disabilities. Lea's (1988) study of six individuals with mental retardation is remarkable in demonstrating an awareness of the world around them; their poetry shows a complex order of thought. Chadsey-Rusch et. al. (1992) study on the loneliness of workers with developmental disabilities documents the alienation experienced by those workers with developmental disabilities who are ignored by their typical coworkers. Alienation in this form may indicate that people with developmental disabilities who work side by side with typical people have an understanding of their situation. This understanding has also been found when looking at relations with parents. The research reports that persons with developmental disabilities feel a need to distance themselves from the control of their parents. (Winik, Zetlin and Kaufman 1985; Zetlin and Turner 1985).

Studies of accepting relationships, that is, those between a typical person and an individual with a developmental disability demonstrate reciprocity which requires compassion and knowledge of others (Bogdan and Taylor 1989; Lutfiyya 1991). To have a friendship, there needs to be benefits for both parties. In this situation, persons with disabilities share similar ideas and expectations about the characteristics of friendships. They understand "the mutual, exclusive and voluntary nature; the rights, obligations, and responsibilities of friends to each other; and the positive regard or affection found between friends" (Lutfiyya 1991, p. 233). Without an ability to meet the needs of the typical person, the relationship would be no different than relations with staff.

The focus of this study is on the effects of deinstitutionalization on the wishes of people with developmental disabilities. A wish is defined as a yearning or desire. It represents the state of mind of an individual and indicates his/her degree of socialization. As each person becomes deinstitutionalized, their state of mind or point of view should necessarily become similar to those of the typical population. This acts as motivation to achieve the same desired goals as the typical population.

While Seyfarth, Hill, Orlove and McMillan (1987) have looked into expectations of family members related to those with developmental disabilities, Brantlinger (1988a; 1988b) has studied the expectations of teachers of these individuals. No studies have included information from the people who have disabilities.

The author (1994) conducted a study of wishes of 781 people with developmental disabilities in four different types of residential placements (state schools, nursing facilities, intermediate care facilities for the mentally retarded, and group homes). It is clear that these individuals can and do express specific wishes and that they vary based on type of residential placement. Those in group homes identified wishes reflecting a broader experience base than the others. Their wishes include such things as 'to live on their own', to have 'lots of money' and 'to have world peace'. Those in other placements wish for food, relationships, and appliances. These differences in wishes by residential placement are likely to be related to level of cognitive ability as well. Many consider those in group homes to be higher functioning and their wishes may also reflect a greater awareness based on their natural ability rather than placement.

This study looks at 160 individuals with developmental disabilities during the years 1989-90 and 1993-94. The researcher will look at the differences in wishes, including an evaluation of how the wishes have changed over time. The differences will be further pursued controlling for other demographic and non-demographic variables, e.g., type of residence, gender, level of mental retardation, other disabilities, ability to read, speak, job status, type of employment, history of seizures, a behavior management plan, ability to dress, bathe and use the restroom.

Because wishes deal with social constructions of reality, a person's definition of the situation must be taken into account. In this sense, a Symbolic Interactionist perspective will be used. A person's self, its development and its function will be addressed, as will self-concept, self worth, role taking ability, identity, and transformations. Finally, the discussion of motivation and action will be centered around the theoretical foundations of Perinbanayagam.

Chapter Two

The Self

A self is the ability to see oneself as an object. "A human being may perceive himself, have conceptions of himself, communicate with himself, and act toward himself" (Blumer 1969 p. 62). Humans have the ability to develop a self; it is not an innate quality. The self develops in stages over time.

The Stages of Self Development:

Mead (1962) and Couch (1989) provide theoretical bases for explaining the processes by which a physical organism comes to form a 'self'. It is suggested that while people with developmental disabilities go through the stages of self development more slowly than the typical person (Rumelhart 1983), they nevertheless experience the course of development. Use of names here, such as, 'toddler' and 'infant' are not generally descriptive of these individuals' physical development in conjunction with their self development. They are used here as a frame of reference.

There are five stages in the development of the self. The first stage is one in which the infant is not a social being. The infant is one with nature, and does not see itself apart from the environment. The second stage is the acquisition of significant gestures by the infant. These develop out of interaction with others, more likely being significant others. A significant gesture is that part of an act that produces an adjustment by another. In this case, the meaning is brought about by the person to whom the gesture is directed. The infant at this point realizes that he/she can cause responses by actions delivered.

The third stage is the acquisition of significant symbols. These are gestures that call out similar meaning in the individual to whom the gesture is addressed. In this stage, the infant is using and beginning to manipulate symbols through gestures. A shared focus with the significant other becomes a reality in his/her life. The acquisition of these symbols attaches meaning to gestures. During this time, the toddler/infant may see a photo of him/herself, but only respond to it as "baby," not recognizing it as a representation of him/herself.

The fourth stage is the point in which the development of the conscious self takes place. The toddler/infant begins the process of categorizing others and their attitudes and in turn realizing that he/she is being categorized by others. This is very similar to the period of development referred to by Mead as the 'play stage'. The toddler/infant sees him/herself as an object. While looking at a photo of him/herself, the toddler/infant will acknowledge the photo as that of a baby, and that he/she is the baby in the photo. The toddler/infant takes the role of a specific other, generally the parent. He/she perceives the parents as smaller versions of the generalized other. He/she is able to see him/herself as the parents or significant others see him/her. Here begins the reflexive aspect of role taking.

The fifth stage is the point at which the individual takes on the role of the generalized other[1], i.e., taking the attitudes or perspectives of the community. A consciousness develops in which the person is now able to distinguish between other groups and categorize the differences among them. As each interaction occurs, adjustment is made as a result of categorizing new information that is gathered.

Having a self implies the individual is neither totally an object pushed around by nature nor a completely free subject who acts out every whim without context to the action. The self allows the individual to be both subject and object of his/her own acts. Humans plan, imagine, and reflect on their every gesture. To be an object is the ability to be self-aware. Without a self, the individual would not be able to discriminate between him/herself and the environment (Mead 1962). By taking the role of the other, the individual is perceiving, evaluating, judging (Felson 1980) and responding to his/her own behavior. Reflection leads to seeing him/herself as objects to manipulate the environment in order

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[1] Taking the role of the other, the generalized other and role taking are used synonymously in this paper.

to achieve goals. One cannot have a self without being able to see oneself as an object.

The self has two phases: the 'I' and the 'Me'. The 'I' is the creative and imaginative phase of the self. This phase creates new lines of action. It emerges in the present and allows the individual to adapt to new situations. "It is the self of unnecessitated choice of undreamt hypothesis, of inventions that change the whole force of nature" (Mead 1964/1981 p. 54). The 'I' is a preconscious facet of the self. It transcends past, present, and future by reacting to all three time stimuli. As the active phase of the self, it reflects upon the 'Me', but is not reflected upon. It is the 'I' and the 'Me' acting together that consciousness in the form of the 'self' emerges.

The reflected upon phase of the self is the 'Me'. The 'Me' contains the knowledge of roles, situations, acts, and other individuals. It is the location of the Generalized Other. The 'Me' is the internalized collection of values, rules, and norms of society. These provide the basis for judging the actions of self and others.

In the course of day-to-day events, the 'I' and the 'Me' are in frequent discourse. The 'I' accesses the 'Me' for information on how to act, then commits to action. The 'I' then proceeds in an adaptive manner in which the entire process repeats itself. As actions and situations change, the knowledge of how one has acted and how others have responded is incorporated into the 'Me', thus expanding one's knowledge of themselves and of society.

The Self Concept:

While the self is considered a process (Gecas 1982), the self concept is the product of this process. Rosenberg (1979) sees the self concept as "the picture of the self;" it is "the totality of the individual's thoughts and feelings having reference to himself as an object" (p. 7). For Gecas it is "an organization of various identities and attributes, and their evaluations developed out of the individual's reflexive, social, and symbolic activities" (p. 4).

Within the self concept are identities and self evaluations/self esteem. Identities, can be the by-product of near total influence from others and the situation, such as a total institution (Goffman 1961). When a person becomes situated, he/she is placed in a category, labeled into expected behavior, attitudes, values and beliefs. This is established when others place him/her in a position or see him/her as a similar object as the individual sees him/herself (Couch 1958; Stone 1970). It is here where separation occurs and the individual has expectations put upon him/her. This can be in the form of dress, language, possessions, hairstyles, and a number of other appearances (Goffman 1959; Stone 1970).

Others, such as Hewitt (1989), see the interaction that goes on between the 'I' and the 'Me' playing a much more central theme in the formation of identities. Hewitt feels that Mead's view of the generalized other, leads to an over socialized view of humans. This is based on Mead at times sounding deterministic or nontransituational.

> It is the process of the generalized other that the social process influences the behavior of the individuals involved in it and carrying it on, i.e., that the community exercise control over the conduct of its individual members; for it is in this form that the social process or community enters as a determining factor into the individual's thinking (1962 p.155).

Hewitt argues that the same processes that make up an interaction i.e., gesture toward an organism, the organism's response to that gesture, and in turn, the acknowledgement of the first person of the second's response to the gesture, are found within the self of each individual. This is 'self talk'. In 'self talk', the 'I' is, throughout much of the day, having a conversation with the different 'Me's' with which it has built up over the life course. During this time, this conversation is taking place with adjustments being made to account for several generalized other's. There is a certain amount of give and take going on within the mind. The development of a personal identity evolves in which the individual is a distinct personality from others around him/her. This allows for the emergent behavior that continues throughout the life course of an individual. The more access to more generalized other's, the more ability to develop more emergent and, therefore, independent behavior.

Most Sociologists would acknowledge the influence of others on the behavior, attitudes, values, and beliefs of the individual. Neither Stone nor Goffman would disagree with Hewitt's claims. Without this emergent quality of a human, boredom would set in as all behavior would be predictable.

Multiple Selves:

The ability to have more than one self is critical in the study of Mead. He realizes that in the course of a day, an individual encounters many different people in many different contexts. Mead sees behavior as being contextual. How a person sees him/herself, and how others may see him/her will depend on the context of the situation. A person will put on different roles or perspectives for each situation. This represents a change in generalized others. The individual is never the same from one encounter to another. One may be a professor in one instance and spouse in the next. He sees these as elementary selves (1962) which make up the complete self. These are represented in the 'Me' phase of the self. They are the perspectives the 'I' reflects on before acting. Each individual over the life course can develop literally millions of selves from which to draw.

Manford Kuhn (1954) recognized this and attempted to find the attitudes (generalized other) which make up the individual. He did this in the form of The Twenty Statements Test, which asked the question "Who Am I?" In this study, Kuhn and McPartland took 288 college students and asked them to answer this question up to twenty times. While this barely tapped the essence of what Mead was saying, it demonstrated the diversity of the individual. There was no one attitude which the individual took upon him/herself; there were several. And within the framework of these answers, one could break them down even more.

It is in this area of multiple selves that Kenneth Gergen (1991) discusses the many changes the individual has to deal with in present day life. In contrasting the changes from present day to the nineteenth century, Gergen demonstrates the differences in amount of stimuli from Durkheim's society of mechanical solidarity to postmodern society.

> "The contrast to my typical day at work makes clear that I am the victim (or benefactor) of profound changes that have been taking place throughout the twentieth century. New technologies make it possible to sustain relationships-either directly or indirectly-with an ever expanding range of other persons. In many respects we are reaching what may be viewed as a state of social saturation." (p. 3)

Self-Esteem:

William James (1971) viewed self esteem as a function of the discrepancy between aspirations and achievements. Typically, the definition is a personal judgment of worthiness that is expressed in the attitudes the individual holds toward him/herself. In the course of one's life, our judgments about ourselves are derived from those with whom we have contact (Gecas 1982; Goffman 1961; Wells and Marwell 1976; Rosenberg 1979). Our ability to take the role of the other allows us to make or perform judgments.

Individuals have a bias toward favorable assessments

(Rosenberg 1973). We tend to group with others who give us these assessments. To protect ourselves from what others think we block and/or ignore negative thoughts (Goffman 1959; Felson 1980). This corresponds with studies that show high levels of general self esteem among minority groups (Rosenberg 1973; McCarthy and Yancey 1971; Zetlin, Heriot and Turner 1985; Stager, Chassin and Young 1981). McCarthy and Yancey (1971) however, use a social structural explanation for high self esteem among those viewed as disadvantaged. They see this as 'blaming the system' for their plight. It is not a matter of ability, it is the 'powers that be'.

Identity and People With Mental Retardation:

The problem of interaction for people with mental retardation is the inability to interact in a typical fashion so as to be inconspicuous in society[2]. Because of this inability, society has typically attached a stigma to them and has often placed them in institutions. Another problem for those with mental retardation is that of time and the inability to interact with typical people in a timely fashion.

For a typical individual, one can role-take quickly, easily, and then adjust, adapt and continue *ad infinitum*. An individual with mental retardation has a difficult time learning anything quickly. Part of the problem is that their

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[2] Rhoades and Browning state that the purpose of deinstitutionalization is to train these individuals to disappear in society. *Mid American Review of Sociology*, Vol. 7, 1982, pp.139-170.

short term memory is inefficient (Schloss 1988). Learning requires repetition. For typical people, partial reinforcement is best for learning. For those with mental retardation, continual reinforcement is needed. The ability to role take is problematic instead of taken for granted. In a Meadian model, this presents significant problems. First, the ability to role take no longer occurs continually in interactions, it is fractured. The process becomes much slower. The inability to demonstrate taking the role of the other as quickly as others causes problems in interaction (Rumelhart 1983; Yoels, Clair, Ritchey and Allman 1993). The inability does not allow for the individual to anticipate, and reflect quickly enough to keep up with a typical person. In a society in which the citizen is expected to assimilate, this places those with mental retardation on the outside looking in.

Second, the individual has fewer Me's from which to draw. Because an individual is less able to role take, their observance of community attitudes is obstructed severely. There are fewer categories in the mind from which to draw information. The fewer categories of 'me's' the less social anchorage. With little anchorage, he/she will be influenced much more by others (Couch 1958; Goffman 1961; Rhoades and Browning 1982).

With less knowledge of society, the emergent character of the individual's with mental retardation behavior is reduced.

Inappropriate behavior is much more likely. A 'response set', that is a standard set of action across multiple contexts, is common. The individual, not able to role take acts identically or similar in any one context due to he/she not being able to understand the contextual matter in the interaction.

In typical people, there are category after category of attitudes of the community in the mind. From this library of knowledge, in any given interaction or encounter, meanings will have several layers of degrees. Along with the degrees are contextual meanings with which they may be applied.

For those with mental retardation, this luxury does not exist. Categories are fewer, There is less abstract thought involved, ideas are concrete[3]. If a situation requires a distinction between good and bad, good can become quite exciting while bad can be something horrific. Therefore, it is not unlikely for those with mental retardation to, in our terms, 'overreact' to a situation that may be stressful. Stone (1970) said as much regarding the 'definition of the situation'. "Definitions of situations are necessary conditions of human conduct. In their absence, human behavior may be paralyzed or so disoriented that what is often called

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[3] While conducting a pretest, individuals listed names of friends instead of giving a number. Also, staff commonly use objects to distinguish between yes and no. So if one were to ask a yes or no question, the staff person would hold out their left hand for 'yes', and their right hand for 'no'. The individual then points to the hand representing the answer.

panic ensues" (p. 147). These definitions are based upon the accuracy and ability to role take. This is dependent upon "the given individuals's ability to take the roles of, or put himself in the place of the other individuals implicated with him in given social situations; and upon his consequent sensitivity to their attitudes toward himself" (Mead 1962 p.141).

Situations are staged. "Elements of a situation are typically assembled, arranged, manipulated, and controlled by human beings so that the vast range of the possibilities of human conduct is circumscribed, once other humans enter the constructed situational scene" (Stone 1970 p. 149). A person with mental retardation has difficulties trying to orchestrate a situation (Waller 1961). They still can control a situation by using several techniques, e.g., remaining silent, saying as little as possible, changing the subject, or elaborating in an area well known by the other person (Rumelhart 1983). However, because of their physical and cognitive limitations, the variety of manipulations available is reduced.

Defining situations are processes (Waller 1961) just as role taking is a process. Role taking allows the person to categorize and develop large histories of knowledge. This allows the individual to manipulate a situation. As Waller explains, an intellectual person "enters into the process, and there ensues a dynamic reorganization of the parts of the situation" (p. 164). This leads Stone to proclaim that an intelligent person is hard to con. Nevertheless, definitions require staging. Goffman used 'setting' i.e. the physical layout of a place which also includes background items and props. This setting gives the actor the proper material and proper expectations needed to perform his/her role or part in an adequate fashion. He also notes that actors often cannot play their part until "they have brought themselves to the appropriate place, and must terminate their performance once they leave it" (1959 p. 22). People with mental retardation have difficulties expressing a knowledge of expected behavior in various contexts (Rumelhart 1983). Their awareness context is incomplete. They could be correct in discovering something wrong, however, their perception of how wrong something is may be distorted. For instance, quite often we find the same behavior used to express either hunger or sadness. Likewise, crying might be used for a multitude of situations.

It is not uncommon for this population to act out the same part regardless of the situation. The setting does not dictate behavior nor have as much emotional impact as it does with most typical people. The person with mental retardation is unable many times to distinguish between the importance or the meaning of given settings which may have a collective representation all their own.

Typical people are able to move from setting to setting, definition to definition quickly. Definitions of situations can and are understood by people with mental retardation, but to a lesser degree (Rumelhart 1983). As with identity, once a definition of the situation is established, it becomes more structured and institutionalized (Waller 1961). This allows people with mental retardation the ability to assimilate into settings that are consistent and repetitive. For those with mental retardation repetitive tasks and situations acquire constant and consistent definitions and then they are able to operate smoothly, albeit slowly[4]. It is here that similarities again arise with role taking and the self concept.

Settings provide the actors with the necessary materials and the context for expectations. This enables the interaction to proceed smoothly. This requires split second timing and often habitual action. For the person with mental retardation, this can be difficult. Both timing and understanding can be rather cumbersome. Zetlin et. al. (1985) demonstrate this in the course of an interview, by administering a likert scale, the Piers-Harris Self Concept Scale. The following is an interaction between the interviewer and the subject:

E: I wish I were different (Piers-Harris #43)
S: I'd like to be a different person.
E: What kind of a person would you like to be?

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[4] At a sheltered workshop visited, it is remarkable how well jobs are performed. This is attributed by the staff as repetition. When new jobs come in, each person in the workshop is tested to see their ability on that job. The person with the most competency takes the new job. This allows the workshop to continue putting out product by not upsetting the balance.

S: Nice and skinny, and pretty.
E: So you wish you were different looking?
S: I'd like-I hope-You think I'll lose weight?
E: Are you trying?
S: Uh, I think I like the way I am.
E: You like the way you are?
S: Yes.

This example demonstrates how both timing and meaning became lost in the course of a discussion. The Interviewer (E) makes the statement; "I wish I were different." The subject (S) is supposed to respond 'strongly agree', 'agree', 'disagree' or 'strongly disagree'. Instead, the subject responds "I'd like to be a different person." At this point, the interviewer does the face work by trying to return (her) to the subject matter at hand. The subject may or may not be trying to respond to the statement. Little evidence is given to indicate the subject is conducting face work other than continuing to interact with the interviewer. The item ends by the interviewer asking "You like the way you are?" The subject answers "yes."

Zetlin et.al. (1985) explain this interaction as `ideal', yet the final response does not apply to the original statement. Wishing you were different and liking the way you are, are distinct. Both could be true. While conducting interviews for the Developmental Disabilities Quality Assurance Project, we ask, 'Do you like living here?' Often the answer is yes, but the follow up, 'Would you like to live somewhere else?' is also answered yes. In addition, 'yes' is associated with being good, or honest, and does not reflect the feelings or the sentiments of the individual at all.

Social Contact Theory can explain the inability to role take. Stryker (1962) believes that when people have shared meanings, that role taking will become more accurate. Improved communication should result if social barriers break down. This could indicate that people with mental retardation will role take well with others with mental retardation, but should not be expected to with typical people. If they do not have common universes of discourse, expectations of role taking are moot. Schwalbe (1986 p. 97) explains that "no individual can take a perspective he is not familiar with, no matter what the external coercion."

Institutional Resource Theory states something different. Thomas, Franks and Calonico state,

> If our theorizing is accurate, any individual should be a more accurate role taker of people in superordinate rather than subordinate positions in the group. Here role taking is motivated by fear, or trying to please a superordinate. (1972 p. 613)

People with mental retardation could then, hypothetically, be better at role taking of typical people due to their always being in a subordinate position. This parallels both Goffman, as well as Browning and Rhoades assumptions that individuals in institutions or that have mental retardation are influenced mainly by those who are their superiors.

Transformations and Social Change:

In *The Mutable Self* (1977), Zurcher found that the more change there is around us, the more apt we are to adjust our attitudes about ourselves to accommodate these changes. When social change occurs slowly, personal continuity is typical (Strauss 1962). In postmodern society for each individual "an open slate emerges on which persons may inscribe, erase, and rewrite their identities as the ever-shifting, ever-expanding, and incoherent network of relationships invites or permits" (Gergen 1991). Instead of seeing his/herself as positions, such as banker, doctor, professor, he/she is seeing him/herself as a characteristic, such as, hard working, sensitive, funny, sad, etc. The likelihood of changing professions over the life course is now widely acceptable, as compared with times past when a person would leave school, get a job and retire from the same place of employment.

As society changes, the person with mental retardation is left further behind. In Durkheim's (1984) society of mechanical solidarity, the redundancy of everyday life allows an individual with mental retardation to fit in the societal framework (Fishley 1992). Repetition in jobs and stability in job title provides a relatively stable environment from which the foundation for a 'normal' life can occur. In this respect, any environment that is stable, settled, and consistent would be beneficial to people with developmental disabilities. Change occurs at a slow enough pace to allow the individual to get a firm grip on the generalized other and provide exclusivity (Hewitt 1989).

This is not to say that typical people do not have the same experiences. The routinization of everyday life, and the settling down which takes place affects the ability to accept change. Many typical people are uncomfortable with change due to the lack of integration and interaction with the rest of the world. However, they still have the ability to adapt to the changes around them. For those with mental retardation this is not the case. Too much stimulation can overload their ability to adapt and adjust to the situation.

This is not unlike the experience of international students. The inability to comprehend the language makes interaction difficult (Guan 1994). The international student can be found nodding their head without completely understanding what is being said. Also, the intent, or context of the conversation can be lost.

As our society moves into the postmodern era, over stimulation raises questions of how people will deal with the world of tomorrow. The bombardment of news from around the world, e.g., T.V., radio, and the multitude of everyday interactions can be equated with those with learning disabilities. The individual's system is given more stimulation than it can process. The individual of today is put in a position in which roles to be played are so diverse that choices are too abundant. Commitment to any particular role or view can only be partial in comparison to a society of mechanical solidarity. We are constantly in a position in which role blurring is a typical experience (Clignet and Brown 1991). A person with mental retardation deals with this experience everyday of their life. Would it not be advantageous to learn how people with mental retardation deal with this phenomena? Postmodern society could put many of us in similar positions.

In *Asylums,* Erving Goffman deals with life in mental institutions. He says that the self judgment of mental patients is almost completely in the hands of other people who have a great deal of control over the physical environment in which they live. He calls these total institutions. These are institutions which are apart from the world society, isolated and regimented. Any positive self judgments depend on the authorities and the actions they wish to support. To obey passively becomes action rewarded with praise and approval. A positive self judgment, as it becomes more and more dependent on authorities, is tied to obedience. Howard (1990) has documented the regimentation for those in group homes, which are a step toward independence. Others talk of the "every waking hour keep em' busy attitude[5]." This may negate a great deal of self reflection. If this be the case, then those in this type of situation would suffer the consequences of the total institution.

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[5] In my observations visiting several forms of living arrangements, staff often convey that the individuals with developmental disabilities rarely have any down time, other than to sleep.

Strauss (1959; 1962), while discussing the transformations one goes through in adulthood, talks of three forms of development that take place. He defines development as a "progressive movement wherein the beginning, middle, and end bear some discernible relationship to each other" (1962 p.64). The three types of development are attainment, variation to a basic theme, and transformation.

Dealing with Goffman's work on institutions, obedience is a highly touted method for gaining acceptance. If an individual obeys the rules, staff praise him/her for their actions. This promotes a higher self judgment. For most individuals with mental retardation, they are given an Individual Habilitation Plan (I.H.P.) in which goals are set for the forthcoming year. Attainment is used as a determinate for development. By reaching your goals, you are developing more, and have the ability to move on to more and more supposedly independent lifestyles. Transformations are similar to Mead's role taking. As the person develops "newer classifications" (role taking), "old ones become revised or qualified, or even drop out entirely from memory. These changes . . . involve . . . changes in behavior, since behavior is not separate from classifying. Shifts in concept connote shifts in perceiving remembering and valuing . . ." (1962 p. 66).

He mentions six major turning points in ones life which would provide the setting for transformation. They are: (1)

changes in relations with others, (2) behavior once predicted, now coming true, (3) a private proclamation to a public audience, (4) meeting a challenge or a self-test, (5) betrayal from someone with which you identify and, (6) passage from status to status. While these six turning points can be separate from attainment, in the case of those with mental retardation, points 2, 3, 4, and 6 are linked with the I.H.P. as they form attainment by positive goal attainment strategies (2), having the individual proclaim their confidence in achieving their goal (3), achieving their goals (4), and altercasting from staff at the completion of the goals (6). Because of high turnover levels of staff, points 1 and 5 can have negative effects on the individual as he/she my lose friends and feel a loss or betrayal from the person who leaves.

If a person is to reach points 2, 3, 4, and 6, he/she will gain approval from those staff and family members with whom he/she are in touch. These transformations will lead to a greater awareness of the world around the individual. In fact, his/her wishes would reflect a change to either match the world or his/her staff person working with the individual. Both Goffman (1961) as well as Rhoades and Browning (1982) find that persons living in institutions, or who have that form of living arrangements are more influenced by those in charge of the facility. Their views do not reflect their observations of society at large. It is the author's observation that the views many individuals with developmental disabilities have reflect only what their family or staff person's are telling them. There appears to be a lack of understanding about the ramifications of particular actions.

The Wish:

In *The Unadjusted Girl* (1969), W.I. Thomas conceptualized his 'four wishes', and the 'definition of the situation'. The latter being the methodological application of the former (Balfe 1981). Thomas viewed the four wishes which include: the desire for new experience, the desire for security, the desire for response, and the desire for recognition as universal psychological demands. They are persistent emotional predispositions of humans. What an individual wishes for determines or influences that individual's definition of the situation. Behavior is explained defining the wish as the motivational impulse from which each individual acts his/her part and/or sees the world. Thomas felt that wishes were the "forces which impel action" (p. 4).

Sociologists quickly disregarded this biological or instinctual motivation for behavior because it does not integrate socialization within the theory (Balfe 1981; Janowitz 1966; and Bulmer 1984). Instead of relying on biology or instincts to explain behavior, sociologists focus on socialization (Parsons 1951; Durkheim 1984) and the perceptions an individual has of others toward him/herself (Mead 1962; Goffman 1959; 1961; and Perinbanayagam 1985).

Here we view the wish as a social construct. Throughout a person's life, he/she is continually role taking and continually observing the world. The wish is representative of a person's wants and needs learned throughout his/her life. The more a person experiences the world, the more likely his/her wishes will be more broad. If a person lives within the confines of four walls, it is expected their wishes will be much more narrow in focus.

Motive:

Motives are defined here as a movement from words to deeds, or a movement forward with anticipated sequences. Dewey (1988) sees motivation as a sense of direction, not an organization of action. Motives do not make us act. According to Dewey humans naturally just act.

Perinbanayagam (1985) lists three types of motives. First is the observers interpretation of the actions of others. This is the process by which we acquire identity. It is very similar to the Looking Glass Self of Charles Horton Cooley and Mead's Generalized Other. A person reflects on the actions of others toward him/herself, and then acts on that interpretation. Second, the actor explains his/her own acts to another. This can be in the form of accounts or disclaimers. Often we are asked 'why?' we did something. An account would explain this. Dewey felt that motivation was explained after the event. Third, the actor becomes his/her own reflexive observer, and makes sense of his/her own action.

This is an account to one's self. This interaction in this instance occurs between the 'I' and the 'me'.

For people with developmental disabilities, the wish touches upon all three points. First, motivation is based on each individual's conception of who he/she is. A person cannot wish for anything without taking this into consideration. Secondly, to wish for something requires a person to give an account or justification for what he/she is wishing. If someone wishes for something, he/she needs to answer the question of 'why?' they wished for it. And third, the person needs to feel comfortable with his/her sense of action. If a person desires something, he/she will formulate a plan of action to attain his/her desire (Perinbanayagam 1985). When one does not feel worthy of something, he/she will subvert their actions, so as not to attain that desire (Perinbanayagam 1985).

A motive for action can be found in language. From language we are able to think and distinguish ourselves from our environment and to make sense of the world we see. This, in turn, enables us to act in given ways within given contexts. A wish acts as a program. Programs are

> signifying acts that elicit responsive validations and in turn become a meaning for the self; they are linguistic instruments that elicit common responses from participants in ongoing relationships and guide people in one direction rather than another. (Perinbanayagam 1985 p. 104)

An individual will inform others of the direction in which they see themselves going or would like to go. Others in turn will treat that person in a way in which they see fit based on the information the individual has given them. By wishing for something, the person with developmental disabilities is giving a program and, therefore, a direction they would like to go. This is based on their perception of others toward them and the way they see themselves. By making this information available, they not only have a direction for themselves to go, but provide information to others that will enable them to make arrangements in their lives to either help or hinder that direction.

The wish as program then is socially influenced:

> Programs are essentially social and systematically involve other human participants as well as investments of time, resources (money etc.), and institutional structures like families, schools, banks and bureaucracies. Programs can be said to give dramatic form to the future and it to be conceptualized in clear and concrete metaphors. Such a dramatic form includes a theory about the proper sequences to an act and to a biography and another about the particular relationship between self, other, and situation. (Perinbanayagam 1985 p. 104)

From the time a wish or any type of program is expressed, those involved in the person's life will help to proceed in the direction. This gives the appearance of order and purpose in the individual's life. There is a certain amount of legitimation to what that person has expressed. This is the case whether the expression is perceived as rational or irrational. From this point onward, based on the expression of a wish or other program, the individual's life will be changed forever. There are numerous possibilities the direction may turn (Perinbanayagam 1985).

Programs are part of texts and can be studied this way. We are trying to reach an essence of the wish as program. One does not have to express wishes in organized sentences. The individual may not be able to express him/herself in a typical fashion, but meanings may be similar to those of typical people. By understanding the context of a wish, one could know the individual's direction, or what it is they perceive in the world he/she lives.

Identity and Motive:

The identity we earn or are given by society will dictate or influence the motives we have at hand. Social validation will encourage or promote a change in motives to meet the identity of the person. These motives keep an identity intact. It allows others and the self to know the individual's past, present, and the direction they are headed in the future. These identities need to be maintained and reinforced continually for the program to remain for an individual to continue acting out these identities. Once the identity is changed, the motive or program also changes (Foote 1970).

Deinstitutionalization attempts to assimilate those with developmental disabilities back into society. By doing this, the wishes, goals and ambitions of this population are meant to be changed. These changes are a major objective in deinstitutionalization. The author's study of this population revealed that deinstitutionalization was effective in changing the wishes of those with mental retardation.

Motives and Role Blurring:

In present day society, individuals are subjected to massive amounts of stimuli. Motives of any one identity, therefore often reflect role blurring (Clignet and Brown 1991). Reaching one identity in any context is becoming more and more difficult. Each individual confronts an endless supply of options. We no longer have the time to keep in touch with family and friends. We hear of events going on all around the world and simultaneously have to deal with everything in our own lives.

A person with a developmental disability, specifically with mental retardation cannot process information quickly. Therefore everyday is consumed with role blurring. The motives of the individual become much more difficult to crystalize. Staying focused on a goal is made difficult at best (Rumelhart 1983). It is important for this population to express their wants and wishes for all of us to hear. When this occurs, we are placed in a position to help them achieve their goals.

Programs are social products. The motives from which we base our lives generally come from the society in which we live, the community (generalized other), and our significant others. From the time we are born, we are told by loved ones, friends, neighbors and mass media how we are to live our lives. We are told what we should want, when we should want it, and how to get it. This is no different for people with developmental disabilities. However, their motives come mainly from their significant others. With so much stimuli, the generalized other is replaced with the audience. The audience for those with developmental disabilities are the staff and family members.

Because this population processes information slowly, their need for patience and repetition is met by family members and the staff who work with them. The staff person or family member often projects their expectations onto that of the person with the developmental disability (Rhoades and Browning 1982). These people also give them their identity. The basis of their motives comes from their interactions with family members and staff personnel. With so much emphasis toward deinstitutionalization, it is not uncommon for family members or staff personnel to inform each individual with a disability as to what their goals are. Validation is given by these people. They offer to the individual with a disability the hope of something more or discourage them from wanting anything at all.

Once a program, or in this case, wish is validated, there is a point at which that wish is accepted or denied. If the wish is denied or becomes implausible, frustration may set in. The wish becomes a fairy tale. This eventually leads to abandonment and then substitution of other identities and programs. This will lead to a change in wishes. These frustrations may be felt by others involved with that person, and results in a loss of support for the prior identity. This facilitates changing identities and programs.

Research Questions:

The purpose of these questions is to provide direction in observing the data at hand. These questions will revolve around the wishes themselves, and the aggregate groups that provide the data. Given the information provided in the previous sections, several research questions arise:

1. What are the frequencies of wishes correlating with each of the variables that tested significant?
2. How do these frequencies change by splitting into level of mental retardation?
3. What variables test significant with wish as the dependent variable?
4. Does the change in political atmosphere in Oklahoma regarding its emphasis on deinstitutionalization have a cumulative effect on the wishes of individuals, regardless of their residential placement?
5. For the aggregate groups who went from institutions to community, how did their wishes change?
6. What does the data demonstrate with regard to the individual with mental retardation/developmental disabilities and his/her ability to understand the world around him/her?

Chapter Three

Methodology

One hundred sixty individuals with developmental disabilities were chosen for the study. They were chosen by selecting individuals interviewed by the Developmental Disabilities Quality Assurance Project (D.D.Q.A.P.) in Oklahoma. Each year the D.D.Q.A.P. conducts surveys of over 3700 individuals with developmental disabilities across the state of Oklahoma who receive services from the Developmental Disabilities Services Division of the Department of Human Services.

Subjects:

Individuals were selected from interviews completed in 1989-90, and again in 1993-94 who answered the question "If you had one wish, what would you wish for?" As noted above, the total number of individuals with developmental disabilities who responded in both periods of study was 160.

There are four levels of mental retardation. People with mild levels have I.Q.'s of 53-68. Those with moderate levels, 38-52, severe, 20-37, and profound, 19 and under. Sixty-five percent are listed as having mild levels of mental retardation or higher. The remaining 35% are listed as having moderate and lower levels of mental retardation. No one is listed as having profound mental retardation. Eighty eight percent are white. Nearly 59% are male, while 41% female. The mean year of birth is 1961, with a standard deviation of 9.48. The oldest person was born in 1927 and the youngest 1981.

Nearly 22% lived in institutions in 1990 as opposed to 11.3% in 1994. Included as institutions are intermediate care facilities for the mentally retarded (ICF-MR's), nursing facilities, and state schools. Community living include foster homes, private homes, semi-independent living, independent living, supported living and group homes.

Procedure:

As noted above, 160 individuals with developmental disabilities were available in both 1989-90 and 1993-94. This was determined by accessing the D.D.Q.A.P. database, and matching annual files. If there was information not recorded, such as, type of residency, or if individuals answered "I don't know", and "I don't want to talk to you," they were removed from the list. Some individuals were not able to be reached in both periods of study. Some individuals may have not been home, no longer receiving services or they may have been unable to respond due to illness or death.

Variables used were date of birth, gender, race, level of mental retardation, disabilities, ability to use the rest room, ability to dress and bathe oneself, ability to speak, ability to read, type of employment, ability to understand directions, history of seizures, is on a behavior management plan and type of residency (See Appendix 1 for a list of items, and Appendix 3 on how items were condensed). These variables were chosen to get a better profile of each individual. In the author's previous studies (1994; 1995), type of residence was the only other variable and it demonstrated statistical significance regarding the wish. These other variables are being used as indicators of particulars that may also be influential in the wishes of people with developmental disabilities.

'Disabilities' are being used as a reference to see if physical disabilities other than mental retardation may have some affect on the person's wish. In an earlier study the author found that those in nursing facilities often wished to do physical activities (Loconto 1994). Those in nursing facilities have more physical disabilities than any other type of residential placement in the state of Oklahoma (Jack 1995). If those in this study have other disabilities, their wishes may reflect those of the 1994 study.

The variables dealing with physical abilities, such as, using the rest room, dressing, bathing oneself and type of employment are used to test for physical independence. By using these variables, the hope is to find if a person's ability to take care of him/herself in daily care will influence his/her wish. This may be in the form of self esteem issues or lead to more independent types of wishes.

The ability to speak, read and understand instructions are very important. In today's society, the ability to communicate in a standard and timely manner are essentials in assimilating into society. Speaking can serve two important factors regarding the wish. First, it will allow the person to communicate to the interviewer what his/her wish is, but also it allows the person to interact more with the rest of society. This could lead to more assimilating behavior and attitudes. Reading will also allow the person to have the ability to live on his/her own. It will provide the person with the opportunity to read newspapers. It also could be an indicator of the adaptive cognitive ability of the individual by showing an understanding of more complex trains of thought. This also holds true regarding the ability to understand instructions.

Whether a person has seizures is an indicator of, again, a disability which may hinder physical abilities, or options in the world. The resulting wishes may reflect differences which may be related to this disability. The same may be said for those who have behavior management plans. This variable reflects not only having a written behavior management plan to control challenging behaviors, but also indicates the taking of psychotropic's as a means for controlling these behaviors.

By using these variables, this allows the researcher to find patterns or trends for the period of study. These would all be used in chi-square analysis and Cramer's V, with wish as the dependent variable. SPSS PC+ is the statistical program used. Excel 4.0 for Windows is used to examine frequencies in graph or chart form.

Wishes were then analyzed and placed in eight categories, with one additional category listed as 'other' (For examples of wishes, see Appendix 2). These categories were chosen and defined with the assistance of an anonymous reviewer. The categories are:

1. Personal Consumption (PerCon), which is an item that is for personal consumption, such as, lipstick or food.
2. Personal Object (PerObject), which is any product from jewelry to a car. It is an item that is used or kept, but not consumable.
3. Relationships (Relations), which is any wish dealing with a person wanting to be with someone, that is, married, a girlfriend etc.
4. Activity, which is any wish in which the person is wanting to do something, go somewhere.
5. Residency (Residence), which is any wish dealing with the person either making a wish to move or not to move.
6. Job or Finances (Job/Finance), is any wish dealing with wanting a job or money, or anything involving investments.
7. Personal Dissatisfaction (Pers Dis), is a wish in which a person wishes that they were different. It is a wish in which the person is not satisfied with their

physical or cognitive handicaps.

8. Altruism, which is wishing for something good for others.

Within the Residency wish, there are four choices from which the individual can specify. The individual may wish not to move. He/She may wish to just move out. This wish insinuates an unhappiness with the present residency, but does not have a knowledge of something more specific from which to move. The individual may also wish to move in with someone specific. Again, this may insinuate unhappiness, but it deals with the individual wanting to move in with someone, usually a family member, an old friend, or someone he/she has an attachment to. And lastly, the individual may wish to move out on his/her own. This represents the person as wanting far more independence than he/she has at the present.

At this point chi-square is used to test for independence with significance at $< .05$. The wish will be the dependent variable with all other variables listed as the independent. Cramer's V will also be used to verify how strong the association is.

Because the author is a research assistant with the D.D.Q.A.P., he will use field notes to help substantiate information brought out in the results and the discussion. When the author interviews a person with developmental disabilities, if the person answers the question "If you had one wish, what would you wish for?", the author asks the individual to explain 'why?' he/she wishes for that. Notes from thirty interviews will be accessed for this information.

Ethics:

Anytime a study is attempted ethics are a problem. There is a tremendous amount of fear of exploitation of this specific population. By using second hand data, that is, data gathered by the D.D.Q.A.P., which is approved by the Department of Human Services, part of the problem is removed. I, myself, as the researcher am not in contact with those interviewed. This prevents the manipulation of those interviewed to communicate what I want them to say. In this respect, the ethics question is not problematic.

However, conclusions based on these data are always subjective and can be manipulated to reach certain conclusions. In Oklahoma, the political climate emphasizes that deinstitutionalization is the best and moral thing to do. If the findings of this or any study suggest that deinstitutionalization is not working, then the ethics question can then become a problem for these other agencies. They may be proceeding to commit to action certain policies without asking the people they are attempting to help how they feel about these policies.

Certainly, their is a question of whom deinstitutionalization is working for. Single parents who placed their child in Hissom Memorial Center are in positions in which they must take care of their child at home now.

There are services provided for these families, however, this can be problematic. Often it has been communicated to myself the problems that single parents, specifically mothers, have dealing with their child. They often talk about the discrimination experienced from friends and other family members. They find themselves isolated from others due to their child being different and others not feeling comfortable around them. In this respect, we may ask who is deinstitutionalization working for?

Given the context of the Hissom lawsuit, however, it is agreed even by these parents that the closure of Hissom Memorial Center was the best thing to do. It must be remembered though, that every action provides a setting in which some will benefit, while others may not. We need to be aware of the problems that deinstitutionalization brings. From here, we can continue to help those effected by this court order.

Chapter Four

Results

The people in this study are relatively high functioning as evidenced by the data gathered. Of those interviewed, 89.4% have no toilet accidents at all. Over 80% bathe themselves with no assistance and another 15% bathe with little assistance. In the years 1989-90 and 1993-94, 88.8 could dress themselves without any assistance respectively. Over 93% could speak in simple sentences or better. During the period of study 52.5% could read simple stories, while another 23% could recognize ten or more words. In 1989-90, 67.9% were competitively employed or in workshops. In 1993-94 75.6% were competitively employed or in workshops. The amount unemployed remained constant at 13.8%. Because the same individuals were followed throughout the period of study, many graduated from school and entered the work force. Ability to understand complex instructions, that is, ability to make decisions in a situation in which original instructions do not work was high. Over 74% were able to comprehend and think independently when problems arose with instructions.

Only 1.9% of the population had physical disabilities, and 27.5% had a history of seizures. In 1989-90, 43.4% of the

Table 1

Frequencies of Wishes by Year, by Percentage

Wish	1989-90	1993-94
PerCon	2.5	1.3
PerObject	19.1	22.5
Relations	22.2	15.6
Activity	17.9	20.0
Residence	17.9	16.9
Job/Finance	13.0	18.8
Pers Dis	4.3	1.9
Altruism	2.5	1.3
Other	.6	1.9
N=	160	160

Table 2

Frequencies of Wishes, 1989-90, 1993-94, by Level of Mental Retardation, by Percentage With Chi-Square Analysis

	1989-90		1993-94	
Wish	Mild	Moderate	Mild	Moderate
PerCon	2.9	1.8	.0	3.6
PerObject	16.2	24.6	17.3	32.1
Relations	21.0	24.6	20.2	7.1
Activity	19.0	15.8	19.2	21.4
Residence	19.0	15.8	15.4	19.6
Job/Finance	13.3	12.3	23.1	10.7
Pers Dis	5.7	1.8	2.9	.0
Altruism	2.9	1.8	.0	3.6
Other	.0	1.8	1.9	1.8
N=	104	56	104	56
Significance		NS		.01026
Chi-Square		NA		20.02116
Cramer's V		NA		.35374
D.F.		NA		8

NS=Not Significant at <.05
NA=Not Applicable

population were taking medications for challenging behavior problems. That number decreased to 21.2% by 1993-94. In 1989-90, 62.3% were their own guardian. That number increased to 66.9% in 1993-94.

The data suggests there is a subtle shift in the wishes of people with developmental disabilities during the period of study. Chi Square analysis and Cramer's V were used to test for association. Cells were combined to accommodate this method and to avoid having cells with less than five. In 1989-90 gender was the only variable that tested significant with regard to what a person wished for. In 1993-94, level of mental retardation, residency, ability to speak, and ability to read tested significant.

For those who moved from institutions to community settings there was also a shift that was similar to the rest of the population. Likewise, there was also a shift in reasons why people wished to move from their present location.

As a whole, wishes changed from 1989-90 to 1993-94 in several ways (Table 1). First of all, there was a movement toward wishes that were oriented toward having a job or having money. In 1989-90 only 13% of the people wished for a job or money. In 1993-94, this number had increased to 18.8%. Secondly, this population also became more materialistic. Although the increase was not great, the numbers increased from 19.1% in 1989-90 to 22.5% in 1993-94. The wish for a

Table 3

Frequencies of Wishes, 1989-90, 1993-94, by Residential Placement, by Percentage

	1989-90		1993-94	
Wish	Institution	Community	Institution	Community
PerCon	.0	3.2	.0	1.4
PerObject	29.7	16.0	27.8	21.8
Relations	18.9	23.2	16.7	15.5
Activity	13.5	19.2	11.1	21.1
Residence	18.9	17.6	33.3	14.8
Job/Finance	13.5	12.8	5.6	20.4
Pers Dis	5.4	4.0	.0	2.1
Altruism	.0	3.2	.0	1.4
Other	.0	.8	5.6	1.4
N=	35	125	18	142

Community responses are listed in parentheses.

relationship of some kind also decreased from 22.2% in 1989-90 to 15.6% in 1993-94. Personal Dissatisfaction decreased from 4.3% in 1989-90 to 1.9% in 1993-94. The last category where there was change was in the altruism wish. It dropped from 2.5% in 1989-90 to 1.3% in 1993-94. In all, there appears to be a shift to a more materialistic, more job or money oriented person, with less dissatisfaction with his/herself, and more self-centered.

These trends occurred when controlling for level of mental retardation (Table 2). People with moderate levels of mental retardation tend to be more materialistic, but also have the biggest drop in the wish for a relationship, dropping from 24.6% in 1989-90 to 7.1% in 1993-94. For people with mild levels of mental retardation their wishes reflect an increase in wanting a job or money and more material goods. Personal Dissatisfaction dropped for both groups over the period of study. Altruism dropped for people with mild levels of mental retardation but increased for those with moderate levels.

When dividing the population into differences regarding residency, we again find the same patterns regarding the change in wishes (Table 3). The wish for consumable items vanishes. People in institutions have a slight drop in their wish for material items, however, there is a substantial increase for people in the community. The wish for relationships drops. Activity remained relatively stable.

Type of residency was a key wish for people in institutions, while for those out in the community it became less of a concern. For those in institutions there is less concern over money and jobs, while for those out in the community, it becomes more of an issue. For both residential placements, altruism and personal dissatisfaction decrease.

Because nominal data was used, Chi Square and Cramer's V were thought best suited for this study. Appendix 3 shows how categories were condensed. All tables were two by nine with wish being the dependent variable. In 1989-90 gender tested significant (Table 4). Cramer's V also demonstrated a strong association. The appearance of the relationship wish for females stands out.

Table 4

Frequencies of Wishes, by Gender, 1989-90, 1993-94, by Percentage With Chi-Square Analysis

	1989-90		1993-94	
Wish	Female	Male	Female	Male
PerCon	1.5	3.2	.0	2.1
PerObject	9.0	26.3	18.2	25.5
Relations	35.8	12.6	19.7	12.8
Activity	19.4	16.8	18.2	21.3
Residence	14.9	20.0	13.6	19.1
Job/Finance	13.4	12.6	24.2	14.9
Pers Dis	3.0	5.3	3.0	1.1
Altruism	1.5	3.2	.0	2.1
Other	1.5	.0	3.0	1.1
N=	66	94	66	94
Significance	.01042			NS
Chi-Square	19.97783			NA
Cramer's V	.35336			NA
D.F.	8			NA

NS=Not Significant at <.05
NA=Not Applicable

In 1993-94, four variables tested significant with regard to wishes (Tables 2; 5; 6; 7). Level of mental retardation was significant, with a mild to moderate association using Cramer's V. There was a movement in wishes toward wanting a job or money, for those with mild levels of mental retardation. Personal dissatisfaction with one's life also decreased. The relationship wish for those with moderate levels of mental retardation dropped significantly in the four year time period. There was an increase in both wishing for an activity and a wish regarding residency.

Table 5[6]

Chi-Square Analysis of Wishes by Residential Placement, Institution and Community, 1994*

Res.	1	2	3	4	5	6	7	8	9	Total
Instit.	0	7	5	2	11	2	0	0	2	29
Commun.	3	33	22	31	21	31	3	2	2	148

Significance	.02369
Chi-Square	17.68780
Cramer's V	.31612
D.F.	8

* $p<.05$
1=PerCon
2=PerObject
3=Relations
4=Activity
5=Residence
6=Job/Finance
7=Pers Dis
8=Altruism
9=Other

Residency was also an important part in the wishes for those in 1993-94. Cramer's V had a mild to moderate relationship. There is, again a tremendous shift in the wishes, during the five year period of study. In 1994, wishes demonstrated less concern with residency for those living in the community. There again, was a greater interest in jobs and money. For those in institutions, the greatest interest is in moving out.

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[6] Seventeen additional people were included from the 1990-91 survey who were also present in the 1993-94. While just using the population from the 1989-1990 surveys, there were only 18 individuals who lived in institutions in 1993-94. This number was thought to be too small with two by nine cells.

The ability to speak tested significant with Cramer's V showing a moderate association also. In 1993-94, people who were more efficient at communicating in a typical fashion tended to have wishes regarding where they lived, and jobs or money. Those with less ability to speak tended to have wishes that fall in the 'personal object' category of wishes (Table 6). Again, comparing the differences between 1989-90 and 1993-94, the same patterns are apparent. There is a movement toward wishing for things regarding employment or money, an

Table 6

Frequencies of Wishes by Ability to Speak, 1989-90, 1993-94, by Percentage With Chi-Square Analysis

	1989-90		1993-94	
Wish	S.S.	C.S.	S.S.	C.S.
PerCon	2.9	2.4	6.3	.0
PerObject	26.5	16.5	37.5	18.8
Relations	20.6	22.8	3.1	18.8
Activity	14.7	18.9	28.1	18.0
Residence	17.6	18.1	9.4	18.8
Job/Finance	5.9	15.0	15.6	19.5
Pers Dis	8.8	3.1	.0	2.3
Altruism	2.9	2.4	.0	1.6
Other	.0	.8	.0	2.3
N=	33	127	32	128
Significance	NS			.00752
Chi-Square	NA			20.86198
Cramer's V	NA			.36109
D.F.	NA			8

S.S.= Speaks in simple sentences or less.
C.S.= Speaks more in complex sentences.
NS=Not Significant at <.05
NA=Not Applicable

interest in material possessions, and less interest in relations.

Table 7

Frequencies of Wishes by Ability to Read, 1989-90, 1993-94, by Percentage With Chi-Square Analysis

Wish	1989-90 10-	1989-90 10+	1993-94 10-	1993-94 10+
PerCon	3.7	1.3	2.6	.0
PerObject	18.5	18.8	27.6	17.9
Relations	27.2	17.5	11.8	19.0
Activity	18.5	17.5	25.0	15.5
Residence	13.6	22.5	11.8	21.4
Job/Finance	11.1	15.0	15.8	21.4
Pers Dis	7.4	1.3	.0	3.6
Altruism	.0	5.0	1.3	1.2
Other	.0	1.3	3.9	.0
N=	80	80	76	84
Significance	NS		.04347	
Chi-Square	NA		15.92481	
Cramer's V	NA		.31548	
D.F.	NA		8	

10- = Reads less than ten words.
10+ = Reads more than ten words. Usually associated with sentences.
NS=Not Significant at <.05
NA=Not Applicable

Reading ability was the fourth and final variable that tested significant using Chi Square. Cramer's V showed mild association, but did not test as strong. The differences for those who had a better ability to read and those who did not were distinct. Nearly every category of wishes changed substantially between 1989-90 and 1993-94 (Table 7).

Wishing to Move:

In a previous study (Loconto 1995), the author found that those living in group homes, when wishing to move, wanted to move on their own. Those that were living in institutions tended more towards just wanting to move out. Although the numbers were small (n=29 in 1989-90, n=27 in 1993-94), there was still a similar pattern (Table 8). Those living in institutions tended to just want to move out. In community settings, those that wanted to live on their own increased from 72.7% to 90.5%.

Wishes that did not Test Significant:

Several other variables did not test significant. A

Table 8

Frequencies, Reasons Wishing to Move by Residential Placement, 1989-90, 1993-94, by Percentage

Wish	1989-90	1993-94
Institutions:		
DNWTM	.0	33.3
JWTM	42.9	33.3
WSOMEONE	28.6	16.7
ONOWN	28.6	16.7
N=	(7)	(6)
Community:		
DNWTM	4.5	.0
JWTM	13.6	9.5
WSOMEONE	9.1	.0
ONOWN	72.7	90.5
N=	(22)	(21)

DNWTM=The person wishes not to move out
JWTM=The person just wants to move out from present location
WSOMEONE=The person wants to move in with someone specific
ONOWN=The person wants to move out on his/her own

Table 9

Changes of Frequencies of Wishes of Those Who Moved From Institutions to the Community, by Level of Mental Retardation, by Percentage

	Mild		Moderate	
Wish	1989-91	1992-94	1989-91	1992-94
PerCon	.0	.0	7.1	7.1
PerObject	40.0	7.0	42.9	35.7
Relations	13.0	13.0	21.4	7.1
Activity	20.0	7.0	14.2	28.6
Residence	20.0	13.0	7.1	.0
Job/ Finance	7.0	60.0	7.1	21.4
N=	15	15	14	14

detailed explanation will follow in the discussion accounting for these findings. The explanation will revolve around the political climate during the period of study in the state of Oklahoma. It will also address expectations of people with developmental disabilities by staff and the rest of society. As one father put it at the closing of Hissom Memorial Center discussing his thoughts on the lawsuit from Homeward Bound Inc.:

> "I was not a member of the Homeward Bound. I was the number one opponent of Homeward Bound Incorporated, which was a sad mistake on my part. Just out of ignorance and fear and insecurities, that's what it was. Ripping up your son's life at Hissom is what I could see. What it really turned out to be, is giving him a chance to develop in the community as a person. I brought him to Hissom to maintain his life; isn't that sad on my part. And they did that. And they did the best they could to maintain his life. I forgot the word development. It wasn't part of my vocabulary."

People who Moved from an Institution to the Community[7]:

There were twenty-nine individuals in the study that lived in institutions in either 1989-91 who were living in the community by 1992 through 1994. These individuals were extremely important with regards to effects of deinstitutionalization on the individual. Table 9 shows the changes that took place for these twenty-nine individuals. Several changes are very apparent. Once the person moves out into the community, there is less of a concern with residency and moving. Secondly, especially for those who have mild levels of mental retardation, there is a tremendous increase in people wishing for things that are money or job related. These changes are similar with those that have moderate mental retardation, although not as pronounced.

Field Notes:

The use of field notes are important for this study in that they provide the researcher and reader to listen to reasons 'why' specific individuals wish for what they wish. While interviewing for the D.D.Q.A.P., when asking the individual what he/she wished for, I proceeded to write down the entire conversation. The purpose for this is to enhance or flush out some of the information related in the data discussed above. The wishes of these individuals in this

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[7] In this area of the study, any individuals who were in institutions in 1989-1991 but who were not in 1992-1994 that answered the wish question in 1992-1994 were included to increase the total number.

section are not included in the data above. However, their explanations for their wishes provides a picture of their thoughts and perceptions.

One woman, Jane, was very talkative. She lived in Hissom Memorial Center for most of her twenty-nine years. She is listed as having mild mental retardation. She moves about in a wheel chair, as both her legs are underdeveloped. Her verbal skills and writing skills are very high. She is able to read and write at a fourth grade level and higher. Jane lives with two other women in supported living who also previously lived at Hissom Memorial Center. They are both non-verbal, have other physical disabilities, and also use wheel chairs. They are referred to as 'total care'. They need to be fed, dressed, bathed, and assisted in the rest room. I asked Jane, "If you had one wish, what would you wish for?"

J: "I would wish that I would have normal roommates."
M: "Why is that?"
J: "When I lived at Hissom, every now and then we would talk to kids who would come to the fence. They would say something about people being retarded. I never knew what that meant. I thought this was how everyone was. It wasn't until I got out of Hissom that I realized that I was retarded."
M: "So, why do you want 'normal' roommates?"
J: "I just want to be away from people like this (Motions her head toward the other two women). Isn't this what closing Hissom is all about? I want to get on with my life. I feel like I am being held down here."

Most of the time, the people interviewed are not as knowledgeable as Jane. Although Jane has some serious physical disabilities, she gets around easily and quickly. When meeting someone like Jane, I wonder whether or not there is any mental retardation. She is very articulate and holds down a job at a major retail store.

Dan is a young man who also is listed as having mild mental retardation. Dan lives independently and also works at a retail store. He is thirty-three years old and lived at Hissom Memorial Center for approximately twenty-five years. To meet Dan you would not know he has any cognitive disabilities. He is a man who sees a psychologist once a week. Here is what Dan had to say:

M: "If you had one wish, what would you wish for?"
D: "I wish people would just give me a chance."
M: "What do you mean?"
D: "The idea is for me to improve myself. How can I do that when they don't let me make my own decisions? My IHP is made up and they don't let me say anything. They make decisions about my life without asking me. Listen, I know I'm slow, and need help, but gawd!"

What is interesting about both Jane and Dan, is that they are very articulate. They appear to have a grasp of what it means to have a disability and what deinstitutionalization is supposed to do for these individuals. For most of the people I took field notes on, this was not the case. At least, they were not able to articulate it very well. Their explanations were either fragmented or not apparent at all.

Sharon is just now living by herself. She still has a house manager who comes in and checks on her daily. She is thirty-five and has been out of Hissom since 1986. She says that "slow" people used to live there. She considers herself to be "slow." Sharon likes time to herself. She is someone who has a history of challenging behaviors and also a history of taking psychotropic's, like Haldol. She enjoys her time by herself. It helps her to relax and not get so angry. Sharon does all her shopping by herself, but does not have a job. She has problems keeping a job.

M: "Sharon, if you had one wish, what would you wish for?"
S: "I wish there was no war, and everyone would get along."
M: "Why is that?"
S: (Looking at me perplexed) "Uh, I don't know. We need to get along."

Sharon's history of behaviors may have influenced her wish. However, her inability to communicate exactly 'why' she felt that way could lead to misinterpretation. She may have a genuine concern for everyone to get along. This is similar to what Rumelhart studied in the early 80's. One can never be quite sure if the conversation is meaning similar things when talking with Sharon.

Bubba on the other hand knows what is going on. He just might not tell you though. Bubba is twenty-nine, lives in a supported living with one other individual. He works both in a workshop and also part time at a hotel as a janitor. He plays in several sports leagues with other people with developmental disabilities. He is very outspoken, has a girlfriend, and knows how to read and write at a fourth grade level or higher. He talks a little slow and sometimes slurs his words. Bubba knows what is going on around him. Sometimes though, he will not tell you. What asked about what he would wish for, he responded as follows:

B: "Money."

M: "Why money?"
B: "Uh, I'd like to go on vacation."
M: "A vacation? Where to?"
B: "Uh, some place."
M: "Why do you want to go on vacation?"
B: "Uhm, I don't know. To San Antonio."
M: "Do you have family or friends there?"
B: "Oh, maybe I'll stay here. Can I go now?"

Bubba really didn't want to talk to me. When I asked him "Why money?", it caught him off guard. Bubba knows that with money he can get things. Yet, he tried to come up with an answer for me. When I pushed him even more, he did not seem willing to keep up with the chase. He began to fall behind in the conversation, then asked to go, reneging on the vacation. He then left and called his girlfriend.

Barry, who is now 24, entered Hissom Memorial Center when he was a child. He now lives in a supported living house with one other gentleman whom he has lived with since the fall of 1993. Barry is somewhat verbal, but also uses sign language, which was taught to most people who lived at Hissom. He is tall and lanky, and occasionally wears braces on his knees and ankles.

M: "If you had one wish, what would you wish for?"
B: (Using Sign Language) Wants to learn how to drive.
M: "Why do you want to learn how to drive Barry?"
B: (Signs) I want a truck.
M: "Why a truck?"
B: (Signs) I like trucks.
M: "What is so special about a truck?"
B: Shrugs shoulders, then signs: I like trucks. (He then gets a magazine and shows me pictures of trucks).

Barry is a pleasure to talk to. But frankly, it was difficult to understand just 'why' he wanted a truck. The problem with language could be the reason. His feelings may not be coming out as readily as is necessary for interaction with the typical person. It was obvious he wanted to learn how to drive, but he wanted to drive a truck. More information is needed to understand what is so special to Barry about trucks and driving. His house manager did not know why either. She did however know that Barry was interested in trucks and wanting to drive.

Barry's roommate, John, is thirty-two, has autism and has been out of Hissom since 1986. He is listed as having moderate mental retardation, and has lived most of his life at Hissom. His wish and explanation were explained ambiguously, but due to his having autism, is easily understandable.

M: "John, if you had one wish, what would you wish for?"
J: "I want an apartment of my own."
M: "Why is that?"
J: "I do."
M: "Can you tell me John why? Please?"
J: (No response).

After talking with the house manager, she said that John is immaculate. He cleans up all the time. This was attributed to his having autism. A typical behavior for people with autism is the necessity to be in control of their surroundings. Barry, although clean, was not quite as clean conscious as John. Barry would sometimes leave things laying around the house. John did not like that. When I went back and asked John if this were the case, he just laughed and said "I can be clean."

Whether or not John's cleanliness is a result of his having autism is debatable. However, it is this kind of label in which we place others behaviors. If John did not have autism, we would not say he is clean because he wants control over his surroundings based on his wearing glasses.

Chapter Five

Discussion

When first looking at the results of this study, there was concern there was no relationship or pattern regarding wishes. However, this is not the case. When taking into consideration the history, and aim of deinstitutionalization, the results prove to demonstrate a pattern.

Deinstitutionalization:

As mentioned earlier, one of the hopes regarding deinstitutionalization is the assimilation of people with developmental disabilities into the fabric of society. The idea is to give this population the opportunity to have as 'normal' a life as possible.

Part of the process involved in this is the changing of values, attitudes, aspirations and wishes toward becoming more like the typical population. When observing the changes that were found we see this happening. If one were to give a simple description of the typical American, what would we find? I would contend that the typical American is materialistic, self-centered, wants a job and/or money, and wants to live independently. When observing the changes that have occurred with people with developmental disabilities, we find that they too have become more typical in their wishes over the periods of study. Their wishes are more materialistic, more self-centered, wanting jobs or money, and wanting to live independently. These tendencies remained fairly constant across levels of mental retardation and residency.

Why is this the case?

First, let's begin with the political climate in the late 1980's, or for that matter, during much of the lives of the people studied. When the first interviewers went out in late 1989 and early 1990, deinstitutionalization was just getting off the ground here in Oklahoma. There were few opportunities for people with developmental disabilities. When listening to administrators for the D.D.S.D., they often talk of how there was little or no organization in the late 1980's. Networking across the state was at a minimum. Services for people with developmental disabilities were inconsistent and uncoordinated. There was no real agenda for improving the lives of these individuals and their relation with the larger society. Questions surfaced, such as, how much work could a person with mental retardation do? There was not much information or people who could answer this kind of question. Life for people with developmental disabilities was moving from a maintenance orientation to an opportunity orientation. There was little certainty as to where this would lead and how to get there.

As mentioned earlier, parents were alarmed at the prospect of their child or children being removed from their 'safe' maintenance oriented housing. Even in community settings, staff were unaware of the services available for the people they worked with. And no one seemed to know or understand what would be expected of the future. The expression, 'flying in the dark', often is used to describe those days.

Now, however, the system is working fairly well. Hissom Memorial Center closed in April, 1994. Other institutions across the state are downsizing. There is talk of closing all institutions across the state, including nursing facilities. Although there are still problems, even skeptics have accepted the reality of deinstitutionalization. Staff are trained and goals are set to help the individual with developmental disabilities to learn tasks that should help him/her to succeed or blend in with society.

Now we find people with developmental disabilities working in fast food restaurants. Some are janitors. Some even are assemblers in large department stores piecing together bicycles and other toys. Companies around the nation are expressing a willingness to hire people with developmental disabilities for simple labor. This may eventually lead to exploitation, but for now, it has worked well and appears to be heading in a favorable direction.

The relationship to political climate and wishes then becomes more clear. In 1989 and 1990, the climate was such that there was little opportunity. When we also include the climate prior to a change in philosophy, it becomes even more clear. For those with developmental disabilities, there was little hope for anything in life. Their life was maintenance oriented. The differences in wishes with regard to gender in 1990 makes sense in this light. The main differences for people were with regard to more biological or gendered stereotypes. Women wished for more things revolving around the relationship, love, and interaction. Their lives were secluded in 1990 and prior. This is not the case in 1994 or now. This is reflected in their wishes.

In 1994, with more opportunities, wishes begin to be significant on different variables. These variables also make sense. These all reflect a greater awareness of the world around them. Their wishes should be different.

When looking at the variables that did not test significant, it can be assumed that the political climate does play a major factor. Most of the individuals in the study had similar abilities with regard to dressing and bathing. Most worked, and few had behavior plans or seizures. Their abilities to understand instructions are similar. Once these individuals were able to get out in the real world and participate it is no wonder that the wishes that tested significant did so. With all other abilities being similar, given the opportunities now given, these four variables appear natural indicators of differences in wishes. Differences in wishes now appear to be based on where a person lives, what their cognitive ability is, and how well they can read and express themselves. I would expect these results to be similar regarding anyone given the same circumstances.

This study was also interested in trying to understand the ability of people with developmental disabilities to understand the world around them. This is with regard to role taking, and the definition of the situation. Given the change in the political climate in Oklahoma, it could be argued that people with developmental disabilities are much more aware of their surroundings. They are much more aware of what is going on around them than they are given credit. Their wishes reflect a much more opportunistic mentality than in 1990. An argument can be made that with deinstitutionalization, people with developmental disabilities have a broader experience base now to use as their point of reference. This will provide motivation for achievement, but also provide the foundation for more typical spontaneous behavior and wants and needs similar to the rest of society.

Field notes provide a slightly different picture. Many of those interviewed were at a loss for words regarding 'why' they wished for something. This could be because of a lack of verbal skills to articulate their knowledge or an inability on the interviewer to sit and wait for a response. It can take several moments for a sentence to come out.

A more likely scenario is that provided by Rhoades and Browning; and Erving Goffman. Although several of these individuals are living out in the community, their lives are still somewhat sheltered and private. Few people in neighborhoods are willing to interact with this population. They may now be tolerant, but interaction is something different. The wishes could easily reflect the expectations put upon them by staff and family members. The person wishes for something because the staff instills in them that this is what they should want out of life.

In this sense, the staff or family member is filling the role of the generalized other, or significant other. Staff or family help in retraining the individual to develop more like the rest of society. Goals on the person's IHP help in the assimilation process. Daily routines provide the groundwork for integration. Even now in the Special Olympics, awards are given on ability, such as, first place, second place and so on. This provides a framework from which the person with developmental disabilities will want things like the rest of society.

This implies, then, that with regard to the wishes of people with developmental disabilities, deinstitutionalization is working. There does seem to be some movement in wishes of people not only who moved, but of those who stayed in institutions. There appears to be an awareness that there is something more out there for them. This is the case whether occur in the person's life. The wish becomes symbolic of the six turning points each person has taken to achieve some form of transformation. As each person achieves goals, moves to new homes, and meets new people their transformations begin and continue. This provides new "me's" from which they draw from to want or wish for differences in their lives. Although these transformations appear subtle, when seeing a change from one year to the next, they are extreme. These changes also influence the person's identity and influence what the person wants or needs. Their wishes reflect changes in identity.

Role Blurring:

Another aspect mentioned was the idea of Role Blurring. In today's society, we are having a much more difficult time committing to any one role due to the amount of options available. The person with developmental disabilities has to endure this for his/her entire life. When asked 'why' a person believes a certain way, or wants something the person with developmental disabilities has a difficult time answering. It is asserted here that this will be one result of postmodern society. With the amount of options available, it will be difficult to explain why we did something. It is also asserted that if the super information highway continues to permeate our lives, then we will continue to become more and more like those with developmental disabilities. Concentration will become more and more difficult to adhere to. In this respect then, it is hoped that sociologists would observe behavior of people with developmental disabilities to make associations with the changing behaviors and attitudes of American society.

Wishes and the Sociology of Dreams:

The sociological study of wishes corresponds with the emerging Sociology of Dreams. In some studies, the Sociology of Dreams revolves around the collective conscious (Vester 1993). The wishes of people with developmental disabilities is developed out of the collective conscious, even if it is through the influence of staff or family. Vester suggests that dreams can be wishes or fantasies such as 'the American Dream.' This kind of dream advocates what is important to a society. The wishes of people with developmental disabilities also reflect what is important to a society. They are wishing for things that are deemed good things to want. Wishes represent this collective conscious fantasy.

Vester also goes on to say that dreams can be optimistic or pessimistic. When looking at the wishes of people with developmental disabilities, we see that the wishes are becoming more optimistically oriented as deinstitutionalization continues. Deinstitutionalization generally increases the opportunities and awareness of the world of people with developmental disabilities

Gary Alan Fine (1993) suggests four points toward a Sociology of Dreams. 1) Dreams are not willed by the self. 2) Dreams reflect social reality. 3) Dreams are public rhetoric. And 4) dreams are interpretable. Point one provides the only problem. In American society wishes are believed to be individually willed. They are however, generally a reflection of the larger society, or the environment from which a person comes. An argument could be made for lack of a free will or freedom. However, even in lucid dreaming, the will of the self is an active participant, changing and interacting with those in the dream. There are emergent qualities apparent.

It is hoped that this study could lead into a Sociology of Dreams, building on the four points put forth by Fine. However, the more global perspective by Vester is a much more likely arena for wishes.

Suggestions For Improvement:

No study is perfect and it would be unwise to proclaim this study as such. There are three major areas in which this study could have been better. The sample size is much smaller than originally hoped for. The records for 1990, 1991 and 1992 are incomplete, which generated a small population of study. It would be desirable to continue this study over the next few years to see if the indicated trend continues.

Secondly, it would be beneficial to determine why each person wishes as they do. A random statement selected off a computer print out does not provide the depth and detail for that individual. In the future is would be beneficial to ask the person interviewed why he/she responded with specific wishes.

And third, it would be best to find out from the individual with developmental disabilities how his/her life has changed over the past few years. Many of the people I see each year tell of how their lives have changed since moving out of Hissom. People around the country and the world would benefit by hearing their stories. This would require the need for in-depth interviews to acquire this information.

Conclusion:

This study has been a learning experience. In the original proposal, it was my intent to study the self esteem of people with developmental disabilities. By doing this I hoped to prove that this population's cognitive ability was not as high as originally thought due to high levels of self esteem found in other studies. This original study was not allowed due to lack of support from the Developmental Disabilities Services Division, and the Institutional Review Board. While disappointing initially, it moved the research in a positive direction. It is my belief now that people with developmental disabilities suffer more from an inability to communicate with typical people giving the impression that they have low cognitive skills. Some of the best conversations I have had, have been with people with I.Q.'s of 19 and under.

This study is a beginning; a beginning to what I hope will bring us into an exploration of wishes of people in general, not just those studied here. As humans have become more and more processual in nature over the past century it would be advantageous to learn the thoughts of all of us in the form of wishes. If nothing else, they should reveal collective representations of which we should be aware.

This study is also a hope; a hope that deinstitutionalization will continually be examined to demonstrate the abilities of people with developmental disabilities and how they have improved the quality of their lives by being given a chance to prove themselves.

Finally, I hope this study will provide the basis for ending the stigma that is associated with developmental disabilities. I have interviewed people who at first appeared to have little or no communication skills, only to find later, when fitted with a communication device they were able to communicate just fine. Except for lack of opportunities, they seemed to be no different than the rest of society.

Yet, there can be problems that are also evident by these changes in wishes. It appears the expectations of people with developmental disabilities are more complex and substantive now than when deinstitutionalization began. These expectations reflect the change in political climate which is pro-independence for everyone. This advocacy for independence, however, is protected by an institution mentality, that is, even life styles in the community are sheltered and protected. This provides some interesting dilemmas.

First, there will come times when the disability of the individual will be prominent keeping him/her from acheiving the goals set forth. Second, more and more exposure to the typical population will also allow for perceptions of discrimination and/or stigma. And third, what of the individuals who do not want to be out in the community?

These dilemmas or problems should be addressed. We need to remember that through deinstitutionalization the definitions of the situation, the perceptions of reality are changing for this population. We should be aware that through this some individuals will not ascend as high as others. These tensions that could develop out of this may push some individuals into a state of self disinterest. They may find that they are not as 'good' as others. If this be the case, where will we be? It is likely, that at that point, people with developmental disabilities will need our help more than ever before. We must remember to be there for them.

However, I am confident that deinstitutionalization is the correct road to travel. These individuals are remarkable in their courage and strength of character. Recently, the 1995 Oklahoma Special Olympics took place in Stillwater, Oklahoma. I had the opportunity to watch some of the events. It reminded me of the effort we put forth in our everyday lives. I wonder, when I watch a person use all his/her energy for motor control, how much discipline that person must have to accomplish such a task. I question the effort of all typical people. If we, as typical people used that much effort and energy, how much could we accomplish? Given that context, maybe we are the ones with the disability.

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Appendix 1

List of Scaled Items Used for Assoication Variables*

A. Does s/he ever have toilet accidents?

4. Never has toilet accidents.
3. Never has toilet accidents during the day.
2. Occassional toilet accidents.
1. Frequenct toilet accidents during the day.
0. Not toilet trained.

B. Can s/he:

6. Prepares bath and bathes unassisted.
5. Washes and dries self completely.
4. Washes and dries reasonably well with prompts.
3. Washes and dreies with help.
2. Attempts to soap and wah self.
1. Actively copperates while being washed.
0. Makes no attempt to wash or dry self.

C. Can s/he:

5. Completely dress self.
4. Completely dresses self with prompts.
3. Dresses self, with help with fastening.
2. Help with dressing and fastening.
1. Cooperates when being dressed.
0. Must be dressed completely.

D. Does s/he:

3. Sometimes uses complex sentences.
2. Asks questions using why, how, when, etc.
1. Speaks in simple sentences.
0. Non Verbal or nearly non verbal.

E. Does s/he:

5. Reads material suitable for a nine year old.
4. Reads material suitable for a seven year old.
3. Reads simple stories or comics.
2. Recognizes ten or more words.
1. Recognizes street signs.
0. Recognizes no words or signs.

F. Does s/he:

3. Understands directions with prepositions.
2. Understands ordered/sequential directions.
1. Understands directions that require a decision.
0. Understands no directions.

*Other variables are not scaled items. They require simple yes or no responses, or fill in the blank. These are level of mental retardation, seizures, behavior plan, guardianship, physical disabilities, employment, residency, gender, year of birth and race/ethnicity.

Appendix 2

Examples of Wishes

PerCon: "Gum." "Candy."

PerObject: "Helicopter." "I would like a black or blue canvas." "It's kinda hard. I wish for a new car." "New Elvis clothes."

Relations: "Adopt me a little kid." "My mother to come back down." "Go visit my mom and dad. I love to visit them." "My mom." "Mom and Dad."

Activity: "Like to go somewhere fishing." "To go downtown." "Go watch wrestling." "Go to Disneyland."

Residence: "To have my own apartment." "My own place." "I want to go the group home in Norman."

Job/Finance: "To be a karate instructor." "A million dollars." "Money." "I wish I could get all these loan companies paid off."

Pers Dis: "A brain." "Eye sight back, be able to walk, diabetes go away." "I wish I could eat anything I wanted to." "Wish my life would change."

Altruism: "I would change society." "Bruce going to school again." "My mom would get better on her back."

Other: "It's my birthday everyday."

Appendix 3

Condensing of Scaled Items*

A. Does s/he ever have toilet accidents?

4. Never has toilet accidents.
3. Never has toilet accidents during the day.
2. Occassional toilet accidents.
1. Frequenct toilet accidents during the day.
0. Not toilet trained.

Answers 0-3 condensed.

B. Can s/he:

6. Prepares bath and bathes unassisted.
5. Washes and dries self completely.
4. Washes and dries reasonably well with prompts.
3. Washes and dries with help.
2. Attempts to soap and wah self.
1. Actively copperates while being washed.
0. Makes no attempt to wash or dry self.

Answers 0-3 condensed. Answers 4-6 condensed.

C. Can s/he:

5. Completely dress self.
4. Completely dresses self with prompts.

3. Dresses self, with help with fastening.

2. Help with dressing and fastening.

1. Cooperates when being dressed.

0. Must be dressed completely.

Answers 0-3 condensed. Answers 4, 5 condensed.

D. Does s/he:

3. Sometimes uses complex sentences.

2. Asks questions using why, how, when, etc.

1. Speaks in simple sentences.

0. Non Verbal or nearly non verbal.

Answers 0, 1 condensed. Answers 2, 3 condensed.

E. Does s/he:

5. Reads material suitable for a nine year old.

4. Reads material suitable for a seven year old.

3. Reads simple stories or comics.

2. Recognizes ten or more words.

1. Recognizes street signs.

0. Recognizes no words or signs.

Answers 0-2 condensed. Answers 3-5 condensed.

F. Does s/he:

3. Understands directions with prepositions.

2. Understands ordered/sequential directions.

1. Understands directions that require a decision.

0. Understands no directions.

Unable to condense categories due to ambiguity of categories.

*All variables except for age were condensed into two categories for purposes of Chi-Square analysis.

VITA

David G. Loconto

Candidate for the Degree of

Master of Science

Thesis: THE SOCIAL PSYCHOLOGICAL EFFECTS OF DEINSTITUTIONALIZATION ON THE WISHES OF PEOPLE WITH DEVELOPMENTAL DISABILITIES, A FIVE YEAR STUDY

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OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
HUMAN SUBJECTS REVIEW

Date: 12-08-94 **IRB#:** AS-95-028

Proposal Title: THE SOCIAL PSYCHOLOGICAL EFFECTS OF DEINSTITUTIONALIZATION ON THE WISHES OF PEOPLE WITH DEVELOPMENTAL DISABILITIES, A FIVE-YEAR STUDY

Principal Investigator(s): George E. Arquitt, David Loconto

Reviewed and Processed as: Exempt

Approval Status Recommended by Reviewer(s): Approved

APPROVAL STATUS SUBJECT TO REVIEW BY FULL INSTITUTIONAL REVIEW BOARD AT NEXT MEETING.
APPROVAL STATUS PERIOD VALID FOR ONE CALENDAR YEAR AFTER WHICH A CONTINUATION OR RENEWAL REQUEST IS REQUIRED TO BE SUBMITTED FOR BOARD APPROVAL.
ANY MODIFICATIONS TO APPROVED PROJECT MUST ALSO BE SUBMITTED FOR APPROVAL.

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

Signature: ______________________ Date: December 9, 1994

Chair of Institutional Review Board