

TREND STUDY OF PSYCHOTROPIC  
MEDICINE USAGE BY INDIVIDUALS  
WITH DEVELOPMENTAL  
DISABILITIES

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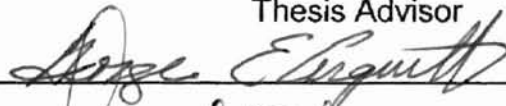
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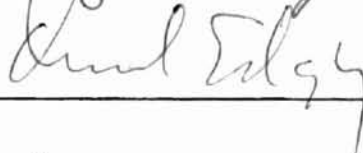
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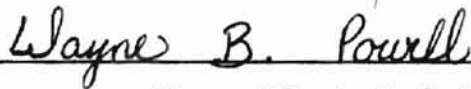
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## Chapter 1

### Introduction

Conroy and Jones (1997) found in 1994, 22.5% of the individuals receiving services from the Department of Human Services/Developmental Disabilities Services Division were on psychotropic medication. Their study used only one year of data for the medication usage for persons with developmental disabilities. This thesis looked at medication dosages for individuals individuals with developmental disabilities 1993 through 1995 to see if there was a trend in medication administration. The placement settings (i.e. institutional, community, nursing facility) were examined to see if there was a change in each of the settings. Blumer's (1969) concept of meanings will be used for the interpretation of the data. The implications for the usage of psychotropic medications in the different settings is explored. There have been several publications regarding medications in different settings and their purpose (Goffman, 1961; Gadacz, 1994; Scheerenberger, 1984). The sample for this study was selected from the population of individuals that were receiving services through the Oklahoma Department of Human Services/Developmental Disabilities Services Division. The data were gathered by personal interview with persons with developmental disabilities and their caregivers. The same sample will be followed throughout the course of the three years using the data set from the Oklahoma State University Developmental Disabilities Quality Assurance project. Those persons with a

diagnosed mental illness were removed to not inflate the level of medication usage. Persons working in the field of developmental disabilities assisted in the interpretation of the data through interviewing. The sample was comprised of 824 persons with developmental disabilities living in a variety of different institutional and community placement settings. There were no consistent trends in the usage of medications for any of the three groups between the years of the study. There were interesting remarks on the part of caregivers in regards to the implementation of the medications used for the study. Overall, the general sentiment of those caregivers in the community was that the medications were used in order to assist in the integration of consumers into a community setting. This is different from the practice of chemical restraint that was used in an institutional setting (Goffman, 1961; Gadacz, 1994; Scheerenberger, 1984).

## History

Imbecile, idiot, feeble-minded, simpleton, fool, and dimwit all are terms that were used in the past two centuries to describe persons with developmental disabilities (Scheerenberger, 1983; Landesman & Vietze, 1987). Through the years, the use of labels to describe persons with developmental disabilities have become narrowed to person first terminology. Those that used these terms were doctors, psychologists, and politicians. The treatment of the mentally retarded has gone through many different stages, and to this day it is still changing. In the

early 1800s psychiatrist Jean-Etienne-Dominique Esquirol formulated the first medical definition of idiocy:

*"Idiocy is not a disease, but a condition in which the intellectual faculties are never manifested; or have never been developed sufficiently to enable the idiot to acquire such an amount of knowledge as persons his own age, and placed in similar circumstances with himself, are capable of receiving. Idiocy commences with life, or at that age which precedes the development of the intellectual and affective faculties, which are from the first what they are doomed to be during the whole period of existence.... A man in a state of dementia is deprived of advantages which he formerly enjoyed. He was a rich man who has become poor. The idiot, on the contrary, has always been in a state of want and misery (as cited in Tyor and Bell, 1984, p. 7)."*

Institutions began as an idea to help those persons within a community that could not take care of themselves (Tyor & Bell, 1984). When the institution began, the idea for treatment was focused on a short term stay, in which the individual would be taught to function within society. The schools taught mathematics, and writing as well as vocational education. The idea of education was first formulated by Jean-Marc-Gaspard Itard (1774-1838). His ideals for education centered around the discovery of a "wild-boy" in Europe (Scheerenberger, 1983 p. 74). The boy was first found by Pierre-Joseph Bonnaterre, a priest and naturalist who thought the boy could be taught to function within the context of the society. He was despondent when the boy showed little progress and soon sent him to Phillippe Pinel, who was the teacher of Itard. Pinel concluded that the wild boy was a "pretend savage", and that he was just a imbecile (Tyor & Bell, 1984 p. 4). Franz Joseph Gall with his formulations in the science of phrenology stated that the 'wild boy' was an "imbecile to a high degree, his forehead is very little extended on the sides and

highly compressed on the top, his eyes are small and quite sunken, his cerebellum is little developed"(Scheerenberger, 1983 p. 53). This had little effect in the later part of the 19<sup>th</sup> century when the theories of phrenology were debunked.

Itard brought the boy to his home and named him Victor. Victor was schooled in a variety of different things that Itard thought useful. Itard had five goals that he wanted to accomplish for Victor, they were as follows:

1. *"To interest him in social life by rendering it more pleasant to him than the one he was just leaving, and above all more like the life which he had just left.*
2. *To awaken his nervous sensibility by the most energetic stimulation, and occasionally by intense emotion.*
3. *To extend the range of his ideas by giving him new needs and by increasing his social contact.*
4. *To lead him to the use of speech by inducing the exercise of imitation through the imperious law of necessity.*
5. *To make him exercise the simplest mental operations upon the objects of his physical needs over a period of time, afterwards inducing the application of these mental processes to the objects of instruction."*

(Scheerenberger, 1983 p.76-77)

After five years of training, Itard became frustrated with the lack of progress that Victor was making and decided to stop the instruction. Although Itard felt that the experiment was a failure, many of his colleagues were complimentary for the advances that Victor had achieved.

Edouard Seguin , a student of Itard, using what he had learned, formulated a physiological method for the treatment of idiocy. His book Idiocy and Its Treatment by the Physiological Method was published in 1866. Seguin immigrated to the United States in 1848 and continued his work in mental retardation. He became the first president of the Association of Medical Officers of American Institutions for Idiotic and Feeble-minded Persons. This organization



later became the American Association of Mental Deficiency (Poling & Breuning, 1982).

The treatment of the mentally retarded in the United States began in 1848, when Dr. Hervey Wilbur opened the first school for the mentally retarded. There had been several previous attempts to treat the mentally retarded. In 1818, the American Asylum for the Deaf and Dumb of Hartford, Connecticut accepted a few persons with mental retardation, and in 1821 they were a part of the population in the Commercial Hospital and Lunatic Asylum. Persons with mental retardation were also included in the Ohio Deaf and Dumb Asylum in 1827, and in 1839 a blind youth that also was paralyzed and mentally retarded was admitted to the Perkins Institution for the Blind (Tyor & Bell, 1984). Hervey was known to not agree with the treatment of the mentally retarded in large institutions, an opinion shared by his contemporary Samuel Gridley Howe. Hervey, as well as Howe, believed that a school environment was not for the cure of mental retardation. He is noted as saying:

*We do not propose to create or supply faculties absolutely wanting, nor to bring all grades of idiocy to the same standard of development or discipline, nor to make them all capable of sustaining creditably all the relations of a social and moral life; but rather to give to dormant faculties their greatest possible development, and to apply those awakened faculties to a useful purpose under the control of an aroused and disciplined will. At the base of all our efforts lies the principle, that the human attributes of intelligence, sensitivities, and will are not absolutely wanting in an idiot, but dormant and undeveloped. (Scheerenberger, 1983 p. 120)*

This was the dominant thought about the mentally retarded at the time. There was no ideal as to the cause of mental retardation, yet the persons that had it were not being seen as social outcasts. Howe believed that those with

mental retardation were the responsibility of the entire community. Idiocy is a "disease of society; an outward sign of an inward malady" (Tyor & Bell, 1984). Howe was the beginning of a backlash towards people with developmental disabilities and their parents.

The beginning of the schools for persons with developmental disabilities were attempts by medical professionals to show that persons that were schooled would show an increase in functioning and skills. The administrators of the schools were selective in the types of persons that they would accept into the schools. They would not allow individuals that had severe physical disabilities nor a severe cognitive impairment. The decision to allow the higher functioning individuals into the schools gave the administrators the ability to show some marked improvement in functioning. It also allowed the living environment to be labeled as schools. These school were located close to the center of the towns or cities. Legislators and administrators wanted to showcase the progress they were making with the students to townspeople as well to visitors.

After the schools had been in operation, the paradigm of care for the administrators began to change from a school environment to more custodial care situation. The motivation for the custodial nature of schools came from the concept of protecting society from the "moral imbecile" (Tyor & Bell, 1984; Scheerenberger, 1983; Zigler & Hodapp, 1986; Gould, 1996). The scientific community began to focus on the inheritance of incompetence and criminality. The administrators of the schools lost the battle to maintain the population of the schools, and the "incurables" became housed within them. The return of persons

within the schools to the communities was halted (Meyers & Blacher, 1987). Samuel G. Howe used case studies of individuals in the schools to show a connection between the "imbecile" and the parents (Howe, 1848). Goddard performed the Kallikak studies to "show" that Mendelian genetics were the causes of feeble-mindedness. Goddard followed the two offspring of Martin Kallikak Sr., one with his wife and illegitimate son with a bar maid. Of the one son, Martin Kallikak Jr., also known as "Old Horror", Goddard found "an unbroken line of degeneration: 143 feeble-minded, only 46 normal, 36 illegitimate, 33 immoral persons, 24 alcoholics, 8 pimps, and a total of 82 who died in infancy" (Tyor & Bell, 1984). Goddard also used Alfred Binet's Intelligence test in his studies with the feeble-minded in order to scientifically prove that the mentally retarded were less valuable. The use of these scales was against the main premise for which Binet had developed. Binet wanted the use of the scales to be focused to "measure the intellectual capacity of a child" to determine "whether he is normal or retarded", and not be used to "distinguish between acquired and congenital idiocy" (Gould, 1996). The scientific study of the mentally retarded also spawned the eugenics movement for the purity of the race. Residents of institutions were sterilized in order to not bring any more "defectives" into the world (Scheerenberger, 1983; Tyor & Bell, 1984). Women were encouraged to leave a husband that was a drunkard rather than bear a child that did not have the opportunity to be born normal.

The schools soon became institutions for the mentally retarded. Each school became an economic unit of production, with the residents performing

many of the duties. Administrators bragged about the amount of money they were saving by using the residents as laborers. One institution director is quoted as saying that he dropped the average cost per resident from \$300 to \$100 (Tyor & Bell, 1984). The institutions were located on large plots of land that could be farmed. The duties in the institutions were segregated by level of intelligence. Those that had the highest level of functioning were relegated to the fields for agricultural labor. The persons with the next lower level of functioning were instrumental in taking care of the least functioning residents.

A change in attitude towards those with developmental disabilities was one that would not come about for several more decades, yet a contemporary of Howe, Walter E. Fernald, began a movement for a less restrictive environment for the mentally retarded. He was predominately responsible for some of the most progressive legislation in Massachusetts. He desired that the following mandates be followed for the treatment of the mentally retarded:

1. *Requiring the census and registration of the feeble-minded in the state.*
  2. *Establish psychiatric clinics for the examination of retarded school children in the public schools.*
  3. *Permit the parole of the feeble-minded from the state schools.*
  4. *Legally recognizing the defective delinquents and making separate institutional provision for them.*
  5. *Require that an inquiry be made into the mental status of prisoners.*
- (Scheerenberger, 1983 p. 158)*

Although the mis-treatment of the mentally retarded continued, Fernald's influence began to influence others in the field of treating the "feeble-minded".

Another lesser known advocate for the mentally retarded in the early 1900s, Charles Bernstein, believed that a community environment was the most functional for the mentally retarded. He advocated the use of individual care and

personalized training. Although not directly linked with Bernstein's treatment regimen, training for teachers of the mentally retarded began in New York, Wisconsin, New Jersey, and several other states. These instructors within the schools, however believed that following a formalized education, the student would end up in an institution anyway, which they believed was how it should have been.

The 1920s saw little social advancement for the mentally retarded. During this time the main focus of social policy was directed towards immigration, prohibition, and crime. In 1930 the label of "feeble-minded" was changed to mental deficiency at a White House Conference on the Handicapped Child. The Great Depression caused a change in the role of government towards its citizens. With the inauguration of Franklin D. Roosevelt, the government began to take responsibility for its citizens. Roosevelt made the statement "Government has the a final responsibility for the well being of its citizenship. If private and cooperative endeavor fails to provide work for willing hands and relief for the unfortunate, those suffering hardship from no fault of their own have a right to call upon government for aid; and a government worthy of its name must make fitting response" (as cited in Sheerenberger, 1983). With Roosevelt being in office as President, and the Great depression continuing, several programs were begun in order to assist the citizens of the U.S. The one major program that was begun during this time was Social Security. This program allowed for the old-age insurance, unemployment insurance, and public health services. Those with

developmental disabilities fell under the administration of the Public Health Service.

During the 1920s, the scientific community began to discover many disorders that could be used to explain mental retardation. These disorders and syndromes were classified by the Committee on Nomenclature of the American Association on Mental Deficiency in 1932. They were categorized into seven separate categories. They included: (1) diseases due to prenatal influences, (2) diseases due to infection, (3) diseases due to trauma, (4) diseases due to convulsive disorders, (5) diseases due to or consisting of static mechanical abnormality, (6) diseases due to disturbances of metabolism, growth, or nutrition, and (7) new growth, or caused from growth after birth such as tumors or other abnormalities. The debate on heredity of mental deficiency was yet to be decided. The influence of the Kallikak study and others swayed the debate numerous times. The government was influenced to focus on topics like immigration and sterilization of persons with mental retardation. The immigration service set limits on the individuals that would be admitted into the U.S., and the institutions were beginning to sterilize their residents in order to stop the spread of idiocy. The Supreme Court case of Buck v. Bell upheld the constitutionality of sterilization with the written decision, "It is better for all the world, if instead of waiting to execute degenerative offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind, The principle that sustains compulsory vaccination is broad enough to cover the cutting of the Fallopian tubes." The use of institutions was becoming

widespread throughout the United States. The institutions used what has become to be known as the "medical model" (Scheerenberger, 1983; Curtis, Begin, & Blinkhorn, 1989; Landesman, 1987; Gadacz, 1994). With this philosophy in place, those within the institutions were being treated as if mental retardation was an illness. The medical model would ideally be replaced in later years to several different treatment modalities, such as the Independent Living Model, or the Developmental Approach, or one that focuses on the active learning for each consumer in a community setting.

Legislative progress specifically for the developmentally disabled was made during the presidential term of John F. Kennedy. President Kennedy had a sister that was developmentally disabled, and he wanted to give the developmentally disabled population, as a whole, more opportunities. He sponsored legislation which he thought would assist the developmentally disabled. The biggest legislation for those with developmental disabilities came in 1990 with the passing of the Americans with Disabilities Act (A.D.A.).

Before the A.D.A. became legislation the deinstitutionalization movement began in Pennsylvania. The Pennhurst school was sued by parents of residents for, what they thought to be, bad treatment of the residents. A similar group in Oklahoma, Homeward Bound Inc., several years later sued the Hissom Memorial Center, in Sand Springs for community based services. The focus of the facility, they thought, was on the maintenance of life and not on the quality of life, similar to the complaints of the plaintiffs in the Pennhurst case. For example, the center used a trolley system to move the residents through a bathing area, somewhat

like a carwash. Homeward Bound Inc. did not seem to agree with the treatment modality of the residents and sued the facility. The precedent set by this lawsuit began deinstitutionalization within the state of Oklahoma. Several other states had previously begun this process.

Deinstitutionalization brought a change in placement types as well as the type of care that would be provided to persons with developmental disabilities. Within the institutional setting, a medical treatment modality was emphasized. There were several wards and placement of individuals was according to their disabilities instead of them as persons. The integration of the residents of Hissom into the community was to follow the mandates of the court. The court ordered a comprehensive plan for community based services for the residents of Hissom. It also ordered a four year time-table for the closing of Hissom. This shifted the focus of attention away from institutions and towards a more diversified community living environment. This change in physical location as well as a change in ideology was the main focus of the deinstitutionalization movement.

Deinstitutionalization focuses on removing the individual from an institutional setting and placing them in a community environment. By moving an individual with developmental disabilities into a community setting, that person is provided with the same rights and responsibilities that are afforded to the general public. These rights were not given to them in an institutional setting. Thus, with a different setting came a different situation.



## Definition of Developmental Disabilities

Developmental disabilities refers to a variety of different areas. These areas could include but are not limited to cerebral palsy, mental retardation, scoliosis, and Down's syndrome. Some of the conditions are categorized as genetic, medical, or gestational. The genetic conditions require testing of either the fetus or the child; for example, Down's syndrome is diagnosed by a third chromosome, usually in the 21st set. The medical conditions require of testing for micro-organisms or abnormalities within the body in order to diagnose a syndrome; for example, hydrocephaly is diagnosed by finding an increased occurrence of fluid around the dura mater. Micro-organisms also fall into the category of medical. An example of this would be meningitis. Gestational problems occur during the pregnancy, either the lack of a certain chemical in a liquid, solid, or gas form or the introduction of a foreign substance into the womb. An example of this would be fetal alcohol syndrome. Another gestational problem could occur at the end of gestation during delivery of the child. This is a critical time for the child, and any problem, such as a lack of oxygen, could cause a developmental disability. This is when the child, during gestation, is exposed to alcohol. Any of these complications can cause mental retardation; however, the child could experience any one of them and have no mental retardation. Postnatal causes also can be linked to mental retardation. Poison, infections, parasites, and trauma can also cause mental retardation.

Mental retardation has been diagnosed using a variety of scales. Each of the scales used throughout history has been focused on different items. The Stanford-Binet test uses an intelligence quotient in order to determine the level of the individual taking the test. Another test that is used for the determination of mental retardation is the Vineland Social Maturity Scale. This used adaptive behavior in order to determine the level of the individual. The test that is currently used is the Wechsler-Bellevue test. This test has two different target test groups. There is a Wechsler-Bellevue test for adults and one for children. This is the test that is currently being used for the diagnosis of mental retardation.

Intelligence testing was the first mechanism by which an individual was diagnosed with mental retardation. Although Alfred Binet was not the first one to come up with intelligence testing, his test had become one of the most influential in the psychological community (Nietzel, Bernstein, & Milich, 1987). The original Binet test consisted of 30 questions and several tasks. The score was based upon the actual number of items answered correctly and the number of tasks completed successfully. The Binet-Simon scale was brought to the United States by H. H. Goddard in 1908 (Nietzel, Bernstein, Milich, 1987). The Binet-Simon scale was modified by Lewis Terman in 1916. Terman was a Stanford University psychologist, and the scale became known as the Stanford-Binet. The values of the Stanford-Binet were based upon the mental age of the child. The scale was used to assess the intelligence of children. The scale soon adopted a scoring system that was known as the intelligence quotient (IQ). The IQ score was figured mathematically by taking the mental age score and dividing it by the

chronological age and then multiplying the total by 100. Terman labeled certain score groups with such words as average, feeble-minded, and genius. These labels were changed to average, mentally retarded, and superior. Today, the Stanford-Binet consists of 4 areas of testing: verbal reasoning, abstract/visual reasoning, quantitative reasoning, and short-term memory.

The Wechsler-Bellevue (W-B) scale was developed in 1939 by David Wechsler, the chief psychologist for New York's Bellevue Psychiatric Hospital. The W-B used some of the components that were included in the Stanford-Binet, but it was divided into two different age groups. Initially it was used only to assess individuals that were age 17 and above. The W-B had 11 subtests that were grouped into two categories- performance and verbal. Each of the subtests had items that were increasingly more difficult. This test has been revised and modified for a variety of areas. In 1949, the Wechsler Intelligence Scale for Children (WISC) was formulated. WISC has been revised three times, and the current version is the WISC-III. The score for the WISC is based upon twelve subtests, in which 10 are usually only administered. The WISC can be used not only to measure IQ but also can be interpreted by verbal comprehension, perceptual organization, freedom from distractibility, and processing speed. The WISC has shown a high correlation to school grades, test scores, and achievement. This is the current standard by which intelligence is measured for persons with developmental disabilities.

## Review of Current Literature

The use of psychotropic medication in the area of persons with developmental disabilities has not been studied to a large extent. A majority of the studies that appear in the literature deal with the implementation of the medications in institutional placement settings. For clarity, psychotropics are a group of medications that alter the brain chemistry of an individual. The drug can be used for severe cases of depression to schizophrenia. They are predominately used for the treatment of a psychological disorder. With the implementation of these type of medications can come side-effects. Some of the literature addresses the side-effects that are associated with the medications used in this study. Some of these side effects would seem to be contrary to some of the goals of normalization and deinstitutionalization. The side effects for some of the medications can be a hindrance to cognitive development. There are also other side effects that will be discussed later in this section.

Lipman, Dimascio, Reatig, and Kirson (1978) outline some of the side effects of psychotropic medication. They state that although the use of these types of medication could improve social desirability, they can hinder the cognitive learning ability of the person taking them. They also outline the most common side effect of the drugs examined in this thesis, that of Parkinsonian type symptoms. These would include tongue wagging, tremors, and sedation (Wilson, Nathan, O'Leary, & Clark, 1996).

Deinstitutionalization is based in the least restrictive therapy and environment, and the drugs used in this thesis have documented proof of negative side-effects, including sedation. As mentioned earlier in Gadacz (1994), the disabilities community deals with the medical community on a regular basis, such that it is the dominant force in their lives. Faux and Seideman (1996) found that the families of persons with developmental disabilities have been devalued by the medical community. There has been a constant struggle to be identified a person with dignity, and in need of health care. Health care professionals were seen by the families as "obstacles to overcome, primarily due to their beliefs and attitudes about the value of individuals with DD/MR" (Faux & Seideman, 1996, p. 219). With this devaluing of persons with developmental disabilities, the medical community also had a tendency to stereotype them. Faux and Seideman (1996) have pointed out several examples of the medical community refusing service or requiring additional expenses in order to treat persons with developmental disabilities.

Bisconer, Sine, and Zhang (1996) examined the prevalence of use of psychotropic medication in community settings, such as independent living or group home environment, for those with mental retardation. The study showed that of the population, only 5% were involved in a medication reduction program. This number increased to 9% when the person with mental retardation was supervised by an interdisciplinary team that performed medication reviews on a regular basis.

Another study of 120 group homes, found that of the population studied, 27% received at least one psychotropic medication for behavioral or emotional problems (Aman, Sarpfere, & Burrow, 1995) In Oklahoma during one year, the medication usage of persons studied by the Developmental Disabilities Quality Assurance Grant was 33.4% (Spreat, Conroy, Jones, 1997). There seems to be little explanation for this phenomenon.

There is little discussion in the literature addressing the implementation of medications outside an institutional setting. There have been even less addressing medications during a transition from an institution to a community setting. This is what this thesis addresses.

## Chapter 2

### Theoretical Perspective

The foundation of the theoretical perspective is within the paradigm of symbolic interaction and the concept of meaning. Blumer (1969) defined how meaning is agreed upon among actors and society. The second part of the theory is based in Erving Goffman's book *Asylums* (1961). In this book Goffman outlined the characteristics of the total institution. Goffman (1961) characterizes institutional placement settings in relation to the developmentally disabled, and the situations that arise because of the power differential between staff and residents within the institution. The final piece of the theory is the concept of normalization. For persons with developmental disabilities, normalization is considered the least restrictive environment and/or therapy.

Written language is comprised of symbols that have a specific sound attributed to them within language. These symbols when grouped together compose words, written symbols that illicit an object within an individual. Ritzer (1992) outlined the importance of symbols (i.e. language) in the process of interaction. Symbols allow for discourse within a dialogue, and are the basis for interaction.

1. *Symbols allow people to deal with the material and social world by allowing them to name, categorize, and remember objects.*
2. *Symbols improve people's ability to perceive the environment.*
3. *Symbols improve the ability to think. Language greatly expands the thinking ability.*
4. *Symbols greatly increase the ability to solve various problems by thinking symbolically.*

5. *The use of symbols allows actors to transcend time space and even their own persons.*
  6. *Symbols allow us to imagine a metaphysical reality such as heaven.*
  7. *Symbols allow people to avoid being enslaved by their environment, in that they can be active rather than passive.*
- (p. 350)

Symbols, specifically language, are what are being generated and adapted to fit into the treatment paradigm for persons with developmental disabilities.

Blumer states that meaning is generated through interaction between actors, thus making meaning a social "creation" (Blumer, 1969 p. 10). In order to understand the change in meaning associated with the deinstitutionalization process, there must be a discussion on what is changed. Blumer outlines that within interaction, there are three different types of objects that can have a change in meaning. An object is anything that can be referred to in a dialogue. For purposes of this thesis, the objects that are being defined are identified as the living environments, the medications, persons with developmental disabilities, and the meanings of medication usage. Each of these items fall into an object category that will be outlined. The first type of object that Blumer discussed is physical objects. This would be the actual physical environment of living, such as the community or institution. The second object that Blumer discussed is that of social objects. This type of object includes people, and the roles that they play in society. In relation to this thesis, this includes all persons involved with the care of persons with developmental disabilities as well as those in their care. The final type of object that is addressed by Blumer is abstract objects. Abstract objects are what could be



considered ideals or concepts. Deinstitutionalization and challenging behavior could be considered abstract objects. All three types of objects can be modified or redefined. In order for an object to undergo a change in the social meaning, it must go through changes outlined by Singelmann. He outlines steps that show the process of change of meaning for what can be called Blumer's objects.

These changes occur within society through the process of interaction.

1. *In exchange, actor construct normative and existential definitions of themselves, other, action, goals, and assessments of "fairness."*
  2. *These definitions are not only subjectively constructed but to a large extent socially shared and thus constitute a constraint external to the individual actors.*
  3. *In exchange, the hedonistic striving of actors are limited and qualified by the nature of the subjective and socially shared definitions of the objective world which includes the self and others.*
  4. *In exchange, actors will change their behaviors or definitions when*
    - a. *Changes in the objective world render existing behaviors and definitions problematic.*
    - b. *changes in some of their subjective definitions render other definitions or existing objective conditions and behaviors problematic.*
- (Blumer as cited in Ritzer, 1992 p. 478)*

In the case of deinstitutionalization, the term community is used to describe the most "normal" living environment. Abraham (1989) suggested that the term community is defined as a positive set of relationships that exists between people living in close proximity one with another. In using this terminology, those facilities that were categorized as custodial care housing for the developmentally disabled were seen as less desirable for persons with developmental disabilities, and seem to make the institutional policies seem like a regressive step into a dismal past (Abraham, 1989). The disabilities community is involved in is a struggle to change their social reality, both as they perceive it and as they experience it. Gadacz (1994) stated that disabled people no longer want

to be understood as cripples, patients, or clients, but as people. In order to do this the nature of their reality must be changed. Within the medical model there is the assumption that the disabled persons must accept their situation, even though the constant attendance by medical professionals reinforces their role as being "sick" (Gadacz, 1994). This is the reasoning behind the multi-disciplinary team that, with the input of the consumer, focuses on the needs and desires of the individual. The primary model that is imposed upon people with disabilities is the medical/rehabilitation model (Gadacz, 1994; Landesman, 1987). This paradigm of treatment is and was used in institutions for the mentally retarded. Within this model there is a power differential that exists between physician, psychiatrist, service providers, agency personnel being superior to the developmentally disabled. In order to be normalized into a community setting, the power difference must be minimized between persons with developmental disabilities and the medical community. As Zola (1983, p.50) explains: "We who have chronic diseases and disabilities must see to our own interest. We must free ourselves from the physicality of our conditions and the domination of the medical professionals". This liberation from the medical professionals falls under the rubric of the least restrictive therapy. The concept of the least restrictive environment and therapy involves three basic assumptions that are implicit within it as a concept. The first being that the restrictiveness is external to the individual and is within the environment or therapy (Bachrach, 1985). Within the implementation of psychotropic medications, the drug is prescribed by a medical professional that is part of the interdisciplinary team of professionals that assist in

the formulation of a habilitation plan for the person with developmental disabilities. The second assumption that is made in relation to the least restrictive environment or therapy is that the "quality of restrictiveness is primarily a function of type of residential facility" (Bachrach, 1985, p. 30). The use of psychotropic medication for behavioral modification is used in the institutions. The third assumption is that "there is a relationship between restrictiveness and residence that is best expressed in terms of a continuum" (Bachrach, 1985, p. 31). In the deinstitutionalization movement, this exemplified by the language used to motivate the movement of persons with developmental disabilities into the community; "all mentally retarded citizens deserve safe, healthy, positive, caring, learning centered programs and services and that these programs and services should be available in the least restrictive, most normalized and appropriate environment" (Homeward Bound v. Hissom Memorial Center, 85-C-437-E, p. 5)

According to Gadacz (1994) the medical community is still in control within a community setting. This would include the use of psychotropic medication, also referred to as anti-psychotics. The medications studied in this thesis have been shown to cause Parkinsonian type symptoms after prolonged use. Travnikar (1993), in a University Affiliated Program, states:

*"the administration of psychoactive/behavior-modifying medication is more than just a medical issue, and more than just an educational issue, it is a rights issue. Such student rights include, but are not limited to.*

- 1. The right to treatment.*
- 2. The right to least restrictive/least intrusive interventions.*
- 3. The right to be free of chemical restraint.*

*Abdication of responsibility occurs when educators propose that a student's body chemistry should be altered, while curriculum and methods of instruction remain unchanged.*

This is the process that those advocates that were involved in the Hissom Law Suit experienced in order to begin the deinstitutionalization movement in Oklahoma. In order to provide a positive community living environment, the plaintiffs in the Hissom Lawsuit had to show that institutions were problematic as living facilities. The lawsuit declared that Hissom Memorial Center was a dangerous place to live and that the plaintiffs had suffered abuse, neglect, injury, and unnecessary physical and chemical restraint. (Homeward Bound v. Hissom Memorial Center, 85-C-437-E). The actions of this group were attempting to redefine the most beneficial living environment. In this manner they were advocating a living environment that was different from the dominant ideology of institutionalized custodial care for those with developmental disabilities.

Goffman separates the total institution into several different categories; however, the definition for those institutions in this study is that the function of them is to care for those "felt to be both incapable and harmless" (Goffman, 1961). In some instances, those that were put into institutions were a danger to themselves and/or others. The early 1900s illustrates the prevalent idea of the time that persons put into institutions were seen as a threat to society and were to be ostracized in order to protect the general populous. The physical separation of persons with developmental disabilities continued to reinforce their role as being sick.

Goffman continues to put forth the characteristics of the total institution. He states that in the institution, "there is a basic split between a large managed group and a small supervisory staff (Goffman, 1961). There are also antagonistic

relationships between staff and residents, or as Goffman calls them, inmates. The split in position between the two groups is essential in the maintenance of order for the inmates. There is also little exchange of information between the two groups. The most important criteria for an institution is that the inmates do not mingle in the outside world. They stay within the institution and have visitors. There was a mandatory six week waiting period before the family could return to visit their children, they could also take their children outside the institution for holidays and birthdays (Living in the Freedom World, 1997). The residents must reside in the facility for either a preset time before they entered the facility for an undetermined amount of time.

The deinstitutionalization movement is focused on characteristics that are not associated with institutions. One of these characteristics within the institution that was being used was that of the medical model of treatment. This model of care focused on mental retardation as an illness (Scheerenberger, 1983). All programs within the institution were under the supervision of the medical clinical director (Scheerenberger, 1983). Desirable living conditions are considered to be anything outside of an institutional custodial care environment and as far removed from the modalities of care that were associated with the institutions.

The last concept to be addressed is normalization. Abraham (1989) states that normalization is the process of enabling people with a mental handicap to live ordinary lives. It requires that the developmentally disabled "be allowed to live and develop under conditions that are as culturally normal as possible, and that

they be accorded the rights and dignities expected by any other citizen”

(Bercovici, 1983 p. 4).

The right of least restrictive therapy are intermingled with the normalization process that should be experienced by many persons with developmental disabilities. As referred to earlier, persons with developmental disabilities generally not only desire to be known as persons, but also to remove themselves from the domination of medical professionals, including the usage of psychotropic medications. This is the focus of this thesis, and questions about the living environments and medication usage will be addressed.

#### Research Questions

1. Is there a difference in average dosage of those residing in institutional placement settings versus those in community settings in 1993?
2. Are there changes in dosages within institutional types?
3. Are there significant changes in mean dosages when moving from institution to the community?

## Chapter 3

### Methods

The subjects for this study were selected from the population of individuals that were receiving services through the Oklahoma Department of Human Services/Developmental Disabilities Services Division. The sample was selected by choosing all persons that were taking psychotropic medication for behavioral purposes in 1993. These individuals were then followed for the two years of the study and their medication usage was determined each year. The sample was divided into three different groups. The first group is composed of those individuals that lived in an institution in 1993 and then moved into a community placement setting in 1994 and remain there through 1995. The second group is composed of persons that maintained residency in a nursing facility for the entire length of the study. And the final group is of those persons that stayed within an institutional setting over the same period of time. All of the medications included in the study are listed by their trademark name, but included within the sample are all generic medications for the brand names. The medications of focus in the study were as follows: Mellaril, Compazine, Orap, Prolixin, Haldol, Loxitane, Serentil, Moban, Etrafon, Navane, Taractan, and Clozapine. These medications were chosen because of the Parkinsonian symptoms that could be caused from continued use. Persons on any of these drugs are tested yearly for Tardive-Dyskinesia which is characterized by Parkinsonian symptoms. The living

environments were also pulled from the mainframe for the three years for the sample. All identifiers were stripped from the data set before analysis in order to eliminate the identity of those within the sample.

The individuals in the study were taking one of the specified medications in 1993. The living environments were divided up into two main categories for the first analysis. The two environments were community settings, which includes group homes, supported living, assisted living, adult foster care, and independent living, and institutional settings which consisted of public and private intermediate care facilities for the mentally retarded (ICF/MR), and nursing homes. Group homes are large homes that are either owned by an agency or rented by an agency which has from 5 to 12 residents. Supported living is a community living environment that has 24-hour staffing and 2 to 3 persons within the home. Assisted living is a home that is rented by the consumer and has less than 24-hour staffing with the same number of persons that reside in a supported living environment. Independent living is where there is little staffing, and the consumer manages their own utility payments as well as rent or mortgage. A sub-sample was then taken from the institutional group. It was divided into public and private ICF/MR's and nursing homes. The dosages were compared across the three years of the study for both group to see if there was a difference in the dosages.



## Data Collection

The instrument was administered to primary care providers of persons with developmental disabilities and the consumer that were currently on the list provided by DHS. The interviewer was either an independent interviewer or a graduate student in the Department of Sociology. Both independent interviewers and graduate students received training on the instrument prior to administering it to the care providers by the Co-Directors of the project, Dr. Barbara Murray and Amanda Fullerton. An interview time was set with the primary care provider by the scheduling secretary of the Developmental Disabilities Quality Assurance Grant. The interview took up to about an hour to complete with the care-giver, and about 15 to 20 minutes with the consumer. The specific data were required for this study were obtained by the interviewer either from the medication bottles or personal medical charts of the consumer that were kept by caregivers. The reading of the charts was part of the training that was received in order to become an interviewer.

The caregiver was utilized as an informant for many of the behaviors that are measured on the instrument, such as adaptive skill, and challenging behaviors. They were the individuals that knew most about the consumers behavior as well as the skills that they possessed because of their continued contact with the consumer.

## Generalizability and Limitations

Babbie (1983) defines generalizability as:

"The quality of research finding that justifies the inference that it represents something more than the specific observations on which it was based. Sometimes this involves the generalization of findings from a sample to a population. Other times, it is a matter of concepts. The likelihood that you will ever be a general (p. G3)."

The concept of generalizability is essential in social research. When conducting research, the data that have been collected should be able to infer what a similar research sample would score. The sample size should be able to make some inference upon the population that has similar qualities. This allows the social scientist to conduct research on a sample such that a census is not required. This decreases both time constraints and financial constraints.

The nature of the Developmental Disabilities Quality Assurance Grant does not allow for these data to make inferences upon other populations of persons with developmental disabilities. The court order in the Hissom lawsuit required that there were to be specific criteria that the study would assess. However, the characteristics can be described so others can borrow the data and decide if they are applicable to another population.

Another limitation of the data is that the care providers probably have a vested interest in portraying their working environment in a positive manner. Funding for individual care provider companies comes from both the state and federal level, and any possible negative response could have an effect upon the continuation of that provider organization.

The responses seemed to be biased towards the socially desirable (Voelker, et. al., 1990). The care provider and the consumer seem to acquiesce towards what they believe the interviewer seems to want to hear. This is a problem that is associated with this population, being that it is an assessment that is sponsored by the state. With the results going back to DDS, there is probably pressure to represent themselves in a favorable manner.

Another limitation with the data is that it does not include all persons receiving services from the Developmental Disabilities Services Division. Both caregivers and consumers have refused to participate with the study, even though compliance by the caregiver is mandatory. Other persons were not able to be located either initially or after moving for participation in the study. Also, persons that became deceased during the time of the study were obviously not able to participate in the study. Table 1 shows the demographics of the persons that were included in this thesis. There were 486 males and 338 females in any of the three movement groups. 83.0% of the sample were Caucasian, with 11% being African-American, 5.1% Native-American, and the remainder being in the Hispanic category or in the other category.

The sample contained all different clinical level of mental retardation. There were 21 persons that did not have a diagnosis of mental retardation. There were 128 persons that had a diagnosis of being mildly retarded. This diagnosis is a measured level of I.Q. between 50-55 and 70. The moderately retarded diagnosis is characterized by a measured I.Q. level between 35-40 and 50-55. There were 136 persons in the study that were classified as moderately

retarded. Severe mental retardation is characterized by a measured I.Q. between 20-25 and 35-40. There were 178 individuals that had a severe mental retardation diagnosis. Profound mental retardation is characterized by an I.Q. level below 20-25. There were 147 people that had a severe mental retardation diagnosis. There were 213 persons that were categorized into an unknown category. Those persons that were categorized as unknown were classified as such because of either not being tested, or not being able to be tested.

### Reliability

"Reliability is a matter of whether a particular technique, applied repeatedly to the same object would yield the same result each time" (Babbie, 1990). In social research, it is necessary to have a reliable instrument, whether it is a questionnaire or the person that is asking questions. When research is reliable, it will gather the same data from a respondent regardless of the technique. There are many different types of reliability that are used in data collection. There is inter-rater reliability, test-retest reliability, and split-half reliability. Inter-rater reliability is the ability of a questionnaire to illicit similar responses from the same respondent when being interviewed by different types of people, for example a man as opposed to a woman. In regard to this project, this would be the ability of the questionnaire to receive similar answers regardless of the interviewer. The test-retest method of reliability testing involves giving a respondent the same questionnaire at two separate times. In order for the test-

retest method to be reliable, the respondent must answer in a similar fashion at both testing times. This method removes the possibility of time biases that the respondent might have at the time of the assessment. The final type of reliability that will be discussed in this thesis is the split-half method. The split-half method involves dividing the instrument into two equal halves and administering it to a pre-test sample. The two halves should be similar in regards to scaled responses and overall responses.

The nature of the data provided that reliability was very high for this study. The living placement type is both placed upon a brief information sheet about each consumer before interviewing the care provider and the consumer, and it is also put into the interview schedule. The second part of the data used for this study is the current medications that the consumer is taking. This information comes from either a book that contains medical information about the consumer or directly from the medication bottles themselves. There has not been a statistical reliability procedure performed on the medication area of the interview schedule; however, Dodder, Bolin, and Foster (1999) found a high inter-rater reliability for demographics and for other scales on the instrument. Inter-rater reliability is the ability of an instrument to illicit consistent responses when administered by different interviewers.

## Validity

“Validity refers to the extent to which an empirical measure adequately reflects the real meaning of the concept under consideration” (Babbie, 1990). There, also, are many different types of validity that are associated with a survey type instrument. Criterion related validity, also referred to as predictive validity, is the ability to estimate some type of behavior that is external to the instrument. An example of criterion related validity is the admissions examinations that are used by universities and colleges nationwide. These exams are used to predict the probability that the individual will do well in college. Content validity is the next type that will be addressed in this thesis. “Fundamentally, content validity depends on the extent to which an empirical measurement reflects a specific domain of” study (Carmines & Zeller, 1979, p.20). In relation to the study that was performed in order to attain this data, the collection of medical information could not be gathered if questions involved playtime activities. The researcher designs the questionnaire such that it gathers the information that is desired. This leads into the last type of validity, that of construct validity. This type of validity is woven in with the theoretical aspect of doing social sciences research. When constructing a questionnaire, the researcher builds the questions such that they relate to the theoretical aspect that is being utilized for the study.

Within the scope of this study, there is little room for interpretation in the reporting of the data used. However, in order to show validity for the Developmental Quality Assurance Project, Bolin (1993) selected random

interviews from the mainframe to check for accuracy in coding. It was found that out of a possible 1650 errors, no errors were found.

In order to assure construct validity, the instrument used to gather this data was formulated from the Pennhurst longitudinal study. This study began with the closing of the Pennhurst State School in Pennsylvania in 1979 (Conroy & Bradley, 1985). The instrument that was used was constructed by experts. It also included sections that were similar to the Vineland Adaptive Behavior Test. The instrument continues to be changed by experts with each year to suit the needs of the Oklahoma population in order to assure content validity.

The medication questions were assessed from legally required medical records. In this regard, the attainment of medication dosages on the instrument is an example of content validity.

## CHAPTER 4

### RESULTS

#### Question 1

Was there a difference in dosages of medications between those living in an institution and the community in 1993?

There were significant differences in the mean dosages for each of the medications that appeared in the analysis in Table 2. All analysis and calculations were performed at the .05 level of significance. There were medications that did not have any one taking them in 1993. These medications were: Clozapine and Taractan. Of the remainder medications, there were significantly larger dosages prescribed in the institution for five of the medications. There were only three medications that had a significantly larger dosage in a community setting in 1993.

Seventeen persons were prescribed Prolixin in 1993 in an institution. The mean dosage was 242.53 milligrams. There were only 2 persons in a community setting that were taking Prolixin, with a mean dosage of 8.00 milligrams. The  $t$  calculated was 46.81 with a probability of less than .0005.

There were 105 persons prescribed Haldol in 1993 that were in an institutional placement setting. The mean dosage was 183.52 milligrams. This dosage is significantly smaller than the community setting. The mean dosage for



the community was 273.38 milligrams, with 24 persons prescribed the medication. The t calculation was 18.15 with a probability of less than .0005.

The mean dosage for Loxapine in 1993 for persons in an institutional setting was 521.67 milligrams with 3 people prescribed the medication. In the community setting, there were 5 people using Loxapine with a mean dosage of 298.8 milligrams. The t calculation was 12.40 and the probability was less than .0005. There was a significant difference between the community and the institutional placement settings. The community had more people on the medication, yet had the lower mean dosage.

There were 19 people in 1993 living in an institution that were taking Serentil. The mean dosage for these people was 525.63 milligrams. There were 4 persons that were taking Serentil living in a community setting. The mean dosage was 576.00 milligrams. The calculated t was 2.22 and there was a probability of less than .025. There was a significant difference in the mean dosages for these two groups with those in an institution taking a higher dosage.

The mean dosage for Moban in an institution in 1993 was 199.00 milligrams. There were 3 people prescribed the medication. There was only one person taking the medication in the institution, with a dosage of 940.00 milligrams. There was a significant difference in the two dosages with the calculated t being 31.86 and a probability of less than .0005.

There were very few people using Trilafon in either an institution or a community setting. There were three people in an institution and two living in a community setting. Those in an institution were on a mean dosage of 1113.67

milligrams, and those in a community setting were on a mean dosage of 309.00 milligrams. The calculated  $t$  was 31.86 with a probability of less than .0005.

There were 320 people taking Mellaril in 1993 with a mean dosage of 410.09 milligrams in an institution. There were 75 persons in a community setting that were taking Mellaril with a mean dosage of 340.60 milligrams. There was a significant difference in the medications between the two settings with the institution using more than the community settings. The calculated  $t$  was 24.64 with a probability of less than .0005.

The mean dosage for Navane in an institution in 1993 was 328.09 milligrams. The dosage for the community setting was 513.31 milligrams. There were 32 persons using Navane in the institution and 13 in a community. The calculated  $t$  was 24.73 with a probability of less than .0005.

## Question 2

The second research question "Are there changes in mean dosages within institutional settings?" is presented in Table 3 and Table 4. For this question, an initial sample of all persons in an institutional setting was taken to determine if there were changes in the average dosage for the selected medication for the three years of the study. For this experimental group three of the medications did not register any observations: Thorazine, Taractan, and Clozapine. Once this task was completed, a sample of nursing homes was taken to determine the trend of medication usage in a living environment that was not specifically for the

treatment of persons with developmental disabilities. For this group, there were four medications that there were observed to have no one taking them. These medications were Thorazine, Orap, Taractan, and Clozapine.

In the institutional group, there were no significant variance for the three years on all of the medication chosen for the study. Prolixin had a mean average dose in 1993 of 19 milligrams, and in 1994 an average dose of 349.50. And in 1995 the average dose for Prolixin was 448.29. The analysis of variance f calculation was 1.18 and had a probability of .347. The variance for Prolixin seems to come evenly from the years as well as from the different persons within the sample. With this medication, there was a decrease between the first two years of the study, from 4 to 2. In 1995, the persons taking Prolixin increased to 7.

The mean dosages for Haldol were measure with 448.36 being the mean dose for 1993, 229.46 for 1994 and 345.23 for 1995. The f calculation was .649 with a probability of .526. There is more variance explained in the within the individuals in an institutional placement. The dosages were not the same across the three years. The mean dosages for Haldol dropped between the first two years and then increased during the next two years. The number of persons on this medication initially decrease from 14 to 13 between 1993 and 1994, but there was a large increase in numbers of persons taking the medication, which was up to 31 in 1995.

The dosages for Loxitane in an institutional setting were recorded as 10.00 milligrams for 1994 and 777.5 for 1995. There was no one recorded to be taking

Loxitane in 1993. The analysis of variance calculation was performed on the two remaining observations with the  $f$  calculation being .46 and the probability being .62. The variance for Loxitane seemed to come more from the different years than from the different years individual observations. For this medication in an institutional setting, there was a difference in medication dosages across the three years of the study. Looking at the means alone, there was an increase in average dosages beginning in 1993 with no one on the medication, and in 1994 there being a slight increase, and then a considerable increase in 1995. In 1994, there was only one person taking Loxitane, and there were 2 persons taking the medication in 1995.

The dosages for Serentil were 409.00 in 1993, 1608.33 in 1994, and 292.08 in 1995. The analysis of variance calculation was 3.22 with a probability of .07. In this category, the variance seemed to come more from the different years than from the individual observations. There was an increase in the total number of people taking the drug. The first two years had only 3 people, yet in 1995 there were 12 persons taking the medication.

During the analysis of the institutional placement settings and medication, there were several prescription psychotropics that did not have sufficient data for analyzation. Orap, Moban, and Compazine had only one person taking the medication in only one year. All of the three medication usages appeared in 1995. Moban had a mean of 475.00 with 2 persons having prescribed the medication. Orap had only one person taking the medication, with a dosage of

123.00 milligrams. There was also one person using Compazine in 1995, with a dosage of 850.00 milligrams.

There was only one person taking Trilafon throughout the length of the study. This person was prescribed 2560.00 milligrams in 1993, and the dosage was decreased in 1994 to 675.00 milligrams and then decreased again to 106.00 milligrams in 1995.

The mean dosages for Mellaril for persons staying in an institution were 439.08 in 1993, 336.76 in 1994, and 474.86 in 1995. The  $f$  calculation was .94 with a probability of .391. The variance for this group seemed to come equally from both the individual observations and from each year of the study. There was an initial decrease in persons taking the medication after the first year, from 50 to 46, however there was an increase between the second and third year of the study up to 85 persons prescribed the medication.

The dosages for Navane were 30.50 mgs. in 1993, 407.00 mgs. in 1994, and 456.75 mgs. In 1995. The  $f$  calculation was .645 with a probability of .535. The variance seems to come from the individual persons prescribed the medication instead of from the between the years of the study. There were only two persons taking the medication in 1993. This number increased to 14 in 1994, and then decreased in 1995 to 8.

The nursing home sample (Table 4) had several medications that only had one person that had prescribed to use them, or there was only year in which the use medications was observed. All of the observations for the individuals that were only taking the medications occurred in 1995. There was only one person

taking Loxitane with a dosage of 130.00 milligrams. There were two people taking Serentil in 1995 with a mean dosage of 163.50 milligrams. There were also two people taking Moban in 1995. The mean for Moban was 293.50 milligrams. There was only one person taking Trilafon in two years, in which case the analysis of variance calculation was not able to be completed. The person was prescribed 606.00 milligrams in 1994 and 675.00 milligrams in 1995. There were only three medication that occurred in this group that could be used for calculation. These medications were: Compazine, Mellaril, and Navane.

There was one person on Compazine in 1994 with a dosage of 55.00 milligrams. There was an increase in persons in 1994 to 2, with a mean dosage of 539.50 milligrams. The number of people prescribed Compazine in 1995 increased again to 4, with a mean dosage of 64.25. The analysis of variance calculation was 3.254 with a probability of .145. The variance seems to come from the individual persons taking the medication.

The mean dose for Mellaril in 1993 was 429.85 milligrams, the dosages decreased in 1994 to 289.84 milligrams and then decreased again in 1995 to 250.68 milligrams. The number of persons taking the medication increased every year that the study was being conducted. In 1993, there were 13 people taking Mellaril. This number increased to 49 in 1994 and then again in 1995 to 161. The f calculation was 1.634 with a probability of .198. The variance seemed to come more from between the years rather than within each year.

There was no one taking Navane in 1993, but in 1994 there were three people prescribed the medication with a mean dosage of 47.67. The mean and

the persons using the medication increased in 1995 to 21 people with a mean dosage of 275.29 milligrams. The variance seemed to be equal for both the individuals in each of the years and between the years of persons living in a nursing home. The f calculation was 1.00 with a probability of .328.

### Question 3

The third research question "Were there differences in the medication dosages when individuals moved from institution to community?" is outlined in Table 5. In this group, there were three medications that did not appear for the analysis. Taractan, and Clozapine were not prescribed for any of the persons that were included in this study during any of the three years. There was also a medication that only appeared in one year with three persons having a prescription for use. The mean dosage for Moban was 463.00 milligrams, and appeared in 1994. There was one medication that had only one person appearing in two years, which did not contain enough information for analysis. There was one person taking Orap in 1993 with a dosage of 123.00 milligrams. There was also just one person taking Orap in 1995 with a dosage of 7.00 milligrams. All other medications had sufficient data in order to calculate analysis of variance. There were several of the medications that the average dosage increased in the second year but dropped from the second to the third year, however there were other medications that decreased in the second year and then increased again in the third.

There were 7 people that were prescribed Prolixin in 1993. The mean dosage was 273.00 milligrams. The number of people decreased in 1994 to 2, yet the mean dosage increased to 737.50 milligrams. The number increased in 1995 to 6, however there was a decrease in mean dosage to 127.00 milligrams. The f calculation was 1.67 with a probability of .23. The variance seemed to come more from the individual observations than from the years as a whole.

There were 32 people taking Hadol in 1993 with the mean dose of 289.84 milligrams. The total number decreased to 10 in 1994 with a mean dosage of 399.60 milligrams. In 1995, the number of people taking Haldol increased to 39 with the mean dosage being 324.51 milligrams. The f calculation was .144 with a probability of .867. Most of the variance came from within the individual observations.

There was only one person on Loxitane in 1993 with a dosage of 125.00 milligrams. The number of persons on the medication increased to 2 in 1994 with a mean dosage of 780.00 milligrams. The number of people increased again in 1995 to 5 with the mean dosage being 274.80 milligrams. The f calculation was .871 with a probability of .474. The variance came predominately from within the groups.

There were 13 persons prescribed Serentil in 1993 with a mean dosage of 290.92 milligrams. There were no observations in 1994. In 1995, the number of persons prescribed Serentil decreased to 8 with a mean dosage of 931.87. The F calculation was 2.99 with a probability of .10. The variance came from between the years with an increase in dosages.



There was only one person taking Trilafon in 1993, with a mean dosage of 106.00 milligrams. There were no observations in 1994 and in 1995 there were 3 persons prescribed the medication with a mean dosage of 1059.33 milligrams. The f calculation was .384 with a probability of .599. The variance was from the individuals with the years.

There were no observations for Compazine in 1993, but by 1994 there was one person using the medication with a dosage of 82.00 milligrams. In 1995 there were 2 people using the medication with a mean dosage of 142.00 milligrams. The f calculation was .159 with a probability of .76. The variation came from the individual observations.

In 1993 there were 64 people taking Mellaril with a mean dosage of 447.72 milligrams. In 1994 the total number of people using the medication decreased to 38 with a mean dosage of 356.50 milligrams. In 1995 there was a large increase in the total number of people taking Mellaril, 142. The mean dosage was 397.39 milligrams. The f calculation was .38 with a probability of .69. The majority of the variance came from the individuals within the years and not from between years.

In 1993 there were 5 people prescribed Navane with a mean dosage of 379.60 milligrams. In 1994, the number of people decreased to 3 with a mean dosage of 422.67. In 1995, the total number of people increased to 14 with a mean dosage of 487.86 milligrams. The variance was almost all from the individual observations and not from the years. The probability was .92.

## Chapter 5

### Discussion and Conclusions

#### Discussion

The first question of difference between the two settings in 1993 showed that there were significant differences in many of the medications between the community and the institution. There were five medications that had higher dosages in an institutional setting. There were three medications that had a higher mean dosage in the community. Overall there were generally fewer people taking medication in a community setting. Of the medications used for this thesis, there were 517 people taking medications in an institutional placement setting, and there were 133 people taking them in a community setting. This would go along with the normalization process of least restrictive environment, including chemical restraint. In an institutional setting, medication was used in order to decrease challenging behavioral outbursts. One caregiver stated that "they would dope them up to keep 'em quiet." When asked about the use of medication in a community, the caregiver responded, "they are used to help them be integrated, you know, to be around people. They're help for us to take them out into the community."

For each of the remaining questions, there was a majority of the medications that had a large portion of variance explained through the individual

observations. There were more differences in the prescription of the medications within each year than there was between the years. This would suggest that there was not a consistent decrease or increase across the years, but a changing in the dosages of medications and numbers of people using the medications within each of the three years. There were a few medications within each of the experimental groups that had more of the variance explained between the years, but these occurrences were few.

In the institutional placement group, there were six of the medications that did not contain enough information for an analysis of variance to be performed. There was also no trend that could be found in either the numbers of persons taking the medication, nor in the mean dosages across the years. Of the six medications that could have any statistical calculations performed, two had a greater portion of the variance explained between the years. When a caregiver was asked as the reason why this was occurring, he responded, "they ( the doctors) move the medications up and down depending on how severe his behaviors are."

There seems to be no consistent trend in the total number of persons that were taking these medications throughout the three years. The observations showed that there were increases in some medications in some of the experimental groups; however, there were also decreases and intermediate spikes of persons as well as troughs in the sample. In the community movement group, most of the observations in the number of persons on the medication showed a trough in the second year of the study for seven of the medications.

One caregiver responded to this by saying, "they (the doctors) try to lower the meds, but sometimes it doesn't work. He needs a certain amount in order to be able to function." There was one medication that had a spike in the second year because of no observations in the first or third year of the study. There was an increase of persons taking Loxitane throughout the three years of the study with the beginning number being 1 and moving consistently up to five by 1995. The mean medication dosages seemed to have not consistent movement either up or down between any of the years.

In the institutional group, those that stayed in an institution for the entire length of the study, there was no significant change for mean medication dose. Again the number of individuals on each medication increased and decreased sporadically throughout the length of the study. There were only seven medications that contained enough data in order to perform any calculations. Of the seven, there were two medications that the variance was best explained between the years of the study rather than the individual observations.

The nursing home group had all of the medications that could have statistical calculations performed have the variance explained more between the years rather than the individual observations.

The process of normalization provides for the concept of the least restrictive therapy, yet in these data, there is little evidence to support the ideal that this is occurring. Gadacz (1994) stated that in a community setting the medical community was the predominate providers of care. The therapeutic model of treatment was the dominant paradigm. The data show that this still is

the case in regard to the sample of persons with developmental disabilities. The medication and its meanings in a community setting have changed from the rhetoric used in an institution. Several caregivers working in the community provided the new explanation for the use of the medications. "He can't go out without taking his medicine. He needs it in order to help him be around people." "An integrative tool, rather than a chemical restraint", commented one astute caregiver. Another responded saying that as caregivers they were the socializers of persons that came out of an institution, "sometimes we need additional help in order to assist in integrating them into the community, this is where medication comes into play." This change of meaning for the implementation of psychotropic medications has occurred parallel to the deinstitutionalization process. The ideals of deinstitutionalization changed the meaning of the most beneficial living environment, as well as changing the meaning of persons with developmental disabilities. The language that is being used is different when referring to this population. They have moved from being physical objects, to being social objects. In the same regard, medication has moved from being a chemical restraint that limits behaviors to an integrative tool that is used to assist with a smooth community experience. "We want him to have a good experience in his home, sometimes there is more stimuli than he can handle. The medication allows for him to handle it."

## Conclusion

The use of psychotropic medication in both a community setting and an institutional setting occurs, yet the rationale behind their use is different. "In the institution they would dope them up enough so that they were easy to manage" said one caregiver. "They just wanted to keep them in line, you know, no behaviors, so they doped them up. We don't do that now. The only reason that the meds are being used is to help them to be a part of the community." The change in meaning from one setting to the other is the most interesting finding of this research. The voices of caregivers in the community and institutional settings were important in order to assist in translation of the data into an understandable form.

There has been little change in the usage of these medications from an institutional to community setting. Normalization might be occurring, yet it seems to not apply when referring to the use of medications. For consumers, normalization includes the concept of least restrictive therapy which includes the "dimension of freedom from medication and other forms of treatment according to the individuals own wishes" (Pandiani, Murtaugh, & Pierce, 1996, p.224). The changing rationale for caregivers allows for the continued usage of these medications to occur in the community. In this regard, the change in meaning parallels Blumer's (1969) nature of objects. The medication is the object that is "being created, affirmed, transformed and cast aside. The life and action of people necessarily change in line with the changes taking place in their world of

objects" ( p.12). The meaning of the medication has changed in the minds of caregivers and the physicians prescribing them. This meaning has been created by those with the capability to cause change in the meaning of medications used on persons with developmental disabilities. Those working with persons with developmental disabilities are in a position to change the meanings behind the medication. "Meaning is not intrinsic to the object, but arises from how the person is initially prepared to act toward it" (Blumer, 1969, p. 68-69).

The medications also have effects upon the individual using them when they are taken off them. Withdrawal effects tend to be exhibited as "anxiety, restlessness, tremors, nausea, cramps, diarrhea, muscle spasms, tics, moodiness, confusion, disorganized thinking, racing thoughts, bizarre dreams, paranoia, violence, and depression" (Liska, 1997 p. 273). Being that the medications in this study were used for only behavioral problems, the withdrawal effects could occur when attempting to decrease the amount of medication that a consumer is taking. The symptoms that were motivating for the persons to be placed on these medications are manifested when the medications are being removed from the body of the consumer. "We've tried to take her off the meds, but when we do her behaviors increase so much that we have to put her back on them" stated a caregiver. Challenging behaviors are subjective in that one person might find something offensive and label it a challenging behavior, whereas another might see the same behavior and have no problem with it. "When I first came here to work, I read the log of all the things that ... had incident reports written, but I wouldn't write the same things up. I don't think that they are

all that bad". The transitory nature of careproviders in community setting for persons with developmental disabilities was expressed by many of the caregivers as being problematic. With this consistent trend of staff change, comes also a consistent change in the reinterpretation of behaviors as challenging or not. Blumer (1969) explained that meaning is brought about through interaction, and in relation to persons with developmental disabilities, when there is a continual redefinition of challenging behaviors, there is the possibility for a caregiver to see a need for more help in integration and decrease in behaviors, and thus an increase or maintenance of medication usage could be a possible outcome. In this study, the maintenance of medication usage in order to assist in successful integration and interaction is what has been seen. The data show that there has been little consistent change in usage of medication. This phenomenon was explained by caregivers as being a change in the interpretation of the medication, rather than a change in treatment modality. Gadacz (1994) explained that the medical model of treatment was predominant in a community setting for persons with developmental disabilities. Caregivers assisted in the interpretation for the usage of medication as an integrative tool. There have been little or no studies on persons with developmental disabilities living in community settings and the use of psychotropic medication. In the mental health profession, deinstitutionalization was possible because of medication for persons with mental illness. The medication made it possible for people with mental illness to effectively function within society. It appears that the same justifications are being used for persons with developmental disabilities.



Because there is no standard of behavioral problems, persons with developmental disabilities could be placed on medication without cause. Social interventions seem to be what is desired for the deinstitutionalization movement. This is what this researcher thought that he would find, that there would be a decrease in medication in lieu of social reinforcement for behavior.

### Suggestions for further research

In the completion of this thesis, there were several issues that were not addressed. There needs to be a qualitative analysis of the purposes of psychotropic medication through caregivers perceptions and physicians reasoning for prescription of the medication specifically in regards to challenging behavior. This could generate a consensus of assessment of what is a challenging behavior. Another aspect that needs to be addressed is the concurrent usage of two or more medications by persons with developmental disabilities for behavioral purposes. This would be to assess the average number of medications that a consumer is taking during a specified period of time. Many of the individuals that were included in this study were on two or more medications. A comparison of persons with developmental disabilities and the general populace in regards to psychotropic medications would be helpful in assessing normalization for people with developmental disabilities.

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## APPENDIXES

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APPENDIX A

Table 1  
Demographics 1993

	Frequency	Percent
<u>Sex</u>		
Male	486	59.0
Female	338	41.0
<u>Race</u>		
Caucasian	684	83.0
African-American	91	11.0
Hispanic	3	0.4
Native-American	42	5.1
Other	3	0.3
<u>Level of mental retardation</u>		
None	21	2.5
Mild	128	15.5
Moderate	136	16.5
Severe	178	21.6
Profound	147	17.8
Unknown	213	25.8



Table 2

Differences in medication dosages  
between institution and community  
settings for 1993

Medication	Mean dosage in milligrams		t<	p<
	institution	community		
Prolixin	242.53	8.00	46.81	<.01
Haldol	183.52	273.38	18.15	<.01
Loxapine	521.67	298.80	12.40	<.01
Serentil	525.63	495.00	2.22	<.025
Trilafon	1113.67	309.00	31.86	<.01
Mellaril	410.09	340.60	24.64	<.01
Navane	328.09	513.31	24.73	<.01

**Table 3**  
**Medications dosages for persons**  
**with developmental disabilities in**  
**institutional placement settings**

Medication	1993	1994	1995	f<	p<
Prolixin	9.00	349.50	448.29	1.179	.347
Haldol	488.36	229.46	345.23	.649	.526
Loxitane	---	10.00	777.50	.461	.620
Serentil	409.00	1608.33	292.08	3.220	.069
Moban	---	---	475.00	---	---
Trilafon	2560.00	675.00	106.00	---	---
Orap	---	---	123.00	---	---
Compazine	---	---	850.00	---	---
Mellaril	439.08	336.76	474.86	.943	.391
Navane	30.50	407.00	456.75	.645	.535
Taractan	---	---	---	---	---
Clozapine	---	---	---	---	---

**Table 4**  
**Medication Dosages For Persons With Developmental Disabilities**  
**In Nursing Facility Group**

Medication	1993	1994	1995	f<	p<
Prolixin	---	---	59.67	---	---
Haldol	735.67	327.06	187.02	3.049	.053
Loxitante	---	---	130.00	---	---
Serentil	---	---	163.50	---	---
Moban	---	---	293.50	---	---
Trilafon	---	606.00	675.00	n/a	n/a
Orap	---	---	---	---	---
Compazine	55.00	539.50	64.25	3.254	.145
Mellaril	429.85	289.84	250.68	1.634	.198
Navane	---	47.67	275.29	1.002	.328
Taractan	---	---	---	---	---
Clozapine	---	---	---	---	---

**Table 5**  
**Medication Dosages for Persons With**  
**Developmental Disabilities in the**  
**Community Movement Group**

Medication	1993	1994	1995	f<	p<
Prolixin	273.00	737.50	127.00	1.670	.229
Haldol	289.84	399.60	324.51	.144	.867
Loxitane	125.00	780.00	274.80	.871	.474
Serentil	290.92	---	931.87	2.989	100
Moban	---	463.00	---	n/a	n/a
Trilafon	106.00	---	1059.33	.384	.599
Orap	123.00	---	7.00	n/a	n/a
Compazine	---	82.00	142.00	.159	.759
Mellaril	447.72	356.50	397.39	.375	.688
Navane	379.60	422.67	487.86	.084	.920
Taractan	---	---	---	---	---
Clozapine	---	---	---	---	---

APPENDIX B

OKLAHOMA STATE UNIVERSITY  
INSTITUTIONAL REVIEW BOARD

Date: June 16, 1999

IRB #: AS-99-073

Proposal Title: "TEND STUDY OF PSYCHOTROPIC MEDICINES BY INDIVIDUALS WITH  
DEVELOPMENTAL DISABILITIES"

Principal Investigator(s): Richard Dodder  
Richard Gee

Reviewed and Processed as: Exempt

Approval Status Recommended by Reviewer(s): Approved

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Signature:



Carol Olson, Director of University Research Compliance

June 16, 1999

Date

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



**OKLAHOMA STATE UNIVERSITY  
DEPARTMENT OF SOCIOLOGY  
STILLWATER, OKLAHOMA**

**DEVELOPMENTAL DISABILITIES QUALITY ASSURANCE QUESTIONNAIRE**

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

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

\*Interviewer -- code this page from ADDENDUM sheet.

<p align="center"><b>Interviewer</b></p> <input type="checkbox"/> 0 1 2 3 4 5 6 7 8 9 <input type="checkbox"/> 0 1 2 3 4 5 6 7 8 9	<p align="center"><b>ID Number</b></p> <p align="center"><input type="checkbox"/> No ID</p> <table border="1" style="width: 100%; height: 20px; border-collapse: collapse;"> <tr><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td></tr> </table> <p>0 0 0 0 0 0 0 0          1 1 1 1 1 1 1 1          2 2 2 2 2 2 2 2          3 3 3 3 3 3 3 3          4 4 4 4 4 4 4 4          5 5 5 5 5 5 5 5          6 6 6 6 6 6 6 6          7 7 7 7 7 7 7 7          8 8 8 8 8 8 8 8          9 9 9 9 9 9 9 9</p>									<p align="center"><b>Class Status</b></p> <p><input type="checkbox"/> Focus</p> <p><input type="checkbox"/> Balance</p> <p><input type="checkbox"/> Non Member</p> <p><input type="checkbox"/> Don't Know</p> <p><input type="checkbox"/> OBRA Member</p>
<p align="center"><b>Interview Date</b></p> <p>M <input type="checkbox"/> 0 1</p> <p>M <input type="checkbox"/> 0 1 2 3 4 5 6 7 8 9</p> <p>D <input type="checkbox"/> 0 1 2 3</p> <p>D <input type="checkbox"/> 0 1 2 3 4 5 6 7 8 9</p> <p>Y <input type="checkbox"/> 0 1 2 3 4 5 6 7 8 9</p> <p>Y <input type="checkbox"/> 0 1 2 3 4 5 6 7 8 9</p>										
<p align="center"><b>Sex</b></p> <p><input type="checkbox"/> Male</p> <p><input type="checkbox"/> Female</p>	<p align="center"><b>Race</b></p> <p><input type="checkbox"/> White</p> <p><input type="checkbox"/> African American</p> <p><input type="checkbox"/> Asian</p> <p><input type="checkbox"/> Hispanic</p> <p><input type="checkbox"/> Native American</p> <p><input type="checkbox"/> Other: _____</p> <p><input type="checkbox"/> 0 1 2 3 4 5 6 7 8 9</p> <p><input type="checkbox"/> 0 1 2 3 4 5 6 7 8 9</p>	<p align="center"><b>D.O.B.</b></p> <p>M <input type="checkbox"/> 0 1</p> <p>M <input type="checkbox"/> 0 1 2 3 4 5 6 7 8 9</p> <p>D <input type="checkbox"/> 0 1 2 3</p> <p>D <input type="checkbox"/> 0 1 2 3 4 5 6 7 8 9</p> <p>Y <input type="checkbox"/> 0 1 2 3 4 5 6 7 8 9</p> <p>Y <input type="checkbox"/> 0 1 2 3 4 5 6 7 8 9</p>								
<p align="center"><b>Level of Retardation</b></p> <p><input type="checkbox"/> Not MR</p> <p><input type="checkbox"/> Mild</p> <p><input type="checkbox"/> Moderate</p> <p><input type="checkbox"/> Severe</p> <p><input type="checkbox"/> Profound</p> <p><input type="checkbox"/> Unknown</p>	<p align="center"><b>Site Code</b></p> <table border="1" style="width: 100%; height: 20px; border-collapse: collapse;"> <tr><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td></tr> </table> <p>0 0 0 0 0 0 0 0          1 1 1 1 1 1 1 1          2 2 2 2 2 2 2 2          3 3 3 3 3 3 3 3          4 4 4 4 4 4 4 4          5 5 5 5 5 5 5 5          6 6 6 6 6 6 6 6          7 7 7 7 7 7 7 7          8 8 8 8 8 8 8 8          9 9 9 9 9 9 9 9</p>									<p align="center"><b>Residential Setting</b></p> <p><input type="checkbox"/> Public ICF/MR</p> <p><input type="checkbox"/> Private ICF/MR</p> <p><input type="checkbox"/> Private Home</p> <p><input type="checkbox"/> Group Home</p> <p><input type="checkbox"/> Nursing Facility</p> <p><input type="checkbox"/> Community Placement</p> <p><input type="checkbox"/> 0 1 2 3 4 5 6 7 8 9</p> <p><input type="checkbox"/> 0 1 2 3 4 5 6 7 8 9</p>

10213



**5. Is the residence private or public?**

Private nonprofit  
 Private proprietary  
 Public  
 Private home (includes FC, SIL, ASL, IL, SUP, AC)  
 Other: \_\_\_\_\_

① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

**2. When did s/he move here?**

**M M D D Y Y**

--	--	--	--	--	--

① ① ① ① ① ①  
 ② ② ② ② ② ②  
 ③ ③ ③ ③ ③ ③  
 ④ ④ ④ ④ ④ ④  
 ⑤ ⑤ ⑤ ⑤ ⑤ ⑤  
 ⑥ ⑥ ⑥ ⑥ ⑥ ⑥  
 ⑦ ⑦ ⑦ ⑦ ⑦ ⑦  
 ⑧ ⑧ ⑧ ⑧ ⑧ ⑧  
 ⑨ ⑨ ⑨ ⑨ ⑨ ⑨

Unknown  
 Life-long resident

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

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

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

① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

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

Unknown     None

① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

**92B. If direct care staff, do they:**

work shifts  
 reside at facility  
 some of both

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

Unknown/unavailable  
 Pays Nothing

① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

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

NO       UNKNOWN

State School  
 Private ICF-MR  
 Nursing Home  
 Mental Health  
 Other: \_\_\_\_\_

0 1 2 3 4 5 6 7 8 9  
 0 1 2 3 4 5 6 7 8 9

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

Currently institutionalized  
 Unknown

M M Y Y

--	--	--	--

0 0 0 0  
1 1 1 1  
2 2 2 2  
3 3 3 3  
4 4 4 4  
5 5 5 5  
6 6 6 6  
7 7 7 7  
8 8 8 8  
9 9 9 9

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

Unknown

--	--

0 0  
1 1  
2 2  
3 3  
4 4  
5 5  
6 6  
7 7  
8 8  
9 9

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

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

0 1 2 3 4 5 6 7 8 9  
 0 1 2 3 4 5 6 7 8 9

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

Verbal communication  
 Sign Language  
 Communication Device  
 Alerting Device  
 Gestures  
 Other: \_\_\_\_\_

0 1 2 3 4 5 6 7 8 9  
 0 1 2 3 4 5 6 7 8 9

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

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

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

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

**Other Disabilities (Mark all that apply)**

Visually Impaired       Mental illness  
 Hearing Impaired       Feeding Tube  
 Physical disabilities       Cerebral palsy  
 Autistic like behavior       Tracheostomy  
 Other: \_\_\_\_\_

0 1 2 3 4 5 6 7 8 9  
 0 1 2 3 4 5 6 7 8 9

**What is this person's average monthly income:**

**93. from employment?**

--	--

0 1 2 3 4 5 6 7 8 9  
0 1 2 3 4 5 6 7 8 9  
0 1 2 3 4 5 6 7 8 9  
0 1 2 3 4 5 6 7 8 9

None  
 Unknown/unavailable

**93A. From entitlements:**

--	--

0 1 2 3 4 5 6 7 8 9  
0 1 2 3 4 5 6 7 8 9  
0 1 2 3 4 5 6 7 8 9  
0 1 2 3 4 5 6 7 8 9

None  
 Unknown/unavailable

Page 1

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

Lives with family  
 About once a week or more  
 About 2-3 times a month  
 About once a month  
 About every 3 months  
 Twice a year or less  
 Never in the past year  
 No family, or no DDS case manager or No Advocate (does not apply)  
 Unknown

7. In the past year, how often has there been contact by phone/mail/letters with the consumer's family?

8. How often did family member(s) (biological/adoptive) visit him/her in the consumer's home in the past year?

9. How often did s/he visit the family (biological/adoptive) home or go on outings in the past year?

10. How often did the DDS case manager make contact with consumer by phone in the last year?

11. How often did the DDS case manager make contact with the consumer in person in the past year?

11A. How many times do neighbors visit this person in their place of residence?

11B. How many times do other people visit this person in their place of residence?

14. How often did other advocates visit him/her or their family in the past year?

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

More than twice a week  
 Twice a week  
 Once a week  
 2-3 times a month  
 Once a month  
 Less than once a month  
 Not sure or refused  
 Never

95. Go out to visit with friends, relatives, or neighbors.

96. Go out to visit a supermarket or food store.

97. Go out to a restaurant.

98. Go out to church or synagogue.

99. Go out to a shopping center, mall, or other retail store to shop.

99A. Go out to recreational activities (movies, arcades, etc.)

99B. Go out to the bank.

102. Has s/he participated, during the past year, in an organization which supports or promotes self-advocacy by persons with disabilities? (Has attended or sponsored meetings or events of such organizations as People First, or other local self-advocacy group).

Yes  
 No (Skip to #104)  
 Don't Know (Skip to #104)

103. How often does s/he typically participate in organized self-advocacy activities? (CHOOSE ONE).

Daily  Every other week  Quarterly  Annually  
 Weekly  Monthly  Semi-Annually

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

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

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

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

	Yes (may be assisted)	Sometimes	No (Paid staff makes these decisions)	No (Family/Friends makes these decisions)	Don't know	Not Applicable
111A. Does s/he choose their activities or does someone else choose their activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
111B. Does s/he choose their friends or does someone else choose their friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
111C. Does s/he choose what food to eat at home or does someone else choose what food they eat?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
111D. Does s/he choose what food to order in a restaurant or does someone else choose for them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
111E. Does s/he choose how to spend their money or does someone else choose for them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
112-113. In the past year, has this person experienced discrimination in: (MARK ALL THAT APPLY)						
<input type="checkbox"/> Physical access to buildings						
<input type="checkbox"/> Access to employment services						
<input type="checkbox"/> Access to educational services						
<input type="checkbox"/> Access to other human services						
<input type="checkbox"/> Access to transportation						
<input type="checkbox"/> Interaction with non-handicapped neighbors and friends						
<input type="checkbox"/> Participation in civic events (with non-handicapped individuals)						
<input type="checkbox"/> Participation in recreation/leisure						
<input type="checkbox"/> Other (Describe): _____						

① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ⑩ ⑪ ⑫ ⑬ ⑭ ⑮ ⑯ ⑰ ⑱

**SECTION II: ADAPTIVE EQUIPMENT NEEDS**

What adaptive equipment does s/he have or need? No Needs <input type="radio"/>	Does not need			
	NEEDS but does not have	HAS	Has but needs REPAIR	
17. Glasses	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Hearing Aid	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Wheelchair/Geri Chair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Helmet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Communication Device	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21A. Dentures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21B. Walker/Cane	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21C. Braces/Splints	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21D. Aids For Toileting/Bathing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21E. Aids for Eating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21F. Transportation Aids	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Other: _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ⑩ ⑪ ⑫ ⑬ ⑭ ⑮ ⑯ ⑰ ⑱

SECTION III: ADAPTIVE SKILLS (ADAPTIVE DEVELOPMENT SCALE)

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

23. How is his/her body balance? Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).

- ⑤ Stand on "tiptoe" for ten seconds
- ④ Stand on one foot for two seconds
- ③ Stand without support
- ② Stand with support
- ① Sit without support
- ① Can do none of the above
- ⑥ Unknown

24. Does s/he use silverware? (MARK HIGHEST NUMBER THAT APPLIES).

- ⑤ Use knife and fork correctly and neatly
- ④ Use table knife for cutting or spreading
- ③ Feed self with spoon and fork - neatly
- ② Feed self with spoon and fork - considerable spilling
- ① Feed self with spoon - neatly
- ② Feed self with spoon - considerable spilling
- ① Feed self with fingers or must be fed
- ⑥ Unknown

25. Does s/he: (VISUAL AIDS ARE ACCEPTABLE) (MARK HIGHEST NUMBER THAT APPLIES).

- ⑤ Order complete meals in restaurants
- ④ Order simple meals like hamburgers or hot dogs
- ③ Order soft drinks at soda fountain or canteen
- ① Does not order food at public eating places
- ⑥ Unknown

26. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).

- ⑤ Drink without spilling, holds glass in one hand
- ④ Drink from cup or glass unassisted - neatly
- ③ Drink from cup or glass - considerable spilling
- ① Does not drink from cup or glass
- ⑥ Unknown

27. Does s/he ever have toilet accidents? (MARK HIGHEST NUMBER THAT APPLIES).

- ⑤ Never has toilet accidents
- ④ Seldom has toilet accidents during the day (but may have problems at night)
- ③ Occasionally has toilet accidents (less than 1 a day)
- ② Frequently has toilet accidents (more than 1 a day)
- ① Is not toilet trained at all
- ⑥ Unknown

28. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).

- ⑤ Prepare and completely bathe unaided
- ④ Wash and dry self completely
- ③ Wash and dry reasonably well with prompting
- ② Wash and dry self with help
- ① Attempt to soap and wash self
- ④ Actively cooperate when being washed and dried by others
- ① Makes no attempt to wash or dry self
- ⑥ Unknown

29. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
- Ⓔ Completely dress self
  - Ⓕ Completely dress self with verbal prompting only
  - Ⓒ Dress self by pulling or putting on all clothes with verbal prompting and by fastening (zipping, buttoning, snapping) them with help
  - Ⓓ Dress self with help in pulling or putting on most clothes and fastening them
  - Ⓗ Cooperate when dressed, e.g., by extending arms or legs
  - Ⓘ Must be dressed completely
  - Ⓚ Unknown
30. How is his/her sense of direction? Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
- Ⓒ Go several blocks from grounds, or from home, without getting lost
  - Ⓕ Go around grounds or a couple of blocks from home without getting lost
  - Ⓗ Go around cottage, ward, yard, or home without getting lost
  - Ⓘ Demonstrates no sense of direction
  - Ⓚ Unknown
31. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
- Ⓔ Use money with little or no assistance (e.g., assistance with budgeting is OK)
  - Ⓕ Use money with minor assistance (e.g., checking for correct change, etc.)
  - Ⓒ Use money with some assistance (e.g., being told the correct bills or coins)
  - Ⓗ Use money with complete assistance of staff
  - Ⓘ Does not use money
  - Ⓚ Unknown
32. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
- Ⓔ Choose and buy all own clothing without help
  - Ⓕ Choose and buy some clothing without help
  - Ⓒ Make minor purchases without help (e.g., snacks, drinks)
  - Ⓗ Do some shopping with slight supervision
  - Ⓗ Do some shopping with close supervision
  - Ⓘ Does no shopping
  - Ⓚ Unknown
33. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
- Ⓒ Write complete lists, memos or letters
  - Ⓕ Write short sentences
  - Ⓒ Write or print more than ten words without copying or tracing
  - Ⓕ Write or print own name or other words without copying or tracing
  - Ⓗ Trace or copy own name or other words
  - Ⓘ Does not write, print, copy, or trace any words
  - Ⓚ Unknown
34. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
- Ⓒ Sometimes use complex sentences containing "because," "but," etc.
  - Ⓕ Ask questions using words such as "why," "how," "what," etc.
  - Ⓒ Communicates in few words, short phrases or simple sentences that make sense
  - Ⓗ Does not communicate verbally, with sign language or with communication device.
  - Ⓚ Unknown
35. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
- Ⓔ Read books or other materials suitable for 4th grade level or above
  - Ⓕ Read books or other materials suitable for 2nd or 3rd grade level
  - Ⓒ Read simple stories or comics suitable for kindergarten or first grade level
  - Ⓕ Recognize 10 or more words
  - Ⓗ Recognize various signs, such as "EXIT" or "STOP" or "WOMEN" or "MEN" or Street Signs.
  - Ⓘ Recognize no words or signs.
  - Ⓚ Unknown

- 36. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
  - ⑤ Do simple addition and/or subtraction
  - ④ Count 10 or more objects
  - ③ Mechanically count aloud from one to ten
  - ② Count two objects by saying "one, two"
  - ① Discriminate between "one" and "many"
  - ① Has no understanding of numbers
  - ① Unknown
  
- 37. Does s/he clean his/her room? (MARK HIGHEST NUMBER THAT APPLIES).
  - ③ Cleans room well, e.g., sweeping, vacuuming, tidying
  - ② Cleans room but not thoroughly
  - ① Does not clean room at all
  - ① Unknown
  
- 38. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
  - ④ Prepare an adequate complete meal
  - ③ Mix and cook simple foods
  - ② Prepare simple foods requiring no mixing or cooking
  - ① Does not prepare food at all
  - ① Unknown
  
- 39. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
  - ③ Clear table of breakable dishes and glassware
  - ② Clear table of unbreakable dishes and silverware
  - ① Does not clear table at all
  - ① Unknown
  
- 40. Does s/he go to: (MARK HIGHEST NUMBER THAT APPLIES).
  - ③ Any type of paid employment
  - ③ Workshop
  - ② Prevocational training, in school, or retired
  - ① Performs no outside work
  - ① Unknown
  
- 41. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
  - ③ Initiate most of own activities
  - ② Initiate some of own activities
  - ② Will engage in activities only if assigned or directed
  - ① Will not engage in assigned activities
  - ① Unknown
  
- 42. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).
  - ③ Pay attention to purposeful activities for more than 20 minutes
  - ② Pay attention to purposeful activities for about 15 minutes
  - ① Pay attention to purposeful activities for about 10 minutes
  - ② Pay attention to purposeful activities for about 5 minutes
  - ① Will not pay attention to purposeful activities for as long as 5 minutes
  - ① Unknown
  
- 43. How is s/he at taking care of his/her personal belongings? (MARK HIGHEST NUMBER THAT APPLIES).
  - ③ Very dependable, always takes care of belongings
  - ② Usually dependable, usually takes care of belongings
  - ① Unreliable, seldom takes care of belongings
  - ① Not responsible at all, does not take care of belongings
  - ① Unknown

44. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).

- 1 Interact with others for more than five minutes
- 2 Interact with others for up to five minutes
- 3 Interact with others in limited ways, e.g., eye contact, handshakes, responsive to touch
- 4 Does not interact with others
- 5 Unknown

45. Does s/he: (MARK HIGHEST NUMBER THAT APPLIES).

- 1 Initiate group activities at least some of the time (leader and/or organizer)
- 2 Participate in group activities spontaneously and eagerly (active participant)
- 3 Participate in group activities if encouraged to do so (passive participant)
- 4 Does not participate in group activities (unless physically guided)
- 5 Unknown

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46. Does s/he: (With cane, crutches, brace, or walker, if used). (MARK ALL THAT APPLY)

- Walk alone
- Walk up and down stairs alone
- Walk down stairs by alternating feet
- Run without falling often
- Hop, skip or jump
- None of the above
- All of the above
- Unknown

47. At the toilet, does s/he: (MARK ALL THAT APPLY)

- Lower pants at the toilet without help
- Sit on toilet seat without help
- Use toilet tissue appropriately
- Flush toilet after use
- Put on clothes without help
- Wash hands without help
- None of the above
- All of the above
- Unknown

48. Does s/he: (MARK ALL THAT APPLY)

- Wash hands with soap
- Wash face with soap
- Wash hands and face with water
- Dry hands and face
- None of the above
- All of the above
- Unknown

49. Does s/he: (MARK ALL THAT APPLY)

- Clean shoes when needed
- Put clothes in drawer or chest
- Put soiled clothes in proper place for laundering/washing, without being reminded
- Hang up clothes without being reminded
- None of the above
- All of the above
- Unknown



50. Does s/he: (MARK ALL THAT APPLY)

- Put on shoes correctly without assistance
- Tie shoe laces without assistance (Velcro is ok)
- Untie shoe laces without assistance (Velcro is ok)
- Remove shoes without assistance
- None of the above
- All of the above
- Unknown

51. Does s/he: (MARK ALL THAT APPLY)

- Say a few words
- Sign a few words
- Nod head or smile to express happiness
- Indicate hunger
- Indicate wants by pointing or vocal noises
- Express pleasure or anger by vocal noises
- Chuckle or laugh when happy
- None of the above
- All of the above
- Unknown

52. Does s/he: (MARK ALL THAT APPLY)

- Understand instructions containing prepositions, e.g., "on," "in," "behind"
- Understand instructions referring to the order in which things must be done, e.g., "first do this, and afterward, do that"
- Understand instructions requiring a decision, e.g., "Put on your shorts, but if they're dirty, put on your jeans"
- None of the above
- All of the above
- Unknown

53. Does s/he: (MARK ALL THAT APPLY)

- Tell time by clock or watch correctly
- Understand time intervals, e.g., there is one hour between 3:30 and 4:30
- Understand time equivalents, e.g., "9:15" is the same as "quarter past nine."
- Associate time on clock with various actions and events, e.g., 6:00 means dinner time
- None of the above
- All of the above
- Unknown

54. Does s/he: (MARK ALL THAT APPLY)

- Recognize significant others
- Recognize others
- Have information about others, e.g., relation to self, job, address
- Know the names of people close to him/her, e.g., in neighborhood, at home or day program
- Know the names of people not regularly encountered
- None of the above
- All of the above
- Unknown

Would you say Adaptive Behavior information is:

- Generally reliable/respondent seems to know individual
- Not reliable/respondent does not seem to know individual well

### SECTION IV: CHALLENGING BEHAVIORS

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

**FREQUENCY CODING**

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

Less than or equal to five times a week in past four weeks  
More than five times a week in past four weeks

**RESPONSE CODING**

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

**BEHAVIORAL PLAN or GOAL  
ON CARE PLAN IN PLACE?**

Yes  
No  
Don't Know  
Not Applicable

No challenging behaviors

55. Threaten or do physical violence to others (on purpose) Describe: _____ _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ <input type="checkbox"/> ⑩ ⑪ ⑫ ⑬ ⑭ ⑮ ⑯ ⑰ ⑱														
56. Damage own or others' property (on purpose)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
57. Disrupt others' activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
58. Use profane or hostile language	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
59. Is rebellious, e.g., ignore regulations, resist following instructions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
60. Run away or attempt to run away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
61. Is untrustworthy, e.g., take others' property, lie, or cheat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
62. Display stereotyped behavior, e.g., rock body, hands constantly moving in repetitive pattern	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
63. Remove or tear off own clothing inappropriately	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
64. Injure self	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
65. Is hyperactive, e.g., will not sit still for any length of time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
66. Inappropriate sexual behavior inside the home Describe: _____ _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ <input type="checkbox"/> ⑩ ⑪ ⑫ ⑬ ⑭ ⑮ ⑯ ⑰ ⑱														
67. Inappropriate sexual behavior outside the home Describe: _____ _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ <input type="checkbox"/> ⑩ ⑪ ⑫ ⑬ ⑭ ⑮ ⑯ ⑰ ⑱														
68. Listless, sluggish, inactive, unresponsive to activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
69. Scream, yell or cry inappropriately	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
70. Repeat a word or phrase over and over	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
71. Did s/he display any other challenging behavior? <input type="checkbox"/> Yes <input type="checkbox"/> No Describe: _____ _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨														

**SECTION V: MEDICAL NEEDS/SERVICES**

**HEALTH INFORMATION**

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

Very Good  
Good  
OK  
Poor  
Very Poor  
Not Applicable  
Unknown

71A. Does this person receive medical services through a managed care organization?

- Yes     No     Unknown

71B. General Health: In general, how is this person's health?

- Very Good     Good     OK     Poor     Very Poor     Not Applicable     Unknown

Please rate the quality of the following services:

- |  |                       |                       |                       |                       |                       |                       |                       |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 71C. Primary Physician   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 71D. Nursing Services  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 71E. Emergency care (First aid, ER)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 71F. Dental care   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 71G. Psychiatrist(s)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 71H. Inpatient hospital care   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 71I. Neurologist(s)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 71J. Medical management of Seizures  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 71K. Nutrition Services  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 71L. Other specialties (Surgery, Allergy, Skin, etc.)                                    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 71M. General Health Care: Overall, how good is the health care this person is receiving? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

72. In general, how urgent is his/her need for medical care? (MARK ONLY ONE)

- Generally has no serious medical needs  
 Needs visiting nurse and/or regular visits to the doctor  
 Has life-threatening condition that requires very rapid access to medical care  
 Unknown

73. How often does s/he receive care for a specific medical need from a doctor or a nurse (OTHER THAN MEDICATION ADMINISTRATION)?

- |   |  |
|---|--|
| <input type="radio"/> Not in last year          | <input type="radio"/> Once a week          |
| <input type="radio"/> Once a year               | <input type="radio"/> Once a day           |
| <input type="radio"/> Twice a year              | <input type="radio"/> More than once a day |
| <input type="radio"/> Three to six times a year | <input type="radio"/> Unknown              |
| <input type="radio"/> Once a month              |  |

73A. How many times in the past year has this person received treatment at a hospital emergency room?

- ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨     Never  
 ⑩ ⑪ ⑫ ⑬ ⑭ ⑮ ⑯ ⑰ ⑱     Unknown

73B. How many times in the past year has this individual been admitted to a hospital for any reason?

- ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨     Never  
 ⑩ ⑪ ⑫ ⑬ ⑭ ⑮ ⑯ ⑰ ⑱     Unknown

74. To your knowledge, has s/he had difficulty receiving medical services in the past year?

- No problem  
 One to three times  
 Four to six times  
 Seven to nine times  
 Over nine times  
 Don't know
- What type of problem?  ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ⑩ ⑪ ⑫ ⑬ ⑭ ⑮ ⑯ ⑰ ⑱

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

M  ① ①  
M  ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
Y  ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
Y  ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

- never  
 unknown

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

M  ① ①  
M  ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
Y  ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
Y  ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

- never  
 unknown

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

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

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

- Same  
 More  
 Less  
 Don't know

SECTION VI: MEDICATIONS USED

DRUG USAGE (QUESTIONS 80-85)

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

FREQUENCY of Administration

- TD or total daily dosage if they take several different doses of the same drug in one day
- PRN or when needed
- QID or four times daily
- TID or three times daily

- BID or two times daily
- HS or one time daily
- AVG or average daily dosage if they take a medication less than one time daily

<p>Drug: <input style="width: 90%;" type="text"/> <b>A</b></p> <p>Frequency <input type="checkbox"/> TD <input type="checkbox"/> PRN <input type="checkbox"/> QID <input type="checkbox"/> TID <input type="checkbox"/> BID <input type="checkbox"/> HS <input type="checkbox"/> AVG <input type="checkbox"/> Other</p> <p>Purpose <input type="checkbox"/> behavioral control <input type="checkbox"/> seizure control <input type="checkbox"/> other <input type="checkbox"/> unknown</p> <p>Units <input type="checkbox"/> Milligram <input type="checkbox"/> Gram <input type="checkbox"/> Milliliters <input type="checkbox"/> CC's</p>	<p>Drug: <input style="width: 90%;" type="text"/> <b>B</b></p> <p>Frequency <input type="checkbox"/> TD <input type="checkbox"/> PRN <input type="checkbox"/> QID <input type="checkbox"/> TID <input type="checkbox"/> BID <input type="checkbox"/> HS <input type="checkbox"/> AVG <input type="checkbox"/> Other</p> <p>Purpose <input type="checkbox"/> behavioral control <input type="checkbox"/> seizure control <input type="checkbox"/> other <input type="checkbox"/> unknown</p> <p>Units <input type="checkbox"/> Milligram <input type="checkbox"/> Gram <input type="checkbox"/> Milliliters <input type="checkbox"/> CC's</p>
<p>Drug: <input style="width: 90%;" type="text"/> <b>C</b></p> <p>Frequency <input type="checkbox"/> TD <input type="checkbox"/> PRN <input type="checkbox"/> QID <input type="checkbox"/> TID <input type="checkbox"/> BID <input type="checkbox"/> HS <input type="checkbox"/> AVG <input type="checkbox"/> Other</p> <p>Purpose <input type="checkbox"/> behavioral control <input type="checkbox"/> seizure control <input type="checkbox"/> other <input type="checkbox"/> unknown</p> <p>Units <input type="checkbox"/> Milligram <input type="checkbox"/> Gram <input type="checkbox"/> Milliliters <input type="checkbox"/> CC's</p>	<p>Drug: <input style="width: 90%;" type="text"/> <b>D</b></p> <p>Frequency <input type="checkbox"/> TD <input type="checkbox"/> PRN <input type="checkbox"/> QID <input type="checkbox"/> TID <input type="checkbox"/> BID <input type="checkbox"/> HS <input type="checkbox"/> AVG <input type="checkbox"/> Other</p> <p>Purpose <input type="checkbox"/> behavioral control <input type="checkbox"/> seizure control <input type="checkbox"/> other <input type="checkbox"/> unknown</p> <p>Units <input type="checkbox"/> Milligram <input type="checkbox"/> Gram <input type="checkbox"/> Milliliters <input type="checkbox"/> CC's</p>
<p>Drug: <input style="width: 90%;" type="text"/> <b>E</b></p> <p>Frequency <input type="checkbox"/> TD <input type="checkbox"/> PRN <input type="checkbox"/> QID <input type="checkbox"/> TID <input type="checkbox"/> BID <input type="checkbox"/> HS <input type="checkbox"/> AVG <input type="checkbox"/> Other</p> <p>Purpose <input type="checkbox"/> behavioral control <input type="checkbox"/> seizure control <input type="checkbox"/> other <input type="checkbox"/> unknown</p> <p>Units <input type="checkbox"/> Milligram <input type="checkbox"/> Gram <input type="checkbox"/> Milliliters <input type="checkbox"/> CC's</p>	<p>Drug: <input style="width: 90%;" type="text"/> <b>F</b></p> <p>Frequency <input type="checkbox"/> TD <input type="checkbox"/> PRN <input type="checkbox"/> QID <input type="checkbox"/> TID <input type="checkbox"/> BID <input type="checkbox"/> HS <input type="checkbox"/> AVG <input type="checkbox"/> Other</p> <p>Purpose <input type="checkbox"/> behavioral control <input type="checkbox"/> seizure control <input type="checkbox"/> other <input type="checkbox"/> unknown</p> <p>Units <input type="checkbox"/> Milligram <input type="checkbox"/> Gram <input type="checkbox"/> Milliliters <input type="checkbox"/> CC's</p>

## MEDICATIONS TABLE

001 acetophenazine	096 Diphen (R)	070 Mesantoin (R)	039 Revia (R)
020 Adapin (R)	096 Diphenhist (R)	034 *mesoridazine	039 Revia (R)
002 alprazolam	096 diphenhydramine	036 methamphetamine	103 *Risperdal (R)
003 amantadine	080 divalproex sodium	065 methsuximide	103 risperidone
100 Ambien (R)	101 Doral (R)	037 methylphenidate	037 Ritalin (R)
004 amitriptyline	020 doxepin	035 *metoclopramide	041 Serax (R)
006 amoxapine	104 Effexor (R)	033 Miltown (R)	034 *Serentil (R)
007 amphetamine sulfate	004 Elavil (R)	011 Mitran (R)	083 sertraline
090 Anafranil (R)	004 Endep (R)	038 *Moban (R)	105 Serzone (R)
026 Anxanil (R)	060 Eptol (R)	038 *molindone HCl	020 Sinequan (R)
087 Artane (R)	033 Equagesic (R)	072 Mysoline (R)	066 Solfoton (R)
006 Asendin (R)	033 Equanil (R)	061 nadolol	018 Spancab (R)
026 Atarax (R)	029 Eskalith (R)	039 naloxone	056 *Stelazine (R)
030 Ativan (R)	102 estazolam	039 naltrexone	058 Surmontil (R)
040 Aventyl (R)	079 ethosuximide	039 Narcan (R)	003 Symmetrel (R)
066 Barbita (R)	043 *Etrafon (R)	044 Nardil (R)	108 tacrine
096 Beldin (R)	076 felbamate	052 *Navane (R)	081 *Taractan (R)
096 Benadryl (R)	076 Felbatol (R)	105 nefazodone	060 Tegretol (R)
096 Benlylin (R)	021 fenfluramine	107 Neurontin (R)	050 temazepam
008 benzatropine	022 fluoxetine	096 Nidryl (R)	051 *thioridazine
007 Benzedrine (R)	023 *fluphenazine	010 Noctec (R)	052 *thiothixene HCl
007 Biphetamine (R)	024 flurazepam	027 Norfranil (R)	012 *Thorazine (R)
091 bupropion	107 gabapentin	017 Norpramin (R)	001 Tindal (R)
009 Buspar (R)	096 Genahist (R)	040 nortriptyline	027 Tipramine (R)
009 buspirone	055 Halcion (R)	096 Nytol (R)	027 Tolranil (R)
059 Calan (R)	025 *Haldol (R)	035 *Octamide (R)	053 Iranlycypromine
060 carbamazepine	025 *haloperidol	045 *Orap (R)	015 Tranxene (R)
014 Catapres (R)	026 hydroxyzine	041 oxazepam	054 trazodone
065 Celontin (R)	027 lamimine (R)	018 Oxydess (R)	039 Trexan (R)
047 Centrax (R)	027 imipramine	040 Pamelor (R)	043 *Triavil (R)
010 chloral hydrate	063 Inderal (R)	073 paramethadione	055 triazolam
011 chlordiazepoxide	063 lpran (R)	073 Paraldione (R)	077 Tridione (R)
012 *chlorpromazine	028 isocarboxazid	053 Parnate (R)	056 *trifluoperazine
081 *chlorprothixene	059 Isoptin (R)	082 paroxetine	086 *trifluopromazine
029 Cibalith-S (R)	027 Janimine (R)	082 Paxil (R)	087 trihexiphenidyl
090 clomipramine	013 Klonopin (R)	042 pemoline	043 *Trilafon (R)
013 clonazepam	106 Lamictal (R)	023 *Permitil (R)	077 trimethadione
014 clonidine	106 lamotrigine	043 *perphenazine	058 trimipramine maleate
013 Clonopin (R)	011 Libritabs (R)	017 Pertofrane (R)	062 Valium (R)
035 Clopra (R)	011 Librium (R)	075 phenacemide	080 valproate sodium
015 clorazepate	098 Limbitrol DS (R)	044 phenelzine sulphate	064 valproic acid
095 *clozapine	029 Lithane (R)	066 phenobarbital	062 Valrelease (R)
095 *Clozaril (R)	029 lithium	075 Phenurone (R)	104 venlatāxine
008 Cogentin (R)	029 Lithobid (R)	067 phenytoin	059 Verelan (R)
108 Cognex (R)	029 Lithonate (R)	045 *pimozide	059 verapamil
048 *Compazine (R)	029 Lithotabs (R)	046 piperactazine	047 Verstran (R)
096 Compoz (R)	030 lorazepam	021 Pondimin (R)	086 *Vesprin (R)
061 Corgard (R)	031 *loxapine	047 prazepam	026 Vistaril (R)
042 Cylert (R)	031 *Loxitane (R)	072 primidone	049 Vivactil (R)
024 Delmane (R)	032 Ludiomil (R)	048 *prochlorperazine	091 Wellbutrin (R)
064 Depakene (R)	066 Luminal (R)	023 *Prolixin (R)	002 Xanax (R)
080 Depakote (R)	032 maprotiline	063 propranolol	079 Zarontin (R)
033 Deprol (R)	028 Marplan (R)	102 Prosom (R)	062 Zetran (R)
017 desipramine	035 *Maxolon (R)	049 protriptyline	083 Zolift (R)
036 Desoxy (R)	069 Mebaral (R)	022 Prozac (R)	100 zolpidum tartrate
054 Desyrel (R)	051 *Mellaril (R)	101 quazepam	
018 Dexedrine (R)	070 mephenytoin	046 Quide (R)	CONVERSIONS:
018 dextroamphetamine	069 mephobarbital	035 *Reclomide (R)	1 ml = 1 cc
062 diazepam	033 meprobamate	035 *Reglan (R)	5 ml = 1 teasp
067 Dilantin (R)	033 Meprospan (R)	011 Reposana-10 (R)	15 ml = 1 tablesp
		050 Restoril (R)	30 ml = 1 fl oz

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

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

SECTION VII: OBRA INFORMATION

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

HEALTH CONDITIONS

- Allergies
  - Drug
  - Skin
  - Other
- Anemia
- Arthritis
- Bed Sores
- Broken Bones
- Bladder/Kidney Problems
  - UTI
  - Other
- Cancer
  - Breast
  - Cervix
  - Lung
  - Prostate
  - Uterus
  - Other
- Chronic Constipation/Diarrhea
- Dementia
- Depression
- Diabetes
- Dizziness
- Electrolyte Imbalance
  - Sodium
  - Potassium
- Falls
- Gallbladder Problems
  - Gallstones
  - Other

HEALTH CONDITIONS

- GI Problems
  - Colostomy
  - Reflux
  - Ulcers
- Hearing Problems
  - Wax build up
  - Other
- Heart Problems
  - Congestive Heart Failure
  - Myocardial Infarction
  - Shortness of Breath
  - Hypertension
- HIV (AIDS)
- Liver Problems
  - Cirrhosis
  - Hepatitis
  - Other
- Mental Health Problems
- Osteoporosis
- Paralysis
- Seizures
- Sleep Disorders
- Stroke
- Thyroid Problems
  - Graves
  - Myxedema
- Vision Problems
  - Cataracts
  - Glaucoma
  - Other

**OBRA Specialized Services - (Ask the following only for OBRA people living in Nursing Facilities)**

Is this person receiving Specialized Services?  Yes  No  Unknown (If no, or unknown, skip to question #114)

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

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

Specialized Service #1 \_\_\_\_\_  ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ⑩ ⑪ ⑫ ⑬ ⑭ ⑮ ⑯ ⑰ ⑱

Area addressed: ① ② ③ ④ ⑤ ⑥ ⑦

Specialized Service #2 \_\_\_\_\_  ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ⑩ ⑪ ⑫ ⑬ ⑭ ⑮ ⑯ ⑰ ⑱

Area addressed: ① ② ③ ④ ⑤ ⑥ ⑦

Specialized Service #3 \_\_\_\_\_  ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ⑩ ⑪ ⑫ ⑬ ⑭ ⑮ ⑯ ⑰ ⑱

Area addressed: ① ② ③ ④ ⑤ ⑥ ⑦

**SECTION VIII: SERVICE PLANNING/DELIVERY**

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

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

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

Date Unknown

M  ① ②  
M  ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
Y  ⑩ ⑪ ⑫ ⑬ ⑭ ⑮ ⑯ ⑰  
Y  ⑱ ⑲ ⑳ ㉑ ㉒ ㉓ ㉔ ㉕



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

For the following, what is the total number of hours spent per MONTH for him/her by:

Prescribed but not received. Why not received?

128. Hours spent on habilitation objectives identified in the IHP.

① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

Reason: \_\_\_\_\_  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

129. Homemaker Services by certified homemaker:

① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

Reason: \_\_\_\_\_  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

130. Occupational Therapy Services:

① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

Reason: \_\_\_\_\_  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

131. Physical Therapy Services:

① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

Reason: \_\_\_\_\_  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

132. Psychological Services by licensed psychologist or psychological assistant:

① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

Reason: \_\_\_\_\_  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

133. Psychiatric Services:

① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

Reason: \_\_\_\_\_  
 ① ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨

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For the following, what is the total number of hours spent per MONTH for him/her by:

Prescribed but not received. Why not received?

146. Formal infant stimulation or preschool development training program outside of home:

<input type="checkbox"/>	0	1	2	3	4	5	6	7	8	9
<input type="checkbox"/>	0	1	2	3	4	5	6	7	8	9
<input type="checkbox"/>	0	1	2	3	4	5	6	7	8	9

Reason: \_\_\_\_\_  
 \_\_\_\_\_  
 0 1 2 3 4 5 6 7 8 9

147. Homebound Education:

<input type="checkbox"/>	0	1	2	3	4	5	6	7	8	9
<input type="checkbox"/>	0	1	2	3	4	5	6	7	8	9
<input type="checkbox"/>	0	1	2	3	4	5	6	7	8	9

Reason: \_\_\_\_\_  
 \_\_\_\_\_  
 0 1 2 3 4 5 6 7 8 9

148. Respite Services:

<input type="checkbox"/>	0	1	2	3	4	5	6	7	8	9
<input type="checkbox"/>	0	1	2	3	4	5	6	7	8	9
<input type="checkbox"/>	0	1	2	3	4	5	6	7	8	9

Reason: \_\_\_\_\_  
 \_\_\_\_\_  
 0 1 2 3 4 5 6 7 8 9

148A. How many hours of HTS are prescribed on the IHP?

<input type="checkbox"/>	0	1	2	3	4	5	6	7	8	9
<input type="checkbox"/>	0	1	2	3	4	5	6	7	8	9
<input type="checkbox"/>	0	1	2	3	4	5	6	7	8	9

149. Any other services received:

<input type="checkbox"/>	0	1	2	3	4	5	6	7	8	9
<input type="checkbox"/>	0	1	2	3	4	5	6	7	8	9
<input type="checkbox"/>	0	1	2	3	4	5	6	7	8	9

0 1 2 3 4 5 6 7 8 9  
 0 1 2 3 4 5 6 7 8 9

If yes, what service: \_\_\_\_\_

150. Any transportation services prescribed:

Yes  No  
 If Yes, from:  DDS  Agency  Facility  Other

151. Any other services needed?

Yes  No

0 1 2 3 4 5 6 7 8 9  
 0 1 2 3 4 5 6 7 8 9

If Yes, what service: \_\_\_\_\_

**PART II: CONSUMER INTERVIEW (COPYRIGHT COA 1986)**

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

Family \_\_\_\_\_ Case Manager \_\_\_\_\_ Advocate \_\_\_\_\_ Favorite Thing \_\_\_\_\_

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

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

Willing Why unwilling \_\_\_\_\_  0 1 2 3 4 5 6 7 8 9  
 Unwilling \_\_\_\_\_  0 1 2 3 4 5 6 7 8 9

Unable Why unable \_\_\_\_\_  0 1 2 3 4 5 6 7 8 9  
 (If unwilling, or unable, skip to Question # 26) \_\_\_\_\_  0 1 2 3 4 5 6 7 8 9

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

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

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For the following, what is the total number of hours spent per MONTH for him/her by:		Prescribed but not received. Why not received?
134. Speech and Communication Therapy:	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9	Reason: _____ <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9
135. Audiology Services:	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9	Reason: _____ <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9
136. Nursing Services by RN or LPN:	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9	Reason: _____ <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9
137. Pre-Vocational Services: (non paid employment)	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9	Reason: _____ <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9
138. Sheltered Employment/ Sheltered Workshop: (provided by workshop but receive less than minimum wage).	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9	Reason: _____ <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9
139. Supported Employment: (Paid & supervised by job coach, mobile work crews, job enclave).	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9	Reason: _____ <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9
140. Competitive Employment:	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9	Reason: _____ <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9
141. Public School (regular classes):	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9	Reason: _____ <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9
142. Public School (special classes):	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9	Reason: _____ <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9
143. Special School:	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9	Reason: _____ <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9
144. Private School: (Paid for by school system)	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9	Reason: _____ <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9
145. Private School: (other than above)	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9	Reason: _____ <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9

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

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

What is the best thing about living here? \_\_\_\_\_  
 ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ⑩ ⑪ ⑫ ⑬ ⑭ ⑮ ⑯ ⑰ ⑱

What is the worst thing about living here? \_\_\_\_\_  
 ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ⑩ ⑪ ⑫ ⑬ ⑭ ⑮ ⑯ ⑰ ⑱

If you could live anywhere you wanted, where would you live? \_\_\_\_\_  
 ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨  
 ⑩ ⑪ ⑫ ⑬ ⑭ ⑮ ⑯ ⑰ ⑱

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

If yes, What? \_\_\_\_\_  
\_\_\_\_\_

	①	②	③	④	⑤	⑥	⑦	⑧	⑨
	⑩	⑪	⑫	⑬	⑭	⑮	⑯	⑰	⑱

Is someone working with you to do that?  Yes  No

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

\_\_\_\_\_  
\_\_\_\_\_

	①	②	③	④	⑤	⑥	⑦	⑧	⑨
	⑩	⑪	⑫	⑬	⑭	⑮	⑯	⑰	⑱

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

Do you believe these answers are:  Reliable  Not reliable

Did you use our Adaptive Communication Device?  Yes  No

Did you work with a facilitator?  Yes  No

**PART III: OBSERVATIONS**

26. Is s/he dressed appropriately?

Yes Explain 'No' answer: \_\_\_\_\_  
 No \_\_\_\_\_

	①	②	③	④	⑤	⑥	⑦	⑧	⑨
	⑩	⑪	⑫	⑬	⑭	⑮	⑯	⑰	⑱

27. Is s/he clean and groomed appropriately?

Yes Explain 'No' answer: \_\_\_\_\_  
 No \_\_\_\_\_

	①	②	③	④	⑤	⑥	⑦	⑧	⑨
	⑩	⑪	⑫	⑬	⑭	⑮	⑯	⑰	⑱

28. Is s/he free of visible bruises, rashes, sores, cuts, or other signs of ill health?

Yes Explain 'No' answer: \_\_\_\_\_  
 No \_\_\_\_\_

	①	②	③	④	⑤	⑥	⑦	⑧	⑨
	⑩	⑪	⑫	⑬	⑭	⑮	⑯	⑰	⑱

**PART IV: PHYSICAL QUALITY**

1. Do you have any concerns about the neighborhood?

Yes Explain 'Yes' answer: \_\_\_\_\_  
 No \_\_\_\_\_

	①	②	③	④	⑤	⑥	⑦	⑧	⑨
	⑩	⑪	⑫	⑬	⑭	⑮	⑯	⑰	⑱

2. Do you have any concerns about the exterior of the residence?

Yes Explain 'Yes' answer: \_\_\_\_\_  
 No \_\_\_\_\_

	①	②	③	④	⑤	⑥	⑦	⑧	⑨
	⑩	⑪	⑫	⑬	⑭	⑮	⑯	⑰	⑱

3. Do you have any concerns about the interior of the residence?

Yes Explain 'Yes' answer: \_\_\_\_\_  
 No \_\_\_\_\_

	①	②	③	④	⑤	⑥	⑦	⑧	⑨
	⑩	⑪	⑫	⑬	⑭	⑮	⑯	⑰	⑱

4. Do you have any concerns about the health or welfare of the consumer(s) living here?

Yes Explain 'Yes' answer: \_\_\_\_\_  
 No \_\_\_\_\_

	①	②	③	④	⑤	⑥	⑦	⑧	⑨
	⑩	⑪	⑫	⑬	⑭	⑮	⑯	⑰	⑱

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VITA

Richard L. Gee <sup>2</sup>

Candidate for the Degree of  
Master of Science

**Thesis: TREND STUDY OF PSYCHOTROPIC MEDICINES USAGE BY  
INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES**

**Major Field: Sociology**

**Biographical:**

**Personal Data:** Born in Stillwater, Oklahoma, on July 6, 1970, the son of LaMont and Nancy Gee.

**Education:** Graduated from Stillwater High School in May 1988; received Bachelors of Science in Sociology and Minor in Psychology from Oklahoma State University. Completed requirements for the Master of Science Degree with a major in Sociology at Oklahoma State University in May 2000.

**Professional Organizations:** Member of Alpha Kappa Delta since 1997. Member of Southwest Sociological Association since 1997.

**Professional Experience:** Employed as an interviewer for the Developmental Disabilities Quality Assurance Project at Oklahoma State University.