

# DEINSTITUTIONALIZATION AND THE MEASUREMENT OF CONSUMER OUTCOMES: THE OKLAHOMA EXPERIENCE 1992-1999

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## Abstract

The deinstitutionalization movement in the United States has taken on many forms and has had significant impact on individuals, governments, and communities. In response to government policy concerns, social scientists have investigated the theoretical and methodological tasks of conceptualizing and measuring the impact of deinstitutionalization. Procedures for examining the impact of community based correctional and mental health facilities have become well established, but far less attention has been paid to the deinstitutionalization of persons with developmental disability. This paper provides an overview of the deinstitutionalization movement as applied to persons with developmental disabilities and places the Oklahoma experience within the context of that movement. The analysis examined four indicators of quality of life (independence, integration, productivity, and satisfaction) drawn from the 1987 Amendments to the Developmental Disabilities Act. Results show higher mean scores on each indicator used to measure quality of life since community placement.

## INTRODUCTION

The purpose of this paper is to provide an overview of the de-institutionalization movement as it applied to persons with developmental disabilities and to place the Oklahoma experience within the context of that movement. This analysis draws on information from several sources including Oklahoma State University Developmental Disabilities Quality Assurance Research Project.

## BACKGROUND

The deinstitutionalization movement in the United States has taken on many forms and has had significant impact on individuals, governments and communities. Typically viewed as a social movement, its organizational phase dates back at least to the 1960s. The movement has as one of its primary goals the removal of individuals from total institutions such as prisons, asylums, and mental hospitals to community-based alternatives. Similar movements occurred (and are occurring) in other countries as well. Several studies for example document aspects of the movement in Canada and Britain. The success of the movement has led to the establishment of community alternatives to prisons, mental hospitals, and state schools. State schools, like mental hospitals, were large total institutions that housed persons who were then referred to as "mentally retarded". Public policy statements and plans paralleling this movement are concerned with assessment of the success of community placement for individuals as well as for the communities in which they are placed.

In response to governmental policy concerns, social scientists began to concern themselves with the theoretical and methodological tasks of conceptualizing and measuring the success of deinstitutionalization. Until recently (last 10 years) in the U.S., most of this effort was concentrated in the area of prison reform and eradication of many large mental institutions. Many of these were replaced with community correctional facilities and community mental health facilities. The procedures for establishing success, or lack of success, of the community based correctional and mental health facilities are well established in research. Far less attention has been paid to deinstitutionalization of persons with developmental disability. Of particular concern is how successful deinstitutionalization is conceptualized and measured for persons with developmental disabilities.

Several forces joined to contribute to broad-based shift in policy. First, the aforementioned deinstitutional movement, as an outgrowth of the civil rights movement, has altered society's perceptions about how people with developmental disabilities should be supported. There is a growing recognition among families, professionals, and policy makers that people with developmental disabilities can and should live in the community (Stancliffe & Hayden, 1998). Second, federal legislation such as the Omnibus Budget Reconciliation Act (OBRA: P.L. 100-203) has discouraged the use of congregate care settings, such as nursing homes, for people with developmental disabilities, favoring instead the use of smaller community based

services. Third, research on the quality of life has accumulated over the past two decades showing that individuals improve in several skill areas when placed in a community setting regardless of the severity of their disabilities (Larson & Lakin, 1989; Larson & Lakin, 1991). Finally, Oklahoma's increased commitment to community based programming was significantly promoted by the litigation that led to the closure of The Hissom Memorial Center in Sand Springs, Oklahoma.

#### **OVERVIEW OF HISSOM MEMORIAL LITIGATION**

In 1987, Oklahoma became one of the testing grounds for the rights of those with developmental disabilities when a lawsuit was filed on behalf of persons living in Hissom Memorial Center in Sand Springs. This lawsuit, *Homeward Bound vs. The Hissom Memorial Center*, was filed on July 24, 1987. The Northern District Court of Oklahoma, in response to the lawsuit, ordered the Department of Human Services to phase out services at Hissom. A similar lawsuit was filed in the State of Pennsylvania in 1979 on behalf of consumers living in the Pennhurst State School and Hospital. The result of that lawsuit was a federal court order mandating that residents of Pennhurst be moved into less restrictive environments outside of the facility. This was to be accomplished by placing consumers in the general community. In order to assure the well being of those who were deinstitutionalized, Temple University Developmental Disabilities Center and the Human Services Institute of Boston undertook a landmark study to track consumer progress through the process of deinstitutionalization. This landmark study is known as *The Pennhurst Longitudinal Study* (Conroy & Bradley, 1985). The Oklahoma experience shares many similarities with the Pennsylvania one.

The Oklahoma lawsuit stipulated that the State of Oklahoma place the Hissom residents in appropriate alternative care facilities around the state. "The court's central finding was that the State's attempt to create a specialized segregated center for the purpose of clustering quality services does not work" (Cook, 1987:350). Further, the court determined that, "...institutions were the least likely settings in which to achieve individual growth and development." (Cook, 1987: 351). Historically, institutions were created because there were no community services, and the development of segregated services through institutions only

further exacerbated the prejudices against "retarded people" by communities. The court concluded, "segregation and the separation from others leads to reduced learning, reduced freedom, and reduced growth" (Cook, 1987:352).

The *Homeward Bound* case is the first to have used Section 508 of the Rehabilitation Act— Disabled Person's Civil Rights Act — to find in general, the "right" to effective and integrated services. Prior to this decision, the courts used Section 508 to support community placements, but never determined a general "right". The *Homeward Bound vs. The Hissom Memorial Center* litigation evoked for the first time the enforcement of regulations mandated by the Social Security Act as administered by the U.S. Department of Health and Human Services. In particular, those regulations that pertain to "all-institutional" residents, and the opportunity to participate in community activities (Cook, 1987:355). The consent decree required the State of Oklahoma to develop discharge plans for all persons who do not need institutional settings. The *Homeward Bound* court order determined that there should be no room for the possibility for any segregated settings for any individuals. The court sought "the removal of the institution as a choice of living environment for such individuals" (Cook, 1987: 356).

As a result of the court's findings, "Nine Guiding Principals" were drafted to guide the parties as they sought to create community-based alternatives for persons with mental retardation in Oklahoma. "While the court acknowledged that this order could not require the citizens of Oklahoma to interact with their fellow citizens with mental retardation in a positive, supportive way, it can require the state to implement strategies designed to bring Oklahomans voluntarily to that same conclusion" (NASMRP:1987:360).

The suit initially filed on May 2, 1985 on behalf of the Hissom Class, sought to obtain relief from alleged unlawful treatment by the Department of Human Services. The class consists of the "focus class", which is made up of all those people who resided at Hissom prior to May 2, 1985 and at the time of the suit. And the "balance class", including all former residents. After several interim orders related to services provided at Hissom, the "court plan and order of deinstitutionalization" became effective on October 21, 1987. The court appointed a monitor in May 1988 to fa-

cilitate the implementation of the decree.

Two years later in 1989 the plaintiffs and the defendants mutually agreed to drop the litigation concerning care and treatment of the class, including the pending appeal. Both moved to an agreed upon structure for carrying out service that would provide appropriate relief for the class in a manner that is consistent with the 1987 order. On December 4, 1989, U.S. District Judge James Ellison, of the Northern District Court of Oklahoma, approved a consent decree that would substitute for the 1987 court plan and order of deinstitutionalization in the case of *Homeward Bound vs. the Hissom Memorial Center*. The consent decree establishes a framework (Nine Guiding Principles) for a community service system that would serve as an alternative to institutional care for current and former residents of Hissom. Thus the December 4 consent decree supercedes the 1987 order and all subsequent court orders.

#### PROVISIONS OF THE CONSENT DECREE

The Consent Decree consists of six sections, each divided into a series of provisions. The six sections are:

1. Provisions Related to the "Focus Class"
2. Provisions Related to the "Balance Class"
3. Provisions related to the Entire Class—the role of parents/families is outlined in the agreement; parents/guardians will be members of the Interdisciplinary Team (IDT) for their family member and involved in all team decisions. Clients and families will have the right to select service providers from a State approved list of providers. A system of safeguards is outlined in the decree, and DHS is directed to secure technical assistance from the outside to assist in the development and implementation of a quality assurance program, including compliance with ACDD standards.
4. Provisions Related to Oversight and Dispute — establishes Homeward Bound Review Panel, a panel of three individuals who will be assigned primary responsibility for assisting the court and the parties in the suit to carry out the decree. The panel will replace the court monitor whose role will be terminated.
5. Financial Provisions — shall not expend more funds on an average per capita basis to maintain and serve clients in the community than the amount required serving

them at Hissom.

6. Miscellaneous Provisions — consent decree will terminate three months after the last client is transferred out of Hissom. (Excerpts taken from Reprinted Newsletter of the National Association of State Mental Retardation Program Directors, Inc.)

#### OKLAHOMA STATE UNIVERSITY QUALITY ASSURANCE LONGITUDINAL ASSESSMENT PROJECT (OSU-DDQA)

The project is a direct outgrowth of two federal lawsuits filed on behalf of persons with developmental disabilities. The first lawsuit being the aforementioned *Homeward Bound vs. The Hissom Memorial Center*. Under Section 3 of the 1989 Consent Decree, DHS is directed to secure technical assistance from the outside to assist in the development and implementation of a quality assurance program. Oklahoma followed a pattern that had already been established in the Pennhurst Study, the OSU Project was established to provide data on the Oklahoma population of concern.

#### CONTENT OF THE STUDY: SIX INDICES OF QUALITY OF LIFE OR CONSUMER OUTCOME

Modifications have been made to meet the specific monitoring requirements mandated by the consent decree; however, the "core indicators" of consumer outcome remain intact. These core indicators are: independence as measured by adaptive behavior and challenging behavior, integration or opportunities for interaction, productivity as measured by specialized work or educational opportunities, consumer satisfaction as measured by perceptions of community placement and choice making opportunities.

Over the years several sections within the instrument have been modified and/or eliminated, but the four basic consumer outcome indicators have remained constant throughout the years. The assessment has expanded to include all known individuals receiving services from The Department of Human Services, Developmental Disabilities Services Division. The actual study does not include all persons who are eligible to be a part of the study, and approximately 3700 attempted assessments are made each year.

The political milieu has significantly influenced the framework in analyzing quality of life outcomes. The pressure to desegregate services or deinstitutionalize individuals has directed the analysis toward a comparison be-

tween those persons who remain institutionalized (stayers) and those who moved out into the community (movers). The research is primarily concerned with assessing changes in indicators over time.

#### *Variables*

Of the more important variables in the study four core indicators were utilized as the primary indicators for consumer outcomes. These indicators were scaled and indexed items designed to assess important quality of life indicators identified in the 1987 amendments to the Developmental Disabilities Act and are a variant of the indicators used in the Pennhurst Study (Conroy and Bradley, 1985). The indicators included independence, integration, productivity and satisfaction. All of the consumer outcome indicators were examined longitudinally. There were two measures of independence — one set of indicators measuring an individual's adaptive skills and one set of indicators measuring the reported ability to control challenging behaviors. Information was obtained during a face-to-face interview with someone who knew the consumer well, usually the primary caregiver. The adaptive development scale was comprised of 32 items designed to measure adaptive skills in terms of physical capabilities, cognitive attributes, group interactions, and the ability to deal with complex instructions. Respondents were asked to reply based on skills and abilities the consumer displayed at least 75% of the time. The scale was scored from 1 to 100 with a higher score indicating more adaptive skills.

The ability to control behaviors that have been defined as challenging was assessed with a scale that measured across five dimensions: 1) inappropriate behaviors directed at others, 2) inappropriate behaviors directed at the self, 3) stereotypical behaviors, 4) acting out, and 5) general listlessness. The scale was scored from 1 to 100 with a higher score indicating a greater ability to control challenging behaviors.

Integration was operationally defined as the number of times consumers left the place of residence to interact in the community. Caregivers reported the number of times consumers visited friends or neighbors, went shopping, dined out, went places for recreation, and visited the bank. Responses were tabulated to show how many opportunities for social interaction individuals experienced each week.

Questions that comprised the consumer satisfaction scale were answered by the primary

consumer of DDSD services. The scale was scored from 1 to 100 with a higher score indicating greater satisfaction. The actual questions are specified below.

#### *Measures of Independence*

1. Adaptive Behavior Skills refers to a series of related life skills that focus on practical activities of daily living. Items contained within the 100-point scale address topics such as toileting, eating, dressing, bathing, and socialization. A higher score on this Adaptive Behavior scale suggests a greater competence in meeting the basic demands of life.
2. Challenging Behavior refers to various forms of socially unacceptable behavior. Such behavior includes assault, self-mutilation, and property destruction, along with a number of less significant behaviors as rocking, repeating words or phrases. The OSU-DDQA assessment instrument measures 16 specific challenging behaviors, and each behavior is rated for frequency: not observed in the past month (2), less than or equal to five times a week in past four weeks (1), more than five times a week in the past four weeks (0).

#### *Measures of Integration*

3. Community Integration was measured by seven indices of opportunities for social interaction. The seven indices represent seven distinct public domains where social interaction can occur. Responses represent the frequency of outings per week. The seven public domains are: banks, movies, malls, churches, restaurants, grocery stores, and friends. The questions were scored: never (0), not sure refused (1), less than once a month (2), once a month (3), two to three times a month (4), once a week (5), twice a week (6), more than twice a week (7).

#### *Measures of Productivity*

4. Productivity was measured as the number of hours each month consumers are engaged with school or work related activities. Educational activity included regular and special classes at public schools, special schools, private schools and homebound education. Work activity included prevocational services, sheltered workshops, supported employment and competitive employment.

#### *Measures of Consumer Satisfaction*

5. Consumer satisfaction was assessed directly by asking consumers several questions

about their lives. Findings are limited to those individuals who had the capacity to respond to the questions. The following questions were asked: Do you like living here? Do you like the people who work with you? Do you think the food is good? Do you have enough clothing? Do you have friends? Are the people who work with you mean or nice? Do you like your day activity?

Questions regarding the opportunity to exercise choice were included in the consumer interview. The six specific questions were: Do you choose what you eat? Do you choose the clothes you buy? Do you choose the clothes you wear? Do you choose your friends? Do you choose how your money is spent? All of the above questions were rated Yes (3), Unsure (2), and No (1).

**PROCEDURES AND DATA**

The OSU-DDQA procedures for collecting data involve visiting each person's home, or institutional setting, inspection of the person's records combined with collection of information from direct care staff, a tour and qualitative assessment of the home, and finally an interview with the consumer. Every effort is made to do direct interviews through alternative means of communication. These include signing, picture book, language board, or non-verbal gestures. For the people who cannot respond directly, there remains a wealth of

qualitative information gathered during the assessment. Trained interviewers conducted assessments, and each visit required 60 to 90 minutes per consumer to complete.

**FINDINGS BASED UPON THE INDICATORS**

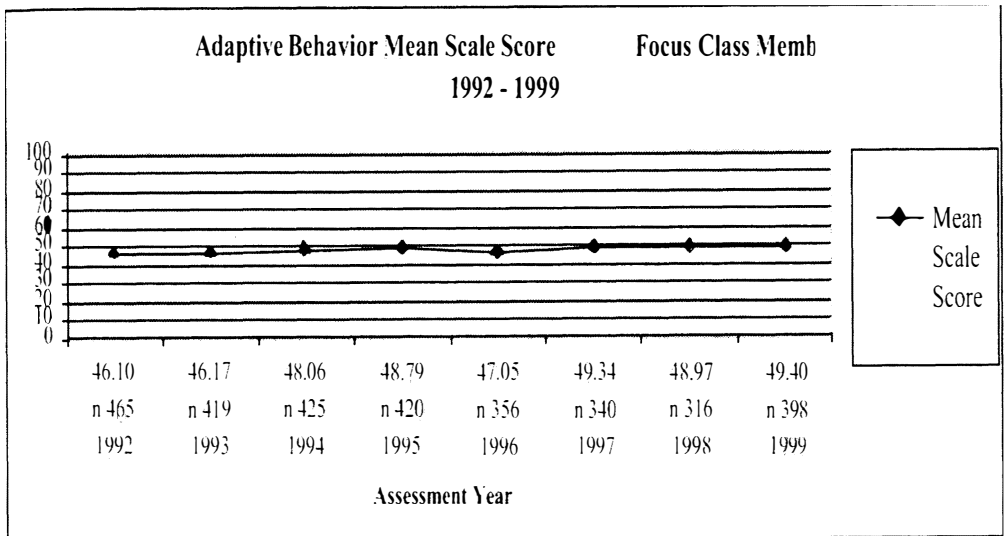
*Adaptive Behavior Score*

Direct care staff were asked to reply based on skills and abilities displayed at least 75% of the time. The scale was scored from 1 to 100 with a higher score indicating more adaptive skills. Figure 1 shows the mean scores for class members since 1992. In 1992, class members' average score on adaptive development scale was 46.10. There has been a steady increase in the mean scores measuring adaptive skills since 1992 except for one low mean in 1996. Further analysis of the data is needed in order to determine if the decrease is significant and what are the contributing factors surrounding the decrease. In general, the adaptive behavior skills of the focus class members have not exceeded 50 on a 100-point scale since deinstitutionalization with a mean score of 49.40 in 1999.

*Challenging Behavior Score*

The ability to control behaviors that are defined as challenging was assessed with a scale item that measured across five dimensions: 1) inappropriate behaviors directed toward the self, 2) inappropriate behaviors directed towards others, 3) stereotypical behaviors, 4)

**FIGURE 1**  
**ADAPTIVE BEHAVIOR SCORE**



acting out, and 5) general listlessness. The scale was scored from 1 to 100 with the higher score indicating a greater ability to control challenging behaviors. Figure 2 shows the average scaled score for the ability to control challenging behaviors since 1992. Class members have scored relatively high on the scale, the lowest score, 87.93 was recorded in 1996, with variation in the scores throughout the years.

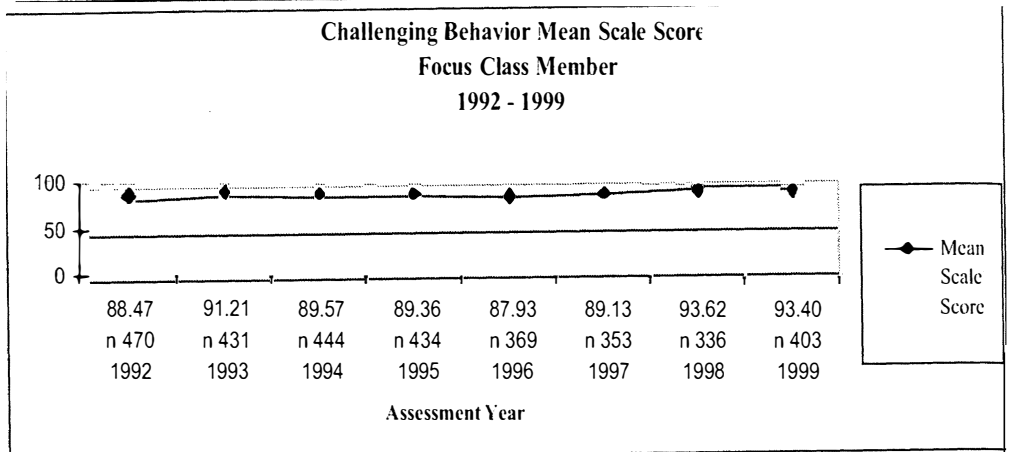
### Social Integration

Integration was operationally defined as the number of times consumers left their place of residence to interact in the community. Such interactions included visiting friends or neighbors, shopping, dining out, going places for recreation, and visiting the bank. Responses

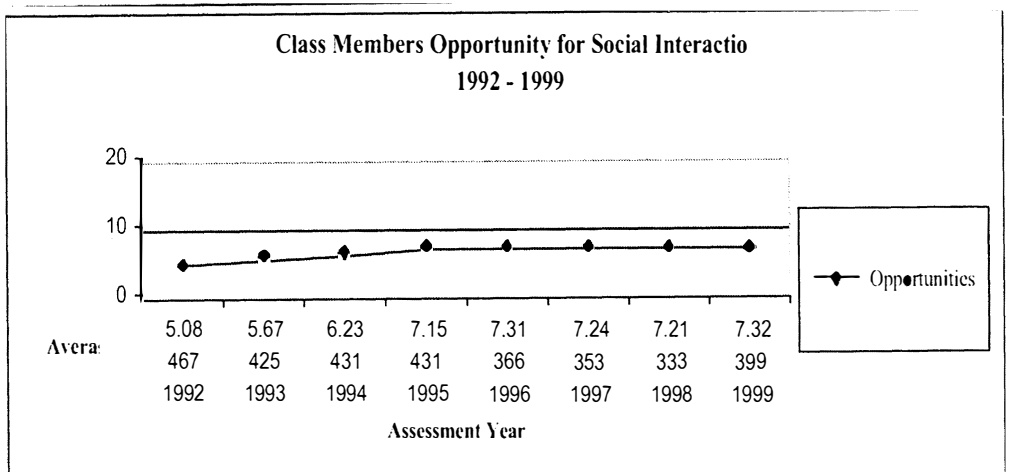
were tabulated to show how many opportunities class members had for social interaction each week since 1992. Figure 3 shows that in 1992, class members left the residence an average of almost 5 times a week. There have been relatively steady increases in the number of opportunities, and in 1999 class members left their residence more than 7 times a week. Class members experienced more opportunities for social interaction after deinstitutionalization.

Figure 4 shows the average number of hours per month class members over the age of 18 were active in work related activities has steadily increased over the years from 47 hours per month in 1992 to 60.83 hours per month in 1999. Mean scores are shown in Table 1. Most of these hours were worked in non-competi-

**FIGURE 2**  
**CHALLENGING BEHAVIOR SCORE**



**FIGURE 3**  
**OPPORTUNITIES FOR SOCIAL INTEGRATION**



tive positions which included hours spent in prevocational training and sheltered or supported employment. The average number of hours per month that class members between the ages of five and 18 were active in educational activities has steadily declined. Part of this decrease may be attributed to individuals aging out of the educational system. In 1992, there were 20 class members in school, and they averaged 118 hours a month of educational activities. In 1998, there were two class members attending school, and they averaged 10 hours of educational activities per month. In 1999 there were no class members attending school.

*Consumer Satisfaction*

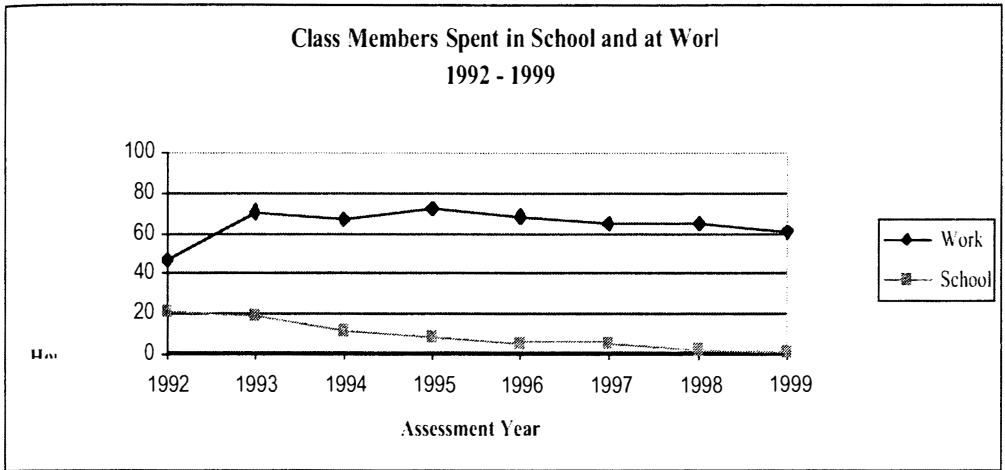
Consumer Satisfaction was assessed with a scale that measured across two dimensions, individual satisfaction with the residential arrangement and satisfaction with the interactions that were available. The consumer an-

swered questions that comprised the consumer satisfaction scale. The scale was scored from 1 to 100 with a higher score indicating greater satisfaction. Figure 5 shows the average scores for class members since 1992. The consumer satisfaction scores through the years indicate that class members have indicated increased satisfaction, over the years, with their residential services and the interactions available to them. In 1992 the average score was 90.98. After a first year drop, there has been a steady increase in consumer satisfaction scores. Consumer satisfaction scores for class members increased to 91.37 in 1999.

**SUMMARY AND CONCLUSIONS**

Today, all persons at Hissom Memorial Center have been placed in the community<sup>1</sup>. Oklahoma officials have extensively studied the closure of Hissom Memorial Center. The over-

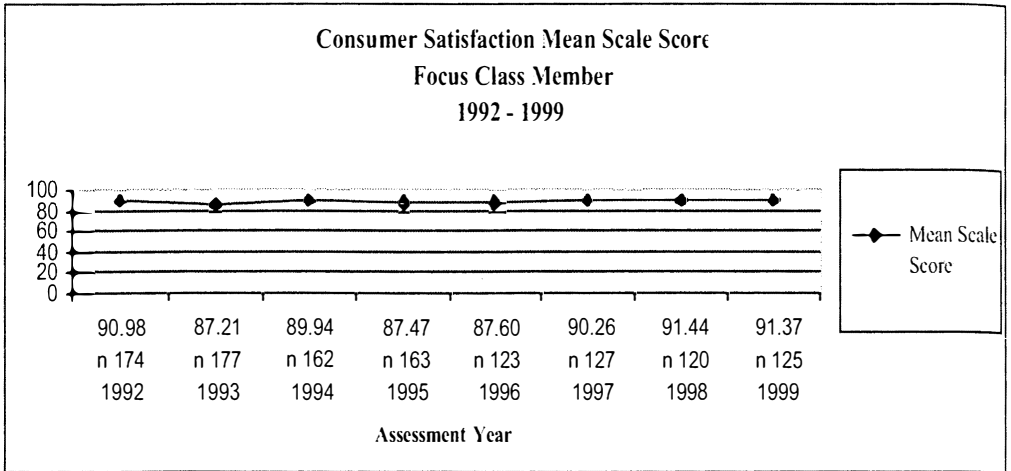
**FIGURE 4**  
**WORK AND SCHOOL ACTIVITY/PRODUCTIVITY**



**TABLE 1**  
**MEAN SCORE ON WORK AND SCHOOL HOURS PER MONTH 1992 – 1999**

	1992	1993	1994	1995	1996	1997	1998	1999
Work	47.32	70.51	67.26	72.14	68.46	65.10	64.47	60.83
n	470	431	444	434	369	353	336	403
School	21.17	19	11.24	8.61	5.48	4.81	1.68	.55
n	470	431	444	434	369	353	336	403

**FIGURE 5**  
**CONSUMER SATISFACTION**



all findings indicate that the former Hissom Memorial Center residents averages increased on the quality of life indicators, subsequent to their placement in the community. The data have revealed that a consistent pattern of increased adaptive behavior skills, increased opportunities for social interaction with persons who are not developmentally disabled, increased opportunities to make choices about one's own life, increased satisfaction, increased family contact, and increased services are associated with those consumers discharged from Hissom and placed into community based services.

Public policy and the administration of community based services for the developmentally disabled have been concerned with the assessment of the success of individual placement. Of particular concern is how one conceptualizes and measures successful de-institutionalization for persons with developmental disabilities ranging from the mildest to the most severe.

Measures of success have come to be defined and based on the premise that the ultimate goal is to utilize specialized services and "mainstream" the entire population of persons formerly classified as mentally retarded. Successful community based services operates under the premise that this group of people could (or should) become productive interacting members of communities in which they were placed thereby enhancing the quality of life of the individual (Schlalock, 1994; White and Dodder, 1996).

This line of reasoning ties the success of deinstitutionalization to social integration and quality of life. The problem for conceptualization is one of being able to clearly delineate the characteristics and criteria for judging the social integration of a person within developmental disability.

Social integration and quality of life are, to some extent, a function of sociability. However, the concept of social functioning usually emerges in developmental research as containing several dimensions. These include interaction with others, social participation, independence and ability to adapt to the environment. On the surface these social and behavioral domains appear to be logical prerequisites for becoming "attached" to one's social and physical environment. What is methodologically troubling is how these domains have become conceptualized and measured in the literature on deinstitutionalization.

There is evidence that the current quality assurance assessments capture individual level profiles of basic physical, psychological, and social functions. There is some concern that they may not capture other important factors such as the quality of the community-based service delivery systems, the quality of community participation, or degree of attachment to the community. For example, the research does not examine the host community and or resident perceptions and/or reactions to their new members of the community. The various service providers, from residential to medical, are also not included in the assessment process. A further examination of the processes



of community-based services is needed in order to help explain the variations that are occurring in consumer outcomes at the individual level of analysis.

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#### NOTES

[1] There remain two State operated institutional settings that refuse to "go away". They are the Southern Oklahoma Regional Center (SORC) and the Northern Oklahoma Regional Center (NORC).