

**The Hissom Outcomes Study:**

**1998 Update**

Brief Report Number 6  
Of a Series on the Well Being of People with  
Developmental Disabilities in Oklahoma

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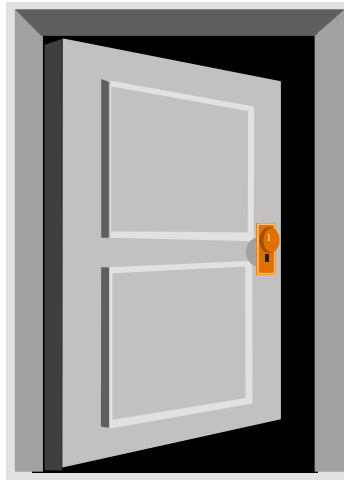
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## Acknowledgement

Data have been obtained through a cooperative agreement with the Oklahoma State University Department of Sociology's Developmental Disabilities Quality Assurance Research Project. Since 1989, the Sociology Department at O.S.U. has conducted yearly independent assessments of consumer outcomes for approximately 3700 individuals receiving services from the Oklahoma Department of Human Services Developmental Disabilities Services Division.



“In 1990, these people were surrounded by walls.  
In 1994, they're surrounded by doors.”

The quotation above is from David Loconto, a graduate student at Oklahoma State University. When he wrote this in 1995, Mr. Loconto was studying the well-being of people who moved from Hissom to community. He personally visited more than 200 Hissom class members in 1995.

## **Executive Summary**

Earlier research had indicated that persons who were relocated to the community from Hissom Memorial Center experienced positive life changes in many areas. They had greater family contact, they evidenced increased skills, they received more services, they were more integrated with the general community, and those who could respond to an interviewer indicated that they were more satisfied with life in the community. This report sought to determine whether these positive changes had been maintained an additional three years. We learned the following:

- The positive life changes were maintained with respect to adaptive behavior, choice making, productivity, integration, service provision, family contact, and consumer satisfaction.
- Continued improvement was noted with respect to challenging behavior and consumer health rating.
- Use of medications, for both behavioral control and other forms of health maintenance returned to levels that were comparable to those found in Hissom Memorial Center.
- On no variable was performance below the levels recorded at Hissom Memorial Center

## Introduction

We know from prior research (Conroy, 1995; Murray, 1994) that the people who left Hissom Memorial Center between 1990 and the closure in 1994 were “better off” in practically every measurable way in their new community situations. They had greater family contact, they evidenced increased skills, they received more services, they were more integrated with the general community, and those who could respond to an interviewer indicated that they were more satisfied with life in the community. The data collection visits upon which these conclusions were based were conducted in 1995.

Is that conclusion still true in 1998, three years later? Have people maintained the gains that they evidenced after initial relocation to the community? The Oklahoma State University’s Department of Sociology conducted another round of visits with Hissom Class Members in 1998. This Brief Report analyzes the 1998 data to answer this question:

*Are the benefits of community placement still evident three years after the last report, and four years after the closure?*

The answer to the question may be relevant to the District Court’s consideration of releasing jurisdiction over the Hissom Class Members. More important for future policies, and future generations, is the issue of whether the

tremendous enhancements we saw in the lives of the Class Members can be maintained over the long term.

This Report is intended to be very brief and non-technical. The details of how the data are collected, with what instruments, and how the statistical data are treated, can be found in the OSU series of Reports on the Developmental Disabilities Quality Assurance Research Project. Here, we are simply updating prior findings for people who lived at Hissom Memorial Center in 1990, and who are now living in Oklahoma's communities.

## **Methods**

### **The People**

This Report concerns the well being of people who lived at Hissom in 1990, regardless of membership in the Focus class. By 1994, practically all of the people who lived at Hissom Memorial Center had moved to community homes in regular neighborhoods. We were able to identify 235 individuals who had contributed data to the research project in 1990, 1995, and 1998. This report concerns these 235 people who were visited in 1990 at Hissom, again in 1995 in the community, and once again in 1998 in the community.

This sample of 235 persons who formerly lived in Hissom Memorial Center was comprised of 138 males and 97 females. The average age in 1998 was 32 years, with the youngest person being 18 years old and the oldest being 55 years old. The breakdown by level of mental retardation was as follows: 7% mild mental retardation, 8% moderate mental retardation, 21 % severe mental retardation, and 64% profound mental retardation. These people displayed a wide range of secondary disabilities, with physical and visual being most frequently cited (34% and 14% respectively). The group was ethnically classified as 82% Caucasian, 14% African American, 4% American Indian, and less than 1% Other. These demographic characteristics seem to be in general agreement with the

characteristics of the overall membership of the Focus Class, suggesting that our resultant data should be generalizable to the entire group.

Of the 235 people, 212 were described as living in some variety of “supported living” in 1998. Nine people’s homes were described as “adult companion” homes, one as “adult foster care,” and six as “other.” There were seven people for whom this item was left blank.

Sixty-one (61) of the people lived in a one person setting (26%), another 123 persons lived with a housemate who also had a disability (52%), and 51(22%) lived with two other persons. It bears emphasizing that Oklahoma’s Hissom Class Members are very unusual in that there are no large groups or large group homes.

### **Analysis of Outcomes**

This report will follow the general format of earlier reports, which discussed the impact of relocation to the community. We will specifically address the following areas of outcome: Adaptive Behavior, Challenging Behavior, Choice Making, Integration Activities, Family Contacts, Productivity, Active Treatment, Medication Use, Consumer Satisfaction, and Health.

## **Results**

### **Adaptive Behavior**

Adaptive Behavior is an inverse measure of the need for support. Higher levels of adaptive behavior generally indicate greater levels of personal competence and independence. In the Oklahoma Quality Assurance Research Project, adaptive behavior is measured annually by the Adaptive Development Scale. This is a derivative of the AAMR Adaptive Behavior Scale.

The chart below presents the 1990, 1995, and 1998 Adaptive Development Scale scores for the 235 individuals included in this study. As this chart reveals, adaptive behavior increased significantly from 1990 to 1995. In the ensuing three years, change has been undetectable. Individuals have maintained their increased adaptive behavior levels, but no further growth has been detected.

## **Adaptive Development Scale Scores**

<b>Adaptive Behavior Scale Score Changes</b>	<b>1990 to 1995</b>	<b>1995 to 1998</b>	<b>N</b>
<b>Average</b>	33.8 to 40.5	40.5 to 39.8	227
<b>Significance</b>	.001	.120 (NS)	

### **Challenging Behavior**

Challenging Behavior is a euphemism for socially offensive behaviors such as assault, self-injury, property destruction, and a variety of related offenses. As might be expected, the emission of such behaviors is sometimes associated with requests for placement in residential treatment facilities. Challenging behavior is measured by a 100-point scale in which higher scores are indicative of lower levels of challenging behavior (and in turn, less need for therapeutic support). The chart below reveals that the individuals who moved from Hissom Memorial Center maintained and even slightly improved upon their challenging behavior. Improvement was noted from 1990 to 1995 and from 1995 to 1998. Although the magnitude of the 1995-98 change was quite small, it was sufficiently consistent across individuals as to achieve statistical significance.

### Challenging Behavior Scale Scores

<b>Challenging Behavior Frequency Scale</b>	<b>1990 to 1995</b>	<b>1995 to 1998</b>	<b>N</b>
<b>Average</b>	85.9 to 89.0	89.0 to 89.3	227
<b>Significance</b>	.001	.001	

### Choice Making

The ability to make personal choices is the hallmark of self-determination. We measure choice making with 7 specific questions, which are asked directly of the service recipients. These 7 questions ask about choice-making opportunities with respect to use of free time, selection of friends, food, clothing, use of money, and privacy. It should be recognized that most of the persons who participated in this study were unable to participate in an interview process due to their cognitive limitations. This, combined with our requirement that each person contribute data from 1990, 1995, and 1998 effectively reduced our sample size to just 28 persons. This drastic reduction in sample size clearly places limits on our ability to generalize the findings in this area to all persons who formerly lived in Hissom.

The choice making scale yields scores that range from 0 to 100, with higher scores indicating greater opportunities to exercise choice. The table below

suggests that the dramatic increases in choice making that were observed in 1995 have been maintained through 1998. There was a modest increment; however, it did not achieve statistical significance with this small sample size. It should be noted that choice making represents the exercise of a freedom, rather than a skill that might reach increasingly higher levels. The data reveal that people were more able to exercise choice in the community.

### **Choice Making**

<b>Choice Making Subscale from Personal Interview</b>	<b>1990 to 1995</b>	<b>1995 to 1998</b>	<b>N</b>
<b>Average</b>	72.8 to 90.9	90.9 to 94.4	28
<b>Significance</b>	.001	.131 (NS)	

### **Integration Activities**

Community placement will be successful to the extent that rhythms and routines of people with disabilities mirror those of persons without disabilities. Mere placement in a house in a neighborhood is meaningless; the person in that house must become a member of that community to the extent that other persons are part of the community. To this end, we have attempted to measure the frequency with which the people who once lived at Hissom now participate in

community activities. Of particular interest are activities that reflect either economic or social intercourse with the general populace. Examples of such activities are shopping, going to the movies, attending church, and dining out.

The chart below presents the number of community activities that were recorded on a weekly basis. It is evident that relocation from Hissom to the community was correlated with a doubling in community exposure activities. This increase level of community integration was maintained through the 1998 year.

### **Integrative Activities**

<b>Integrative Activities Per Week</b>	<b>1990 to 1995</b>	<b>1995 to 1998</b>	<b>N</b>
<b>Average</b>	3.2 to 6.4	6.4 to 6.7	221
<b>Significance</b>	.001	.200 (NS)	

### **Family Contacts**

Families can be a source of tremendous social support to individuals who have disabilities. In our earlier analysis, we learned that family contact almost doubled following relocation from Hissom Memorial Center to the community. With smaller homes located closer to the family homes, family members were better able to maintain contact with the member of the family who receives services from the mental retardation system. This increased level of contact was

maintained from 1995 to 1998. The amount of family contact has doubled from Hissom levels, and this increased level of contact has been maintained.

### **Family Contacts**

<b>Family Contacts Per Year</b>	<b>1990 to 1995</b>	<b>1995 to 1998</b>	<b>N</b>
<b>Average</b>	28.4 to 55.3	55.3 to 58.5	235
<b>Significance</b>	.001	.130 (NS)	

### **Productivity**

Legitimate self-esteem comes only from achievement, and in our American cultures, most achievement tends to be somehow related to the vocational experience. People work, and they take pride in their work. This opportunity to work is essential to the welfare of individuals who have disabilities. For purposes of this analysis, we have defined productivity in terms of the number of hours that an individual is involved in some sort of vocational experience. The chart below reveals that productivity increased significantly subsequent to relocation from Hissom Memorial Center, and that this increased level of productivity has been maintained through 1998.

### Productivity

<b>Productivity: Hours per Month</b>	<b>1990 to 1995</b>	<b>1995 to 1998</b>	<b>N</b>
<b>Average</b>	54.5 to 77.5	77.5 to 72.2	235
<b>Significance</b>	.001	.298 (NS)	

In addition there have been major changes in what people do. The chart below reveals that reliance on Pre-Vocational activity programs has diminished. Use of Sheltered Workshops has increased, as has Supported and Competitive Employment. It is interesting that the 1998 data indicate that 42 individuals were productively engaged in “other” activities. Our data do not permit further analysis of this finding, but we do note that some states have begun to strongly encourage volunteer activities (like handing out food at a homeless shelter, etc.) as a legitimate alternative to paid work. Perhaps these 42 individuals reflect this sort of change in orientation.

## Types of Productive Activities

Type of Activity	1990	1996	1998
Pre-Voc	125	38	38
Sheltered	13	77	55
Supported	3	54	40
Competitive	0	7	15
School	70	30	12
Respite	4	10	4
Other	0	0	42
# with 0 hours productive day activity	51	56	39

These data reveal that, on the average, vocational complexity increased.

People had more complex jobs that they had at Hissom Memorial Center. Perhaps the most noteworthy growth was in the area of Supported Employment and Competitive Employment. In 1990 at Hissom, only three persons were engaged in such activities. In 1995 in the community, 61 persons were so employed. The comparable figure for 1998 was 55. Perhaps the one concern remains for the 39 individuals who have no productive day activity. While this is an improvement over both 1990 and 1995, it remains an area of concern.

### **Active Treatment**

One of the most important aspects of a successful transition from life in a large congregate care facility to life in the community is the availability and provision of appropriate resources, services and supports. Among these are

specific services that meet the needs of individuals who have made this transition. We measured the number of hours received per month in 15 service and support areas such as habilitation training, nursing services, homemaker services, work activities training, physical therapy, psychiatric services, etc. As the chart below reveals, monthly service hours increased by about one-third subsequent to relocation from Hissom Memorial Center. This increased level of service was maintained through 1998.

### **Active Treatment**

<b>Hours of “Active Treatment” Hours Per Month</b>	<b>1990 to 1995</b>	<b>1995 to 1998</b>	<b>N</b>
<b>Average</b>	60.3 to 82.1	82.1 to 79.7	223
<b>Significance</b>	.001	.703 (NS)	

### **Use of Medications**

As part of the annual quality assurance assessment, the name, dose, frequency of administration and reasons for use were collected for a maximum of six medications. The primary purpose for the use of each medication was recorded in three broad categories: seizure control, behavior control and other/unknown reasons.

The two charts below summarize the findings with respect to medication use. It is evident that while overall medication use dropped subsequent to relocation from Hissom Memorial Center, three years later, they returned to Hissom levels. This pattern was evident for behavioral medications and for all medications. Reductions in medication use have not been maintained, but have instead returned to the levels of use that were evident in Hissom Memorial Center. Our data do not afford us the opportunity to analyze the appropriateness of this outcome. It is a clinical matter, perhaps best investigated on a case-by-case basis. It should be noted that other Oklahoma research (Spreat & Conroy, 1999) found that medication usage rates in Hissom and in the community were roughly comparable, but that the medications were being used by many different people. That is, many persons were withdrawn from medication after community placement, but their numbers were replenished by a roughly equal number of persons starting on medications in the community. These data seem congruent with that earlier finding.

### Use of Medications

<b>Average Number of Medications Each Day</b>	<b>1990 to 1995</b>	<b>1995 to 1998</b>	<b>N</b>
<b>Average</b>	1.3 to 1.1	1.1 to 1.4	227
<b>Significance</b>	.001	.001	

<b>Average Number of Behavioral Medications Each Day</b>	<b>1990 to 1995</b>	<b>1995 to 1998</b>	<b>N</b>
<b>Average</b>	.38 to .27	.27 to .42	227
<b>Significance</b>	.022	.002	

## **Satisfaction**

Individuals were asked how they felt about their lives in community homes. There were seven specific questions, addressing topics such as food quality, staff quality, friendships, and general satisfaction with their home. These seven questions were used to create a Satisfaction scale that yields scores that range from 0 to 100. Higher scores are indicative of higher degrees of satisfaction. It should be noted that, like the Choice Making Scale, the Satisfaction Scale is collected directly from consumers through interview. Many individuals were unable to participate in an interview process, so our findings are based on a relatively small sample, and the findings might not be generalizable to all persons who formerly lived at Hissom Memorial Center.

The chart below reveals that there was a statistically significant increase in Consumer Satisfaction subsequent to relocation from Hissom Memorial Center. This increased level of satisfaction has been maintained through 1998. It should be noted that initial satisfaction levels with Hissom Memorial Center were not particularly low; relocation to the community was followed by an increase from already high levels of satisfaction.

## Consumer Satisfaction

<b>Consumer Satisfaction Scale</b>	<b>1990 to 1995</b>	<b>1995 to 1998</b>	<b>N</b>
<b>Average</b>	82.2 to 92.6	92.6 to 92.0	34
<b>Significance</b>	.005	.828 (NS)	

It is interesting to note that only 2 persons indicated dissatisfaction with their community programs, and that these same 2 individuals had indicated dissatisfaction with Hissom Memorial Center.

### **Health**

Each year, we obtained a health rating for each consumer. Health could be rated as (1) Life Threatening Condition, (2) Needs Visiting Nurse or regular Physician Visits, or (3) Generally has no Serious Medical Needs. This question yields a metric in which higher scores are indicative of better health, as perceived by the informant who supplied the rating.

The chart below reveals that this health rating increased significantly subsequent to relocation from Hissom Memorial Center. It increased again by the 1998 data collection. In the perception of those staff members who best knew the

persons who formerly lived at Hissom Memorial Center, these individuals were healthier.

### Health

<b>Health</b>	<b>1990 to 1995</b>	<b>1995 to 1998</b>	<b>N</b>
<b>Average</b>	2.41 to 2.55	2.55 to 2.72	225
<b>Significance</b>	.009	.001	

## Summary

It is evident that improvement has been maintained across the dimensions discussed above. The quality of life for persons who formerly lived at Hissom Memorial Center did improve subsequent to relocation to the community, and these improvements were maintained over time. The chart below summarizes the findings reported above. They suggest that the individuals who formerly lived at Hissom Memorial Center were indeed better off than they were before.

<b>Quality Dimension</b>	<b>1990-1995 Outcome</b>	<b>1998: Outcome Maintained?</b>	<b>1995-1998: Further Improvement?</b>
Adaptive Behavior	Positive	Yes	No
Choice-Making	Positive	Yes	No
Challenging Behavior	Positive	Yes	Yes
Productivity	Positive	Yes	No
Integration	Positive	Yes	No
Developmental Services	Positive	Yes	No
Family Contacts	Positive	Yes	No
Medications	Positive	No (Returned to baseline)	No
Health	Positive	Yes	Yes
Satisfaction	Positive	Yes	No
<b>Overall Conclusion</b>	<b>Positive</b>	<b>Yes</b>	<b>Variable</b>

## Discussion

Earlier research had indicated that persons who were relocated to the community from Hissom Memorial Center experienced positive life changes in many areas. They had greater family contact, they evidenced increased skills, they received more services, they were more integrated with the general community, and those who could respond to an interviewer indicated that they were more satisfied with life in the community.

This study determined that the positive changes associated with discharge from Hissom Memorial Center were maintained. Increased levels of adaptive behavior, choice making, productivity, integration, service provision, family contact, and consumer satisfaction were all maintained at the higher levels noted in 1995. Continued improvement was noted with respect to challenging behavior and consumer health ratings.

Only the variables relating to the use of medications returned to levels comparable to those recorded at Hissom Memorial Center. These were the only areas that did not continue to exceed performance recorded at Hissom. On no variable did performance in the community fall below performance at Hissom.

These long term data add weight to the evidence that community placement has been overwhelmingly beneficial for the persons who had lived in Hissom Memorial Center in 1990. They contribute to the existing knowledge base that

affirms the positive contributions of community life to persons who have mental retardation.

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