

**Comparison of Health Care Services in a Congregate Care Setting
and in Supported Living Arrangements in Oklahoma**

Brief Report Number 14
Of a Series on the Well Being of People with
Developmental Disabilities in Oklahoma

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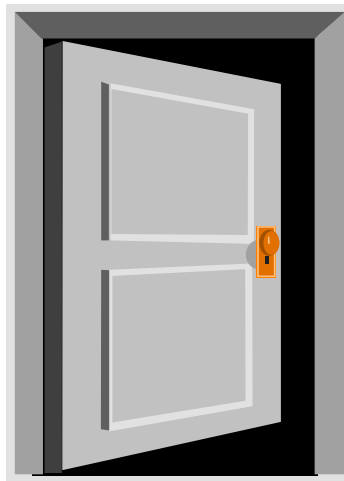
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Acknowledgement

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

This study examined a variety of health care indices for persons with profound mental retardation who lived in a public institution in 1990 and in community based Supported Living Arrangements in 1995. Nursing services increased in the community settings, however, there was slightly greater difficulty in obtaining medical services in the community. In spite of this difficulty, persons in the community were seen by physicians and/or nurses more often in the community.

Introduction

The deinstitutionalization movement has been responsible for the transfer of well over 100,000 persons with mental retardation from public congregate care facilities to smaller group home like settings in the community (Conroy, 1977; Prouty and Lakin 1996). Although there has been opposition towards community placement, numerous empirical studies have shown that community living is associated with improvements in the quality of life for persons who have mental retardation (cf. Conroy & Bradley, 1985). Larson and Lakin (1989) conducted a meta analysis of 18 research studies that met specific criteria for experimental design and recency. The community placements of 1,358 persons were reviewed in these studies. Eight studies involved comparison between experimental and contrast groups, and all eight found significant improvements in adaptive behavior, self-help, and domestic activity skills among the persons who moved to community placements. The remaining ten studies were longitudinal in nature, and half reported statistically significant improvements in adaptive behavior. Larson and Lakin (1989) concluded that community placement was generally associated with positive life changes.

Positive changes have also been noted with respect to the more subjective measures of satisfaction. Larson and Lakin (1991) noted that an overwhelming

majority of families "became satisfied with community settings once their son or daughter moved from the institution despite general predispositions to the contrary" (p.37). Similarly, Latib, Conroy, and Hess (1984) reported a near complete reversal in family attitudes toward community placement after the family member was moved from congregate care to a community placement.

The one exception to the generally positive pattern of outcomes for persons who move to community homes has to do with the provision of health care. Strauss and Kastner (1996) reported that risk adjusted odds of mortality were approximately 72% higher in community programs than in congregate care settings for persons over the age of 40 years.

The court ordered closing of Hissom Memorial Center (Ellison, 1987) in Oklahoma afforded the opportunity to examine the impact of deinstitutionalization on the health care services provided for 208 persons who had profound mental retardation. These individuals were members of the Hissom Focus Class. All lived in a large congregate care setting (Hissom Memorial Center) in 1990, and by 1995, all had been transferred to small supported living arrangements in the community. The purpose of this study was to describe various health care indicators for these persons in Hissom and in the community five years later.

Methods

Instrumentation

Oklahoma administers the Developmental Disabilities Quality Assurance Questionnaire (DDQAQ) (Oklahoma State University, 1992) for all consumers within its mental retardation service system on an annual basis. This assessment is administered by interviewers contracted by the state, and it includes major sections on adaptive behavior, challenging behavior, living site conditions, health, social interactions, community integration, service planning, and consumer satisfaction. In this study, we focused on the following items.

Service Provision - Informants were asked to estimate the number of hours in the previous month that each Focus Class Member received Occupational Therapy, Physical Therapy, Nursing Services, and Psychiatric Services.

Use of Medications - Records were reviewed to collect information on the psychiatric medications used by the participants. Individual psychiatric medications were grouped according to the guidelines put forth by the American Medical Association (1978), and as reported in Spreat, Conroy, and Jones (1997).

Health Care Indicators - Informants were asked about the medical needs and access to medical services for the members of the Hissom Focus Class.

Urgency of medical need was rated on a three point scale in which a life threatening

medical condition received a score of one, need for regular physician visits received a score of two, and the absence of a serious medical problem was scored three.

Data Collection Procedures

Data were collected by graduate students and staff from the Sociology Department at Oklahoma State University. The University conducts annual two-day training sessions on data collection methods to prepare the collectors. Appointments with participants were coordinated by the data collectors and a scheduling clerk from the University. The collectors were instructed to be flexible and avoid interference with routines and schedules. Data collection required access to: (a) the person, (b) whomever knew the person best on a day to day basis (i.e., a knowledgeable informant), (c) the person's home, and (d) records concerning the person's services and supports. Data collection visits required approximately 70 minutes at the residence.

Characteristics of the Hissom Focus Class Members

Our analysis was limited to 208 Focus Class members who had profound mental retardation and for whom a DDQAQ was completed in Hissom Memorial Center in 1990 and in a Supported Living Arrangement in the community in 1995. There were 116 men and 92 women. The average age was 29, with a range from 15 to 52 years.

Results

Initial analysis addressed the provision of services to individuals in Hissom in 1990 and in the community in 1995. No differences were found with respect to Occupational Therapy, Physical Therapy, and Psychiatry, although it was noted that for each variable, the standard deviations were considerably larger in the community, perhaps suggesting a different pattern of services. Nursing services were reported to increase in the community. In 1990 at Hissom Memorial Center, the average person with profound mental retardation received 9.38 hours of Nursing service per month. In 1995 in the community, the average person with profound mental retardation received 39.64 hours of service per month. This quadrupling of nursing services achieved statistical significance on a correlated t-test ($t=2.83$, $df=207$, $p=.005$).

Third party informants were asked about problems in receiving medical services over the previous year. On a rating scale that yielded scores from one (no problem) to five (nine or more problems), the mean 1990 value was 1.03. The mean value increased to 1.11 in 1995. This increase achieved statistical significance on a correlated t-test ($t=2.00$, $df=188$, $p=.047$). Further inspection of these data revealed that in 1990, at least one instance of difficulty in obtaining medical services was reported for six persons. In 1995, twenty (20) persons reported at least one instance

of difficulty. Using category midpoints on the questionnaire item as reference points, one can estimate that there were approximately 12 specific instances of difficulty in 1990 and 63 instances of difficulty in obtaining medical services in 1995. Thus, while the mean change on the questionnaire is small, increased difficulty in obtaining services is evident. This increased difficulty contrasts with the finding that persons in the community saw physicians and/or nurses more frequently than they had in Hissom Memorial Center ($t=5.16$, $df=190$, $p=.000$).

Staff at Hissom and staff in the community homes did not differ in their perception of the urgency of need for medical care. In both years, it was reported that most persons simply needed routine access to medical services.

Seizure frequency was estimated by knowledgeable informants in both 1990 and 1995. A correlated t-test was unable to detect a significant difference between the 1990 and 1995 ratings ($p=.063$). The analysis was repeated using the nonparametric Wilcoxon test because the seizure frequency scale did not really yield data that could be construed as having equal intervals. The Wilcoxon test suggested that seizures were occurring more frequently in 1995 in the community ($Z=2.09$, $p=.0364$). The Wilcoxon is less conservative than the t-test, but is better suited to the data.

Data were also collected on use of psychotropic medication. In 1990, 41 persons were using antipsychotic medication. By 1995, this number had decreased to 18. Use of Sedatives/ Hypnotics increased from three in 1990 to 13 in 1995. Anxiolytic use was essentially unchanged, with 22 persons receiving anxiolytics in 1990 and 23 receiving them in 1995.

Discussion

These data suggest that while persons who lived in the community saw nurses and physicians more often than they had at Hissom Memorial Center, they experienced slightly increased levels of difficulty in obtaining medical services. Approximately 10% of our sample was reported to have at least some difficulty in obtaining medical services in the community, whereas only about 3% had such trouble when they lived in Hissom. Given that consumers who lived in the community appeared to have overall greater access to medical personnel, the increased difficulty levels might reflect problems in obtaining specialty care or in establishing initial medical care arrangements.

It was encouraging that knowledgeable informants at Hissom and in the community were in agreement with regard to the urgency of need for medical care. Assuming a relatively constant actual need for medical care, the inability to find differences in perceptions suggests that community staffs are not immune or insensitive to medical needs of persons living in the community. Indeed, the dramatic increase in the number of monthly hours of nursing contact suggests quite the opposite.

This study found that persons with profound mental retardation actually had increased access to nursing services, with no decrease in ancillary services such as Occupational and Physical Therapy. In addition, use of antipsychotic medication was reported to be slightly less. The study did, however, reveal that it might be more difficult to obtain some health care services in the community.

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