

**The Impact of Deinstitutionalization**  
**On Family Contact**

Brief Report Number 10  
Of a Series on the Well Being of People with  
Developmental Disabilities in Oklahoma

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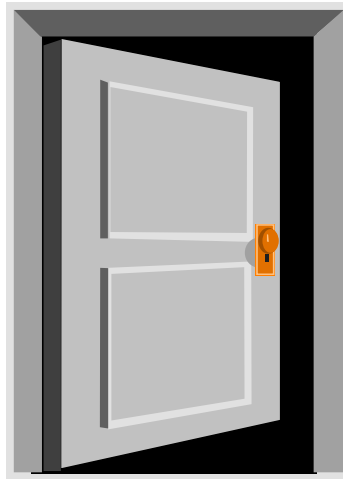
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## Acknowledgment

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**

Indices of family contact were reviewed across four cohorts of persons with mental retardation who were transferred from a large public institution to small Supported Living Arrangements. In this longitudinal study, it was found that family contact increased subsequent to community placement, and that these increased levels of contact were maintained for as much as four years.

## **Introduction**

Quality of life must be viewed as multidimensional in nature (Conroy and Elks, 1999). Factors such as community integration, job satisfaction, and friendships all seem to be essential components, but family contact must also be considered a significant element of life quality (Schalock and Lilley, 1986). Not only are there the social components of family linkages, there is the fact that the greatest advocates and protectors for individuals who have mental retardation are their families. Let us not forget that it was parents who filed the lawsuit that led to the closure of Pennhurst Center. It was parents who sued for and subsequently obtained the right to education for children with mental retardation. As a general rule, family contact must be viewed as both beneficial and protective of persons with mental retardation (Zetlin, 1986).

When individuals enter residential placement, family contact becomes perhaps an even greater concern. In past generations, parents were advised to sever their ties with children who were placed in residential settings. Such advice is rarely given today, yet there is the observation that family contact diminishes as time passes (Baker and Blacher, 1993). This loss of contact, sometimes called detachment, involves not only the loss of emotional support, but also the loss of advocacy and protection. It would

seem that family contact is a valued outcome that should be nurtured and maintained, yet it is unclear the extent to which agencies and providers court and encourage family contact.

There have been a number of studies that examined family contact with persons who had been placed in congregate residential programs. Baker, Blacher, and Pfeiffer (1996) reported that children and adults in residential placement averaged 21 contacts per year with family members. In an earlier study, Baker and Blacher (1993) reported that 81% of the children placed in a residential program still experienced at least monthly visits with family members two years after placement. Skeie (1990) later reported that older persons with mental retardation had less family contact than did younger persons in institutional settings. Dalglish (1985) reported a similar finding with respect to age, but also noted that contact diminished when families lived more than 8 miles from the residence. Baker, Blacher, and Pfeiffer (1996) reported that lower visitation rates were associated with increased distance, the expectation that the child will remain in placement, and greater degrees of cognitive impairment. In an earlier study that explored the correlates of family visitation, D'Onofrio, Robinson, Isett, Roszkowski, and Sprent (1980) found only a limited ability to predict family contact (Multiple R = .42), using years of prior institutionalization, integrity

of the family unit, presence of seizures, and presence of Psychological Disturbances as predictors.

Transfer to community-based homes has yielded mixed results with respect to family contact. Spreat, Conroy, and Rice (1998) compared family contact for persons with mental retardation who either remained in Nursing Homes or transferred to community-based programs. Family contact increased by about 31% for persons who transferred to the community, but it was unchanged for persons remaining in the Nursing Homes. Similar findings were reported by Latib, Conroy, and Hess (1984) in a study of persons transferred from a large institution to community based alternatives. A pattern of increased family contact was also observed subsequent to community placement by de Kock, Saxby, Thomas, and Felce (1988). In contrast, Grimes and Vitello (1990) reported a decrease in family visits to the residential placement subsequent to transfer from a large public institution to smaller community alternatives.

The court ordered closing of Hissom Memorial Center (Ellison, 1987) in Oklahoma afforded the opportunity to examine the impact of sequentially introduced community placement on rates of family contact for persons who have mental retardation. Judge James Ellison of the United States District Court for the Northern District of Oklahoma ordered Hissom Memorial

Center closed in July 1987. Judge Ellison's order gave strong preference to community based models in which only two or three persons shared a house or apartment.

The purpose of this study was to examine patterns of family contact for persons who have mental retardation and who live in Oklahoma. In particular, we were interested in visitation patterns of persons who were discharged from a large state institution to Supported Living Arrangements in Oklahoma. In contrast with earlier research, we have the opportunity to study family contact for a relatively large sample in both institutional and community settings over a relatively long period of time. This enables us to address not only the question of contact frequency and its correlates, but also the question of detachment.

## **Methods**

### **Characteristics of Hissom Class Members**

There were 520 individuals who were included in the class that was affected by the closure of Hissom Memorial Center. Of those who had been assigned a level of mental retardation, approximately 73% were labeled as having severe or profound mental retardation. The average age (in 1995) was approximately 29 years, with a range from 17 to 52. There were three males for every two females. Slightly over 80% of the class members were white. Significant additional disabilities were reported at the following rates: Vision, 44.3%; Physical Disabilities, 40.7%; Hearing, 13.3%; Other Disabilities, 10.8%; Cerebral Palsy, 8.9%; Feeding Tube, 8.7%; Autism, 6.3%; and Mental Illness, 2.6%.

### **Characteristics of Study Sample**

For the purposes of the primary analysis, we selected individuals for whom annual data were available from 1991 through 1995 and who had been placed in supported living arrangements during that time period. We defined four study cohorts, based on year of discharge from Hissom. There were 33 individuals who left Hissom Memorial Center for Supportive Living Arrangements in 1992, 56 who left in 1993, 38 who left in 1994, and 50 who

left in 1995. Demographic information on these four cohorts is provided in Table 1.

**Table 1**  
**Demographic Characteristics of Longitudinal Sample**  
**By Discharge Cohort**

	<u>1992</u>	<u>1993</u>	<u>1994</u>	<u>1995</u>
Year of Birth	64.97	65.04	66.11	64.98
Percent Male	73	54	74	48
Level of Retardation				
Mild	2	0	1	0
Moderate	4	1	0	2
Severe	7	10	4	3
Profound	20	44	33	45
Other	0	1	0	0
Race				
White	23	48	28	36
Black	7	3	5	7
American Indian	2	5	5	6
Other	1	0	0	1

**Experimental Design of Primary Analysis**

The aptly named Institutional Cycle design (Campbell and Stanley, 1966) was an appropriate design with which to assess the impact of deinstitutionalization on the rate of family contact. This design enabled us to evaluate the effects of an ongoing intervention (i.e., movement to the community) as it was sequentially introduced across groups. The design is somewhat similar to the multiple baseline across groups design that is used by behavior analysts (Hersen and Barlow, 1976).

In this particular study, placement in a Supported Living Arrangement was treated as a sequentially introduced treatment across four cohorts. Cohorts were formed on the basis of the year in which individuals left Hissom and entered a Supported Living Arrangement. Cohort 1 (n=33) was discharged in 1992, cohort 2 (n=56) was discharged in 1993, cohort 3 (n=38) was discharged in 1994, and cohort 4 (n=50) was discharged in 1995. The design is depicted in Figure 1.

**Figure 1.**  
**Illustration of Recurrent Institutional Cycle Design.**

	<u>Data Collection Year</u>				
<u>Discharge Year</u>	<u>1991</u>	<u>1992</u>	<u>1993</u>	<u>1994</u>	<u>1995</u>
<u>1992</u>	INST*	SLA	SLA	SLA	SLA
<u>1993</u>	INST	INST*	SLA	SLA	SLA
<u>1994</u>	INST	INST	INST*	SLA	SLA
<u>1995</u>	INST	INST	INST	INST*	SLA

\* – Moved to Supported Living Arrangement

**INST** – Data were collected at Hissom Memorial Center

**SLA** – Data were collected in Supported Living Arrangement

As can be seen in Figure 1, the 1992 discharge cohort provided data at Hissom in 1991 and in the community all other years. The 1993 discharge

cohort provided data at Hissom in 1991 and 1992 and in the community the other years. The 1994 discharge cohort provided three years of data at Hissom and the latter two years in the community. Finally, the 1995 discharge cohort provided all data, except 1995, at Hissom.

Individuals were not randomly assigned to community placement, and it is reasonable to assume that persons discharged earlier were probably specifically selected for some reason. In most experimental analyses, this lack of random assignment would be a significant threat, however, with the recurrent institutional cycle design, it can actually be a strength. If a consistent response to community placement is evident across notably different groups, generalizability of findings is enhanced (See Hersen and Barlow, 1976 for a discussion of this matter with respect to multiple baseline designs).

### **Instrumentation**

Oklahoma administers the Developmental Disabilities Quality Assurance Questionnaire (DDQAQ) (Oklahoma State University, 1992) for all consumers (i.e., service recipients) within its mental retardation system on an annual basis. This assessment is administered by interviewers contracted by the state, and it includes major sections of adaptive behavior, challenging behavior, living site conditions, health, social interactions,

community integration, service planning, family contact, and consumer satisfaction. A copy of this comprehensive assessment device is available from the authors.

Of particular interest to this study is the section on Family Contact. There are three questions in the questionnaire that address family contact. These three questions are answered by knowledgeable informants who work with the consumer. Summing these three scores yields a brief family contact scale that has an internal consistency reliability of .8655. A score of 18 on this scale would indicate maximal family involvement, while a score of 3 (lowest possible) would indicate that either the individual had no family or had not had family contact within the past year.

### **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, (c) the person's home, and (d) records

concerning the person's services and supports. Data collection visits required approximately 70 minutes at the home.

## Results

Table 2 presents the mean family contact scores for each discharge cohort across the five years of the study. Because treatment was introduced at different times for each cohort, we elected to run separate analyses for each discharge cohort, adjusting the alpha level per the Bonferroni correction. Statistically significant increases in family contact over time were noted for each cohort (Cohort 1 –  $F[4,128]=3.89$ ,  $p=.005$ ; Cohort 2 –  $F[4,220]=8.93$ ,  $p=.000$ ; Cohort 3 –  $F[4,148]=11.40$ ,  $p=.000$ ; and Cohort 4 –  $F[4,192]=5.36$ ,  $p=.000$ ). Family contact increased over the five years of data for each cohort.

**Table 2**  
**Mean Family Contact Scores for the Four Discharge Cohorts over Time**

<b><u>Discharge Cohort</u></b>	<b><u>1991</u></b>	<b><u>1992</u></b>	<b><u>1993</u></b>	<b><u>1994</u></b>	<b><u>1995</u></b>
<b><u>1992</u></b>	7.45	<b>9.70</b>	<b>8.48</b>	<b>9.42</b>	<b>8.91</b>
<b><u>1993</u></b>	7.32	7.77	<b>9.70</b>	<b>9.52</b>	<b>8.96</b>
<b><u>1994</u></b>	7.71	7.76	8.05	<b>10.16</b>	<b>9.45</b>
<b><u>1995</u></b>	6.66	7.34	7.14	6.47	<b>8.14</b>

**Bold** = Data collected in Supported Living Arrangements

With the recurrent institutional cycle design, the issue in this study is not simply whether there was change in the dependent measure, but whether that change was temporally contiguous with the experimental condition. That is, was the increase in family contact associated with placement in the Supported Living Arrangements? Post hoc analyses (Tukey HSD) revealed a consistent pattern. For the discharge cohorts from 1992, 1993, and 1994, the only statistically significant changes in family contact occurred immediately after placement to the community, and these higher rates of contact were maintained. Data from the 1995 cohort are a little more complicated. There was a statistically significant increase in family contact subsequent to community placement. Family contact in 1995 in the community was higher than either the previous year at Hissom or in the first year of the study (1991). It was not distinguishable from contact rates at Hissom in 1992 and 1993, which, oddly, were not distinguishable from the lower rates of 1991 and 1994. While there is general conformity with the earlier pattern, data from the 1995 cohort are a bit more confusing.

In this limited sample, we found that the overall family visitation score for institutional data was 7.33 (of 18 possible), while the overall family visitation score for Supported Living Arrangement data was 9.24. Lack of independence precludes more detailed analysis of these figures; the

question can be better addressed by referencing the larger Oklahoma database. In doing this, we found that in 1997, the average resident of an Oklahoma institution (n=1533) had a family visitation score of 8.29 (SD=5.30), while the average resident of a community based program (n=1295) had a family visitation score of 10.99. These values were significantly different per t-test ( $t=13.34$ ,  $df=2826$ ,  $p=.000$ ).

We next tried to predict family contact in 1997 using a variety of consumer and placement descriptors. We found that a linear combination of placement type (community or institution), adaptive behavior, number of medications for behavior, and time in residence was able to predict approximately 12% of the variance in family contact (Multiple R = .3490). Higher levels of family contact were found in community programs and for persons with higher levels of adaptive behavior, lower use of behavior modifying medications, and shorter time in residence at the current placement.

## **Discussion**

The data reveal that there was an increase in family contact subsequent to placement in Supported Living Arrangements, and that this increased family contact was maintained for as long as four years.

Unfortunately, we cannot identify the cause for this increased family contact. It is conceivable that families promoted greater contact because of increased concern about the new residential site. Under such circumstances, one might expect an increase in contact, but one would probably expect this increased concern to dissipate over time and levels of contact to return to baseline levels. Latib, Conroy, and Hess (1984) noted that parental dissatisfaction with community placement seemed to not only end, but completely turn around after about 6 months of placement. Thus, if increased concern were the likely cause of increased visitation, one would have expected visitation to decline over time. This was not the case. The increased levels of family contact were maintained over time.

We saw no evidence of detachment (Baker and Blacher, 1993). Examining only those cohorts who remained in the community for 2 or more years, we saw no evidence of declining family involvement. In fact, family involvement seemed to simply be an increase in level of contact, and this increased level was maintained over time. It should also be noted that we

saw no evidence of declining involvement for those who remained longer at Hissom. Of course, we lack data on the early period of their stay at Hissom, so it is conceivable that initial family contact levels were higher.

Our data suggest that across a relatively large number of individuals, placement in Supported Living Arrangements was associated with increased family contact. The increased level of family contact was maintained across as much as four years with no signs of decrement. No trends were evident in the data, other than a simple shift in level of family contact subsequent to community placement. For whatever reason, families were more able or more willing to visit and maintain contact with family members who lived in Supported Living Arrangements.

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