



Family Involvement by Aging Parents and Adult Siblings with Individuals with Intellectual Disabilities Living in Residential Settings

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The majority of persons with intellectual disability (ID) live with their families throughout childhood and well into adulthood. Whereas in the 1970's and 1980's, most persons placed in community residential settings moved there following years of institutionalization and limited contact with their families, at the present time there is increasing placement of adults with ID directly into residential settings after decades of living with their parents. Often, this placement is propelled by the aging of the parental generation, although the transition to non-parental care may precede parental death by many years. Little is known about the extent of parental involvement after placement, although the complex factors associated with how older parents of adults with ID plan for the residential future of their son or daughter has received increased attention in recent years (Essex et al., 1997; Freedman et al., 1997; Heller & Factor, 1991).

The importance of this issue is derived from three phenomena. First, because family-based care is the dominant residential arrangement for persons with ID (Fujiura & Braddock, 1992), there is a sizeable population of families who must eventually decide how to make the transition from the parental home to a non-parental placement for their son or daughter with ID. Second, most individuals with ID now outlive their parents, resulting in a sizeable population who enter the formal residential service system for the first time well into adulthood. Third, there are growing waiting lists for residential services within almost every state (Hayden, 1992), resulting in bottlenecks in service access and producing even more pointed pressures on families to develop various options for the future.

In our past research, we have learned a great deal about the factors leading up to the placement of adults with ID out of their parental homes. However, to date, no research has been conducted to document the frequency of contact between aging parents, adult siblings, and the individual with ID after placement, the quality of these family relationships after the residential relocation, the likelihood that the family members will continue to provide any direct or indirect care, or the consequences of varying levels of family involvement after placement for the well-being and quality of life of the adult with ID. These are the issues that will be addressed in the proposed project.

Purpose and Objectives

1. What is the extent of family involvement?
2. How have patterns of parental and sibling involvement changed during the first three years after placement?
3. What are the factors that predict varying levels of family involvement after placement?

Sample Population and Methodology

This study is a secondary analysis using data collected at each of the eight points of data collection. Three domains of data were analyzed: 1) indicators of the extent of family involvement, 2) predictors of family involvement, and 3) outcomes of family involvement.

Sample. This builds on an ongoing study of 461 families who have an adult son or daughter with ID (Essex et al., 1997; Freedman et al., 1997). About half of the families live in Wisconsin, while the other half live in Massachusetts. At the outset of the study in 1988, all adults with ID lived at home with their aging mother (age 55-85) and father (if alive). During the ensuing ten years, 124 adults with ID moved out of their parents' home to a home of their own. Because families continue to participate in our study after the placement of the son or daughter, we have assembled a longitudinal database uniquely appropriate to addressing questions regarding the predictors, along

with the extent and consequences of family involvement after placement.

Families were recruited for the research in 1988 via three strategies. For the majority, recruitment was accomplished with the assistance of the state agency on aging and the state or county agency responsible for providing services to persons with ID. Others were referred by service providers, and still others were nominated by participating family members. All families volunteered to participate.

When recruited for the study in 1988, the mothers ranged in age from 55 to 85 years of age (mean = 65.52, SD = 6.55). Their sons (54%) and daughters (46%) with ID ranged in age from 15 to 66 years (mean = 35.55, SD = 7.61). At the present time, these individuals are 10 years older, so the mothers are in their mid-seventies on average, and the adults with ID are about 45 years of age. Most of the adults in this sample had a diagnosis of mild (38%) or moderate (42%) mental retardation, while 15% had severe and 6% had profound mental retardation. More than one-third (38.7%) had Down syndrome.

Data Collection and Measures

Data were collected from families every 18 months. There were multiple respondents in each family. The mother was the primary respondent and participated in an in-home interview and completed a set of self-administered questionnaires at each wave of data collection. Within two weeks of the mother's interview, the father was interviewed separately by telephone and also completed the self-administered questionnaires. The sibling who was most involved with the brother or sister with ID was surveyed by mail as a part of the Time 3 and Time 6 points of data collection. These methods of data collection were continued even

after the adult with ID moved away from the parental home, and in such cases we asked additional questions about family involvement after placement. In some families in our study, the mother, father, or both died during the course of the research. In such instances, the role of primary respondent shifted to the family member who was most involved with the individual with ID, usually a sibling. Thus, there was continuity of information about family involvement starting from the point at which the adult lived at home with the parents to the transition to an out-of-home residential placement, and beyond the point of parental death.

Data Analysis

In this study, we conducted secondary analyses to examine family involvement with adults who have ID following a residential transition to a non-parental living situation. Specifically, we examined the extent of maternal involvement in the process of relocation, including selecting the residence and facilitating the transition from the parental home and patterns of

maternal involvement change during the first 3 to 4 years after the adult son or daughter moved away from home. Lastly, we analyzed patterns of sibling involvement change after the adult with ID moved away from the parental home.

Our first research question, which examined the extent of family involvement in the placement process, used primarily descriptive statistics to quantify the role of aging parents and adult siblings in facilitating the transition from parental home to placement.

For our second research question, which asked how patterns of parental and sibling involvement change during the first three years after placement, a three year period was selected as the time frame for this analysis. This time frame provides a sufficiently "long lens" on the relocation process and subsequent





adaptation to give a valid estimate of family involvement after placement. A three-way repeated measures analysis of variance was used to address this question for the parents. There were three repeated measures of levels of involvement (at the first, second, and third points of data collection following placement). A contrast group was included, consisting of parents who did not place their son or daughter at any point in the project period. This contrast is possible because the same measures of family involvement are available on both families who have placed their son or daughter and those who still co-reside.

Data about sibling involvement are available at two points in time, Times 3 and 6. Thus, adults who lived at home at Time 3 but who were placed at Times 4, 5, or 6 constitute the sample for the analysis of change in sibling involvement after placement. Again, a three-way repeated measures ANOVA was the approach to data analysis, with two repeated measures (Time 3 and Time 6) and two groups (placed, home) contrasted with respect to sibling involvement.

To address our third research question, which investigated the factors that predict varying levels of family involvement after placement, we used multiple regression techniques. Characteristics of the family, measured prior to placement was used to predict the extent of family involvement after placement. The sample used in this analysis was restricted to the families who have placed their son or daughter during the study period.

In response to our fourth research question, which examined the consequences for the well-being of the individual with ID of varying levels of family involvement after placement, the sample was restricted to the families of adults who had been transitioned to a nonparental living situation. In this case, the independent variables were the levels of involvement after placement and the dependent variables were indicators of the well-being of the adult with ID.

Findings

Maternal involvement in the relocation process. To answer our first research question, “What is the extent of maternal involvement in the relocation process, including selecting the residence and facilitating the transition from the parental home?”, we examined data from the research interview after the adult with ID moved away from the parental home. On average, this interview occurred 9.2 months after the relocation.

For the majority of families, maternal involvement began before the adult moved out of the parental home. Well over half of the mothers (61%) reported that their son or daughter was on a waiting list for residential services prior to the move. In addition, it was the norm for the mother to visit the residence before the son or daughter moved, with fully 87% of the mothers having made at least one visit. Mothers typically visited the residence about three times prior to the move (mean = 2.97). It was also common for mothers to facilitate visits by the adult with ID to the residence, with over three fourths of the adults (78%) making such visits. The average number of visits made by the son or daughter to the new residence was 3.26, of which about one (mean = 1.3) was an overnight visit.

Maternal Relationship following Relocation of Adult with ID

Mothers reported the following:

- ◆ Increase in maternal satisfaction with this level of contact
- ◆ Remain highly involved emotionally with their son or daughter
- ◆ Reduction in their level of worries about his or her future care
- ◆ Decreasing levels of direct caregiving and contact with residential staff

During the initial period following the move away from the parental home, over one quarter (27%) of the mothers reported daily contact either in person or by phone with their son or daughter, another third (36%) reported between five and eight contacts per month, two fifths (21%) reported weekly contact, and the remaining 14.3% had less than weekly contact. Only one mother had no contact with her adult child after the move away from home. Thus, frequent contact between the mother and the adult son or daughter was the norm for the families in our study, during the period immediately after the move. Most mothers were highly involved in the relocation process and facilitated actively the transition from the parental home to the adult's new residence by visiting beforehand, arranging for the son or daughter to visit, and by having frequent contact either in person or by phone with the son or daughter during the period immediately after he or she moved away from home.

Changes in maternal involvement following relocation. We examined data from the 64 mothers who participated in the first three research interviews after the adult with ID moved away from the parental home, each 18 months after the previous one. Our goal in selecting this sub-sample was to investigate levels of involvement among mothers who were in relatively good health when their son or daughter moved away from home and who remained in fairly good health during the 3- to 4-year period after relocation.

This sampling decision reflected our interest in investigating maternal involvement in the context of more normative patterns of relocation (i.e., launching) rather than relocation in the context of a crisis (such as declining maternal health). We checked mothers' health ratings across the points of data collection used in this analysis and found that mothers of individuals who moved away from home, on average, were stable or improved in their health status during this study period.

The results suggest that contact is stable and frequent between the mother and the son or daughter after relocation. Also, there is a concomitant increase in maternal satisfaction with this level of contact, and a decrease in maternal contact with residential staff.

Sibling Relationship following Relocation of Adult with ID

Adult siblings reported the following:

- ◆ Improved sibling relationships over time
- ◆ Increase in the frequency with which siblings “do things together”
- ◆ Less worried or pessimistic about the future care of the brother or sister with ID

Although mothers relinquish the hands-on caregiving role to the formal service system after the daughter or son moves elsewhere, they remain highly involved emotionally with their daughter or son and experience a reduction in their level of worries about his or her future care.

Changes in sibling involvement. For our third research question, “How do patterns of sibling involvement change after the adult moves away from the parental home?”, we included 26 siblings who participated in both waves of our sibling study and whose brother or sister with ID moved away from the parental home during the interval between these two waves in the analysis. Those siblings whose brother or sister remained living in the parental home throughout the study period reported greater levels of emotional involvement than those whose brother or sister moved away from home. In addition to this group difference, there was a significant increase for both groups from Time 3 to Time 6 in the sibling's feeling of emotional involvement in the sibling relationship.

For siblings whose brother or sister moved away from the parental home between Time 3 and Time 6 as compared with siblings whose brother or sister remained at home, the following divergent pattern over time was observed:

- 1) a significant increase in the frequency with which siblings “do things together” and



- 2) siblings felt less worried or pessimistic about the future care of the brother or sister with ID following relocation, $p = .056$.

There was no change in frequency of shared activities among those whose brother or sister with ID continued to live with the parents; and, these sibling had no change in pessimism for their brother or sister with ID. These findings mirror the patterns reported earlier regarding the reduction of maternal pessimism following this transition.

Implications for Research and Practice

Our secondary analyses demonstrated that aging mothers were highly involved in the relocation process and had frequent contact and continued emotional involvement with their adult child. Mothers became increasingly satisfied with their level of contact with their child over time, less worried about the future, and had decreasing levels of direct caregiving and contact with residential staff. Adult siblings reported improved sibling relationships over time. Siblings whose brother or sister moved out of the parental home increased their shared activities and felt less pessimistic about the future.

Our study demonstrates that the transition from the parental home to a nonparental setting is often a planned event, including several steps. Most of the adults with ID who moved had their name included on a waiting list for residential services, had mothers who visited the prospective home several times prior to the move, had themselves visited the new setting (including overnight trial visits), and had mothers who continued active involvement with them and the staff at their new home on a frequent basis throughout the 3- to 4-year study period. The degree of continuity of family involvement was, indeed, impressive.

The residential relocation involves a gradual transmission of direct caregiving from the family to the residential setting staff. Although the mothers quickly relinquished the responsibility for direct care, they

maintained frequent contact with their son or daughter, their emotional involvement continued, and their previously elevated worries about the future for their son or daughter subsided. Furthermore, the siblings of the adults who relocated remained involved with their brother or sister and even increased the frequency with which they did things together after the move. The relocation was also associated with a decrease in siblings' worries about the future.

For service providers and policymakers in the field of I/DD this study has several implications. First, the value of planned transitions is highlighted by our findings. Advance planning makes it possible for both the mother and the individual with ID to have some familiarity with the future residence before the transition, which may well enhance the likelihood of continued family involvement. However, it was notable that the individual with ID averaged only three pre-transition visits, which may be fewer than the number of visits made by many adults in the general population when they decide on a new home to buy or rent. Service providers should, therefore, consider encouraging more advance visits, which may enhance feelings of control and choice in families and in the individual with the disability as they negotiate this significant life transition.

The findings also confirm the importance of siblings to the quality of life of adults with ID. That their level of involvement with their brother or sister with ID increases after the move signals their availability as long-term sources of support. Service providers would be wise to facilitate sibling involvement, recognizing that the sibling tie is the longest lasting of all relationships, and it is this source of support that will remain constant for the individual with ID for years to come and may buffer the stress of high staff turnover that is characteristic of the contemporary residential service system.

The findings might also be useful in educating service providers about the fidelity of family involvement

following lifelong family care. Many agencies that provide services to individuals with ID were created in the era of deinstitutionalization and may still serve individuals who previously lived in state institutions whose families may not be highly involved. Therefore, some service providers may view families with ambivalence. As Stoneman and Crapps (1990) reported earlier, and as confirmed by the present research, there is a markedly different level of family involvement when the adult with ID has lived at home throughout his or her life as compared with when the adult's involvement with the family was already disrupted by institutionalization. Thus, it is important for service providers to actively encourage the involvement of families, recognizing that historical patterns of involvement may not be characteristic of families whose son or daughter is making the transition today.

Publications and Products

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