Continuity or Discontinuity of Family Involvement Following Residential Transitions of Adults Who Have Mental Retardation

Marsha Mailick Seltzer, Marty Wyngaarden Krauss, Jinkuk Hong, and Gael I. Orsmond

Abstract
Family involvement with adults who have mental retardation following a residential transition to a nonparental living situation was examined. We found 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. Findings address a critical gap in knowledge about the life course roles of families of persons with mental retardation.

There is now widespread recognition of the central role that families of persons with mental retardation occupy throughout their lifespan (Fujiura & Braddock, 1992). The majority of adults with mental retardation continue to live at home with their parents well into adulthood, and this increasingly recognized normative pattern has been the subject of considerable research (Englehardt, Brubaker, & Lutzer, 1988; Heller & Factor, 1994; M. Seltzer & Krauss, 1989). Key issues that have been investigated include the benefits and challenges to families of providing long-term care (Krauss & Seltzer, 1999; Smith, Fullmer, & Tobin, 1994), the factors associated with the psychological and social well-being of the parents (Heller & Factor, 1993; Krauss & Seltzer, 1993), the role of adult siblings in the caregiving context (Griffiths & Unger, 1994; Fruchno, Patrick, & Burant, 1996; G. Seltzer, Begun, Seltzer, & Krauss, 1991), and the factors that lead to a change in the living circumstances of the family member with mental retardation (Essex, Seltzer, & Krauss, 1997; Heller & Factor, 1991). Parental death or incapacitation may prompt a crisis in the family and often results in a hasty relocation of the adult with mental retardation to another setting (Gordon, Seltzer, & Krauss, 1997). However, it is far preferable for all involved to have residential transitions from the parental home take place in a more planned context in which different options can be evaluated to arrive at an optimal and paced residential change (Butterworth, Steere, & Whitney-Thomas, 1997).

There is a dearth of literature on family involvement in the lives of their adult child with mental retardation following a planned residential change away from the parental home, resulting in a critical gap in our knowledge about the ongoing roles of families throughout the life course. In our research we provide insight into this increasingly common, though as yet undocumented, phenomenon by reporting on the experience of families whose son or daughter with mental retardation lived at home well into adulthood and who moved to a nonparental living situation while the mother was healthy enough to support her son or daughter through this transition. These families were part of a longitudinal research study in which family involvement was tracked prior to and after the residential relocation of the adult son or daughter with mental retardation (Krauss & Seltzer, 1999).

Understanding continuity or discontinuity in family involvement following a change in the living situation of the son or daughter with mental retardation is important from several perspectives. For
families of adolescents and young adults whose child with mental retardation lives at home, information about the experiences of older families who have experienced this transition provides valuable insights regarding how such a major life change can be navigated and managed. For residential service providers, information on family involvement following such residential relocations can assist in anticipating how to make the initial and subsequent adjustment period to a new residence smoother for both the adult with mental retardation and his or her family. For policymakers charged with planning for the resolution of extensive waiting lists for residential services now reported around the country (Lakin, 1998; Lakin, Anderson, Prouty, & Polister, 1999), information on family involvement patterns may suggest new opportunities for partnerships with families that reflect parental and sibling preferences for ongoing roles. Finally, for researchers, studies of family involvement after their adult son or daughter with mental retardation moves away from home will begin to fill the knowledge gap that now exists regarding the ways in which families manage their atypical parenting responsibilities over the full life course of the family (Marshak, Seligman, & Prezant, 1999).

The most extensive recent literature on family involvement following the transition of an individual with mental retardation away from the parental home has been reported by Blacher and Baker in their studies of children with mental retardation and/or psychiatric disorders in residential treatment settings (Blacher & Baker, 1994; Baker, Blacher, & Pfeiffer, 1993, 1996; Baker, Heller, Blacher, & Pfeiffer, 1995; Blacher, Baker, & Feinfield, 1999). A central question in their studies was whether, over time, parental contact with and emotional attachment to their placed child decreases. In general, Blacher and Baker have concluded that parents remain attached to and involved with their child after placement. For example, in Baker et al.’s (1996) research on children and adults in private residential treatment centers in Arizona, California, and Florida, about two thirds of the 163 families in the study reported at least weekly phone contact with the residential treatment facility (although not necessarily with their child). Family visits to the treatment center and visits home by the individual with disabilities occurred between 3 (the mode) and 6 (the median) times per year. Further, most respondents said that their feelings of attachment to their family member with the disability had remained the same since placement. No relation was found between length of time in placement and level or degree of family involvement (Baker et al., 1996), suggesting a pattern of continuity rather than abatement of family contacts over time.

In another longitudinal study of family involvement, mothers of 53 children with severe levels of mental retardation in residential settings were interviewed at approximately 1 year, 2 years, and 3.5 years postplacement (Blacher et al., 1999). The settings into which the children were placed ranged from medium-sized (7 or fewer residents) foster homes to large group homes, large private residential schools, and state developmental centers, about half of which were at least 30 miles from their family’s home. The sample included mothers of children between the ages of 4 and 17 years at the time of the first interview. They found that across the three measurement points, the vast majority of families (in excess of 80%) reported some type of contact with their son or daughter at least monthly. They also found stability over time in the family’s level of behavioral, emotional, and cognitive involvement with their placed son or daughter. Specifically, families reported feeling less guilty over time regarding the decision to place their child, continued to think about their child at least daily and to talk with others about their child, and perceived their child’s placement as permanent. They also found that families reported a range of beneficial changes in their family life following placement, such as greater opportunities for recreational activities and improvements in family relationships.

Extending their research to siblings, Eisenberg, Baker, and Blacher (1998) contrasted three groups: siblings of children with mental retardation who continued to live at home (n = 25), siblings whose brother or sister had been placed (n = 20), and siblings whose brother or sister did not have a disability (n = 28). The siblings in this study ranged in age from 9 to 20 years (mean about 13). These three groups showed very similar profiles of psychological adjustment, self-esteem, and perceptions of the family environment but were quite different in their appraisals of the sibling relationship. Those whose brother or sister had mental retardation showed less warmth and less conflict than normative sibling relationships, but they did not differ in the importance they placed on the sibling relationship or their satisfaction with it. Of particular relevance to the present study, there were no differences between siblings whose brother or sister with
mental retardation lived at home or was placed, suggesting that placement out of the home did not alter the sibling relationship, at least with respect to the measures included in the Eisenberg et al. (1998) study.

In an investigation of a markedly different population, Stoneman and Crapps (1990) reported low rates of family involvement with a sample of persons with mental retardation (most between the ages of 18 and 45 years) living in licensed foster homes (family care homes) in Georgia. Although approximately 90% of the sample had at least one living family member (mother, father, or sibling), fewer than half had contact with their families (based on data collected from the home care provider). Among the explanations for this low level of family contact were that the average distance between the foster home and the family's own residence was well over 100 miles and that only 14% of the sample had lived with their family prior to moving to their current residence (the others moved there from institutions, group homes, or other foster homes). The findings suggest that the prior place of residence was an important factor conditioning family involvement because individuals in the Stoneman and Crapps study who moved to their current residence directly from the parental home had the most family participation in the placement process and the most family involvement after the residential transition. They also found that among residents who visited their siblings, most of the visits were with sisters. Indeed, the home care providers rated their residents as having stronger ties with their siblings than with their parents.

This brief review of the literature is instructive in documenting the persistence of family involvement following placement of individuals with mental retardation into private residential treatment settings or into publicly supported settings of various sizes. The Stoneman and Crapps (1990) study suggests the fragility of family involvement when geographical distance is great, when family bonds may have been challenged by multiple prior placements, and when family members are not involved in the placement process. Counterbalanced against these findings is the recognition that the literature on family involvement after the son or daughter moves away from the parental home is limited in quantity and scope, consisting primarily of studies of families who placed their minor child in institutional or community-based residential programs during childhood or adolescence, a practice that is increasingly rare among families of children with mental retardation and nonnormative from the perspective of family life course theories (Carter & McGoldrick, 1999).

In light of the prevalence of long-term family caregiving responsibility, it is important to extend our knowledge about familial roles in the lives of the family member with mental retardation. Our longitudinal study of families of adults with mental retardation offers an opportunity to examine prospectively the patterns of family involvement following relocation from the parental home to another living situation. In some of our earlier analyses, we studied relocation prompted by parental illness or death (Essex et al., 1997; Gordon et al., 1997). In this paper, in contrast, we examined a different pattern of residential relocation by adults with mental retardation, a pattern not prompted by a parental health crisis. Rather, the adults in the present analysis moved to a nonparental residence while the mother was still healthy. The residential transitions we report on here are, therefore, more consistent with normative patterns of the “launching” of adult children, albeit occurring in our study at a later point in the family life course than is characteristic of typical families and with a greater degree of familial and professional support.

Family life course theorists note that the launching stage, defined as the period when children move out of the parental home to establish a life independent from the family of origin, is a period of considerable disequilibrium because it precipitates profound changes in the relationships between parents and their children (Aldous, 1996; Carter & McGoldrick, 1999). This period is particularly difficult for mothers who must cope with the loss of the maternal role. Although families of adults with mental retardation who live at home have typically experienced the launching of their other children without disabilities, the launching stage is not fully completed until the adult with mental retardation has also moved from the parental home. One purpose of our research is to examine whether the disequilibrium that is associated with the launching stage is also manifest when full launching has been postponed.

As we have reported elsewhere, the families in our 12-year longitudinal study avowed an explicit preference for family-based care (Krauss & Seltzer, 1999), formed the nucleus of the social support networks of their son or daughter with mental retardation (Krauss, Seltzer, & Goodman, 1992), and in-
cluded siblings without disabilities, who were often deeply committed to the current and future welfare of their brother or sister with mental retardation (Krauss, Seltzer, Gordon, & Friedman, 1996; M. Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997). Over a 12-year period, about one quarter of the families in our study sought and secured an alternative living situation for their son or daughter with mental retardation. Although the sample on which the findings reported here is small (in numbers), and select (with respect to securing an alternative setting while the mother was healthy enough to orchestrate the transition), our study provides an initial prospective investigation of the continuities and discontinuities of family involvement among persons with mental retardation who have lived with family for most of their lives.

We addressed three research questions: What is the extent of maternal involvement in the process of relocation, including selecting the residence and facilitating the transition from the parental home? How do patterns of maternal involvement change during the first 3 to 4 years after the adult son or daughter moved away from home? How do patterns of sibling involvement change after the adult with mental retardation moved away from the parental home?

Method

Since 1988, we have collected data from 461 families from Massachusetts and Wisconsin who, at the outset of the study met two criteria: the family included a mother between the ages of 55 and 85 and a son or daughter with mental retardation who lived at home with her. In total, the study encompassed eight research interviews with all families, each scheduled 18 months apart. Because the eighth set of interviews is not yet available for analysis, this present paper is based on data from the first seven interviews with the families in our study, conducted between 1988 and 1999. At each point of data collection, interviews were held with the mother, and supplemental data were collected from fathers. In addition, at Time 3 and Time 6, the “most involved” sibling, as designated by the mother, was surveyed. Participation rates were high, with fully 88.6% of the families still participating at the seventh wave of data collection.

The prospective design of our study is uniquely tailored to address the question of continued family involvement because we collected pre- and postre-location data from the sample. The sample for this paper is restricted to the 117 families in our overall sample whose son or daughter moved away from home after the study began and in which the mother remained healthy enough to continue to participate in at least one research interview after the son or daughter moved. This analysis excludes families in which the mother died or became too incapacitated to participate in the first research interview after relocation. Thus, this paper does not represent the patterns characteristic of all families, just those with potential for continued maternal involvement after relocation.

Sample

The sample for the first research question, which assessed the extent of maternal involvement during the process of relocation, consisted of these 117 mothers. At the time their son or daughter moved away from home, they ranged from 58 to 87 years of age, with an average age of 71.0 years. Over two thirds (68.9%) rated their health as good or excellent, and 60.8% were still married. Of those who were not married, most (36.3%) were widows; only a few (2.9%) were divorced. Although the sample was virtually all European American (99%), there was diversity in socioeconomic status, with 42% earning less than $20,000 per year and 15% earning more than $50,000. The sons and daughters with mental retardation ranged in age from 21 to 66 years when they moved out of their parents’ home, with an average of 38.9 years. A little over half (53.8%) were sons. Most (78.1%) had mild or moderate mental retardation; 21.9% had severe or profound levels of retardation.

Following the transition away from the parental home, the 117 individuals with mental retardation moved to a variety of types of residences. Most (64.1%) moved to fully supervised community residential settings (group homes and foster homes). Fewer (17.5%) moved to more independent living arrangements (partially staffed or unstaffed apartments) or to congregate care facilities, such as nursing homes or public or private institutions (14.5%). The remaining 4 individuals moved to the homes of other relatives.

We used different subsamples of these 117 families for the analysis of the second and third research questions. For the second research question, in which we examined the extent of longer term family involvement with the son or daughter after relocation, the sample consisted of 64 families in
Family involvement

which the mother was healthy enough to participate in three consecutive research interviews after the son or daughter’s move. In addition, we randomly selected a comparison sample of 64 families whose son or daughter remained at home throughout the study period.

For the third research question, concerning the extent of sibling involvement before and after the adult with mental retardation moved away from the parental home, the sample consisted of 26 siblings who participated in our two-wave sibling study (Time 3 and Time 6) and whose brother or sister with mental retardation moved away from the parental home after the Time 3 point of sibling data collection and before Time 6. These siblings constituted 63.4% of the siblings who were eligible for this analysis. The siblings ranged from 22 to 36 years of age, with an average age of 38.2 years at Time 3. Nine of these siblings without disabilities were brothers; 17 were sisters. A large majority (76.9%) were married. Many had children of their own (69.2%). All of them lived apart from their parents. Half (49.9%) lived within an hour’s drive of their parents’ home. In addition, we randomly selected a comparison group of siblings whose brother or sister remained in the parental home throughout this study period. (More details about the sampling design are available from the authors.)

Data Collection and Measures

A core set of questions was posed to all mothers in our study, regardless of where the son or daughter lived at any given point of data collection. In addition, a special set of questions addressing continued maternal involvement was asked of mothers whose son or daughter had moved to a nonparental residence.

For the first research question, we used data on three measures that describe the mother’s and the adult’s preparation for and involvement in the process of relocation to a nonparental living arrangement: (a) whether the adult was on a waiting list for residential services prior to moving away from the parental home (0 = no, 1 = yes), (b) the number of visits to the new residence made by the mother and the adult, and (c) the frequency of contact (in person or by telephone) between the mother and the adult after the move. Frequency of contact was measured on the following scale: 0 = no contact, 1 = less than weekly, 2 = weekly, 3 = 5 to 8 contacts a month, 4 = daily.

For the second research question, we used six indicators of maternal involvement: (a) the frequency of contact between the mother and adult with mental retardation, either in person or by telephone (using the previously described scale); (b) the mother’s rating of her satisfaction with her level of contact with her son or daughter (0 = completely dissatisfied, 1 = somewhat dissatisfied, 2 = somewhat satisfied, 3 = completely satisfied); (c) the frequency of contact between the mother and the staff at the residential setting (also using the same scale); (d) direct caregiving by the mother (measured by the number of caregiving tasks performed by the mother, ranging from 0 to 31), (e) the level of emotional closeness reported by the mother in her relationship with her son or daughter (measured by the Positive Affect Index, α = .71 (Bengtson & Black, 1973); and (f) the extent of the mother’s worries about the future care of her son or daughter with mental retardation. This last variable was measured using the Pessimism subscale of the Questionnaire on Resources and Stress—F—QRS-F, α = .80 (Friedrich, Greenberg, & Crnic, 1983).

For the third research question, we used four indicators of sibling involvement. First, we employed the previously described Positive Affect Index (Bengtson & Black, 1973), reflective of the emotional closeness of the sibling with the brother or sister with mental retardation. Second, we used the sibling’s rating of how well he or she got along with the brother or sister. Third, we used the sibling’s rating of how often he or she “did things together” with the brother or sister. For the latter two measures, ratings were made on a 6-point scale (1 = not at all to 6 = extremely). Finally, we measured siblings’ worries about the future of their brother or sister with mental retardation using the same measure (Pessimism subscale) as used with mothers.

Data Analysis

The analysis conducted for the first research question (“What is the extent of maternal involvement in the process of relocation, including selecting the residence and facilitating the transition from the parental home?”) involved descriptive statistics (means and percentages) of maternal involvement in the residential relocation process.

The analysis for the second research question (“How do patterns of maternal involvement change during the first 3 to 4 years after the adult son or daughter moved away from home?”) involved comparison of two groups of mothers: (a) the 64 mothers whose son or daughter moved during the study...
period and who were healthy enough to participate in our study for three postrelocation interviews and (b) a randomly selected comparison group of 64 mothers whose son or daughter remained in the parental home throughout this time period. Two types of analyses were conducted for this research question. First, for the analysis of questions asked only of mothers whose adult child had relocated to a new residence, we conducted a series of one-way repeated measures ANOVAs tracking the relocation group across the first three research interviews conducted after the move. Second, for the analysis of measures obtained both from mothers whose son or daughter had relocated and from mothers whose adult child continued to live at home, we conducted a series of $2 \times 4$ repeated measures ANOVAs, with the factors being Residential Status (continued co-residence vs. relocation) and Time (Wave 1 was the research interview conducted prior to the move of the son or daughter away from the parental home; Waves 2, 3, and 4 were the first, second, and third research interviews conducted after the move, respectively). The points of data collection for the comparison group were linked temporally with those in the relocation group. Post-hoc comparisons were conducted to examine the significance of the degree of change from the first point of data collection (Wave 1) to each subsequent point.

The third research question was “How do patterns of sibling involvement change after the adult with mental retardation moved away from the parental home?” In order to provide a comparison of the trajectory of sibling involvement following the move away from the parental home, we randomly selected 26 siblings whose brother or sister had remained in the parental home between Time 3 and Time 6. These siblings constituted the comparison group for Research Question 3. A series of $2 \times 2$ repeated measures ANOVAs was conducted for this research question, with the factors being residential status at Time 6 (continued residence in the parental home versus moved to an out-of-home setting) and time (Time 3 and Time 6).

**Findings**

**Maternal Involvement in the Relocation Process**

Our first research question was, “What is the extent of maternal involvement in the relocation process, including selecting the residence and facilitating the transition from the parental home?” For this analysis, we examined data from the first research interview after the adult with mental retardation moved away from the parental home. On average, this interview occurred 9.2 months after the relocation. There was no significant correlation between the time between the relocation and the next interview and the variables we report on in the discussion that follows. The sample for this analysis was the 117 mothers described earlier.

The evidence suggests a very high level of maternal involvement in the relocation process. For the majority of families, maternal involvement began before the adult moved out of the parental home. Well over half of the mothers (61.0%) 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 86.8% 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 mental retardation to the residence, with over three fourths of the adults (78.3%) 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 = 1.30) was an overnight visit.

During the initial period following the move away from the parental home, there was a dominant pattern of continued contact between the mother and the son or daughter with mental retardation. Over one quarter (27.4%) of the mothers reported daily contact either in person or by phone with their son or daughter, another third (35.7%) reported between five and eight contacts per month, two fifths (21.4%) 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.

To summarize the findings regarding the first research question, our data show that 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**

Our second research question was “How do patterns of maternal involvement change during the first 3 years after the adult son or daughter moved away from home?” For this analysis, we examined data from the 64 mothers who participated in the first three research interviews after the adult with mental retardation moved away from the parental home, each 18 months after the previous one.

Our goal in selecting this subsample 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. (Data are available from the authors.)

As shown in Table 1, which portrays the results of the one-way repeated measures ANOVAs, we found stability in the frequency of contact between the mother and the son or daughter with mental retardation, as measured at the first three research interviews after the adult moved away from home. Mothers averaged more than one contact each week by phone or in person with their son or daughter at each of the three points of data collection following relocation. Although there was no change in frequency of contact over the study period, there was a statistically significant increase during this time in maternal satisfaction with the amount of contact she had with her son or daughter, perhaps reflecting an increasing level of comfort with her adult child’s new living arrangements. Post-hoc comparisons indicate that although maternal satisfaction was stable between Waves 1 and 2, there was a significant increase in satisfaction between Wave 1 (immediately after the residential transition) and Wave 3 (36 months later), \( p = .034 \). Mothers’ frequency of contact with the staff from the new residence also changed over the study period, with significantly more contact reported right after the move than several years later. Post-hoc comparisons indicate a significant decrease in frequency of contact with staff from Wave 1 to Wave 2, \( p = .002 \), as well as from Wave 1 to Wave 3, \( p = .007 \).

Table 2 portrays the results of two-way repeated measures ANOVAs to contrast mothers whose son or daughter moved with those in the comparison group. Not surprisingly, mothers provided significantly less hands-on care for their son or daughter after he or she moved away from home than before. Whereas the number of caregiving tasks performed by mothers in the comparison group (Group 1) was stable over time (i.e., those mothers provided assistance with about 11 daily living tasks at each of the four research interviews), for the families in which the adult had moved, maternal caregiving decreased from a prior (i.e., co-resident) level of help to help with about one task as measured at each of the three research interviews conducted after relocation. The residential status by time interaction effect for the number of caregiving tasks performed by the mother was highly significant, reflective of the divergent caregiving pattern characteristic of the two groups over time. Post-hoc comparisons indicate that there was a significant decrease from the pretransition point of data collection to each of the posttransition points in the number of caregiving tasks performed by mothers of those who moved away from home (all post-hoc contrasts were at the \( p < .001 \) level). The caregiving tasks most likely to be performed by mothers after the son or daughter moved away from home were assisting the adult with shopping and helping him or her with money management.

Next, we examined whether the mother’s level of emotional involvement with the son or daughter changed over time. In contrast to the sharp decrease in the extent of hands-on care following the move, there was a gradual increase in the mother’s level of emotional involvement with her adult child across the four research interviews (see Table 2). This pattern was characteristic of both mothers whose adult lived at home throughout the study period (Group 1) and mothers of adults who moved away from home (Group 2). These data suggest sustained and growing emotional involvement by the mother with her son or daughter with mental retardation over time, regardless of residential status.
Table 1 One-Way Analysis of Variance of Maternal Involvement During the First Three Research Interviews After Relocation

<table>
<thead>
<tr>
<th>Maternal involvement</th>
<th>Wave 1</th>
<th>Wave 2</th>
<th>Wave 3</th>
<th>F (time)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of contact between mother and adult child</td>
<td>3.56</td>
<td>3.56</td>
<td>3.40</td>
<td>0.757</td>
</tr>
<tr>
<td>Maternal satisfaction with contact</td>
<td>2.44</td>
<td>2.51</td>
<td>2.68</td>
<td>3.173*</td>
</tr>
<tr>
<td>Frequency of contact between mother and residential staff</td>
<td>3.38</td>
<td>2.79</td>
<td>2.87</td>
<td>6.279**</td>
</tr>
</tbody>
</table>

Note. This table does not include data from the research interview prior to relocation because the measures of maternal contact and satisfaction apply only to the postrelocation period. Wave 1 refers to the first point of data collection after relocation. Wave 2 refers to the second point of data collection after relocation. Wave 3 refers to the third point of data collection after relocation. *p < .05. **p < .01.

For both groups, post-hoc comparisons indicate that the increase in emotional involvement between Wave 1 and Wave 2 was marginal, p = .069, but that the increases from Wave 1 to Wave 3 and Wave 4 were statistically significant, ps = .035 and .023, respectively.

Finally, we examined changes in the mothers’ level of worries about her son or daughter’s future.

Table 2 Two-Way Analysis of Variance of Maternal Involvement With Co-Resident Versus Relocated Adults With Mental Retardation

<table>
<thead>
<tr>
<th>Maternal involvement</th>
<th>Wave 1</th>
<th>Wave 2</th>
<th>Wave 3</th>
<th>Wave 4</th>
<th>F (time)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of caregiving tasks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group 1</td>
<td>11.21</td>
<td>11.19</td>
<td>11.00</td>
<td>10.90</td>
<td>64.73,</td>
</tr>
<tr>
<td>Group 2</td>
<td>11.86</td>
<td>0.73</td>
<td>1.22</td>
<td>1.37</td>
<td>0.73,</td>
</tr>
<tr>
<td>Level of emotional involvement by the mother</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5.96,</td>
</tr>
<tr>
<td>Group 1</td>
<td>25.78</td>
<td>26.33</td>
<td>26.56</td>
<td>26.74</td>
<td>5.96,</td>
</tr>
<tr>
<td>Group 2</td>
<td>25.39</td>
<td>25.78</td>
<td>25.75</td>
<td>25.94</td>
<td>0.49,</td>
</tr>
<tr>
<td>Level of worries/pessimism</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group 1</td>
<td>6.13</td>
<td>6.10</td>
<td>5.52</td>
<td>6.02</td>
<td>0.71,</td>
</tr>
<tr>
<td>Group 2</td>
<td>7.68</td>
<td>5.75</td>
<td>5.14</td>
<td>5.68</td>
<td>0.791,</td>
</tr>
</tbody>
</table>

Note. Wave 1: all co-resident; Wave 2: Group 1 = co-resident, Group 2 = relocated; Wave 3: Group 1 = co-resident, Group 2 = relocated; Wave 4: Group 1 = co-resident, Group 2 = relocated.
care, using the Pessimism scale of the QRS-F (Friedrich et al., 1983). As shown in Table 2, prior to the move, mothers whose son or daughter later moved away from home (Group 2) had a higher level of pessimism than did mothers whose son or daughter remained living at home throughout the study period (Group 1). Notably, following relocation, these mothers’ worries about the future declined dramatically and dropped below the level of worries of co-residing mothers. Post-hoc comparisons indicate that there was a significant reduction of worries between Wave 1 and each of the subsequent waves (all contrasts were at the \( p < .001 \) level).

Thus, in response to our second research question, the data suggest that there is stable and frequent contact between the mother and the son or daughter after relocation, a concomitant increase in maternal satisfaction with this level of contact, and a decrease in maternal contact with residential staff. Although mothers relinquish the hands-on caregiving role to the formal service system after the son or daughter moves elsewhere, they remain highly involved emotionally with their son or daughter and experience a reduction in their level of worries about his or her future care.

**Changes in Sibling Involvement**

Our third research question was “How do patterns of sibling involvement change after the adult moves away from the parental home?” For this analysis, we included those 26 siblings who participated in both waves of our sibling study and whose brother or sister with mental retardation moved away from the parental home during the interval between these two waves. As noted, we compared them (using repeated measures ANOVAs) with a randomly selected group of 26 siblings whose brother or sister remained at home during this period. (Due to the small-size of the sample of siblings whose brother or sister moved away from home between the Time 3 and Time 6 point of data collection \( [n = 26] \), we checked the pattern of findings reported in Table 3 using nonparametric statistics [Mann-Whitney U Test]. The overall pattern of findings that emerged in the parametric analysis was replicated with the nonparametric tests [data available from authors].)

As shown in Table 3, the two groups differed in the sibling’s feelings of emotional involvement with the brother or sister with mental retardation. Those siblings whose brother or sister remained living in the parental home throughout the study period reported greater levels of emotional involve-

---

**Table 3 Two-Way Analysis of Variance of Sibling Relationships of Siblings With Co-Resident Versus Relocated Siblings With Mental Retardation**

<table>
<thead>
<tr>
<th>Sibling relationships</th>
<th>Time 3(^a)</th>
<th>Time 6(^b)</th>
<th>( F ) (residential status)</th>
<th>( F ) (time)</th>
<th>( F ) (Res. Status ( \times ) Time interaction)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Siblings’ level of emotional involvement</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group 1</td>
<td>24.46, 3.82</td>
<td>25.96, 3.28</td>
<td>7.25, ( p = .010 )</td>
<td>6.46, ( p = .014 )</td>
<td>0.45, ( p = .833 )</td>
</tr>
<tr>
<td>Group 2</td>
<td>22.02, 4.35</td>
<td>23.29, 3.88</td>
<td></td>
<td>3.79, ( p = .057 )</td>
<td></td>
</tr>
<tr>
<td>Siblings get along</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group 1</td>
<td>4.88, 0.95</td>
<td>5.00, 0.75</td>
<td>0.92, ( p = .343 )</td>
<td>3.79, ( p = .057 )</td>
<td>0.95, ( p = .335 )</td>
</tr>
<tr>
<td>Group 2</td>
<td>4.54, 0.99</td>
<td>4.88, 1.14</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Siblings “do things together”</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group 1</td>
<td>3.23, 1.36</td>
<td>3.15, 1.19</td>
<td>1.47, ( p = .232 )</td>
<td>2.78, ( p = .102 )</td>
<td>5.05, ( p = .029 )</td>
</tr>
<tr>
<td>Group 2</td>
<td>2.56, 1.19</td>
<td>3.08, 1.04</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worries/pessimism about the future</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group 1</td>
<td>6.39, 2.74</td>
<td>6.56, 2.97</td>
<td>1.40, ( p = .243 )</td>
<td>2.22, ( p = .143 )</td>
<td>3.84, ( p = .056 )</td>
</tr>
<tr>
<td>Group 2</td>
<td>6.34, 2.61</td>
<td>5.04, 2.68</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^a\)All co-resident. \(^b\)Group 1 = co-resident, Group 2 = relocated.
ment 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. The latter pattern was also found with respect to the sibling’s report of how well he or she got along with the brother or sister with mental retardation, with a trend-level increase, p = .057, in both groups of siblings’ report of how well they got along at Time 6 as compared with Time 3, regardless of residential status.

In two other respects, there was a divergent pattern over time evidenced by 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. First, there was a significant increase in the frequency with which siblings “do things together” from before to after the time that the brother or sister moved away from the parental home, but no change in frequency of shared activities among those whose brother or sister with mental retardation continued to live with the parents. Second, there was a trend for siblings to feel less worried or pessimistic about the future care of the brother or sister with mental retardation following relocation, p = .056, but no change in pessimism for siblings whose brother or sister remained in the parental home. This finding regarding the reduction of sibling pessimism following relocation mirrors the patterns reported earlier regarding the reduction of maternal pessimism following this transition.

Thus, in response to Research Question 3, we found that sibling relationships tend to improve affectively over time, regardless of the place of residence of the adult with mental retardation, although the sibling relationship is closer when the adult continues to live in the parental home. Among those adults who moved, there was an increase in frequency of shared activities and a decrease in the sibling’s pessimism about the brother or sister’s future care.

**Discussion**

In our longitudinal study of older families of adults with mental retardation, we investigated the impact of lifelong caregiving and the circumstances that propel a change in the residential status of adults with mental retardation. The present analysis focused on an increasingly common, though less well-documented, change in the family: the planned residential relocation of an adult with mental retardation from the family home while the mother was well enough to help orchestrate the move and provide continued support. This transition typically occurs in most families who do not have a child with a lifelong disability when the child is in his or her late teens or early 20s and, in family life course theory, is called the “launching stage” (Carter & McGoldrick, 1999). In the case of families of adults with mental retardation, the launching stage is often postponed until the adult child is in his or her 30s or 40s, primarily due to parental preference and the limited availability of suitable options within the community-based residential service system.

Although most past research on residential transitions for persons with mental retardation has used the term placement, we have deliberately used the term residential relocation in this paper. It is currently more prevalent than in the past for an adult with mental retardation to move from the parents’ home and establish an adult lifestyle characterized by greater independence from the family. The launching stage described in this paper occurred while the mothers were healthy enough to help plan and oversee the residential transition, provide enduring emotional support to their son or daughter following the transition, and continue involvement in monitoring the quality of care for their son or daughter. This is an increasingly normative life pattern for adults with mental retardation, and we contend that the language used by social scientists who study the life patterns of this population also needs to be “normalized.”

Proponents of life course theory note that transitions between life stages (in this case, from co-residing with parents to being launched into a non-parental residence) are often times of disequilibrium and stress, as relationships between family members are re-calibrated and altered by the changing family circumstances (Carter & McGoldrick, 1999). Further, our analyses indicate that both mothers and siblings of adults with mental retardation who moved from the family home, indeed, were more worried about the future for their family member than were mothers and siblings of those who remained at home. This may indicate one motivation for the relocation, namely, an acute level of concern and stress about the adult’s future welfare, or, alternatively, it may reflect normative parental (and in this instance, sibling) anxiety associated with the
launched of a family member. We speculate that the emotional disequilibrium hypothesized in life course theory regarding the stresses associated with the launching stage are as applicable to families of adults with disabilities as they are to families whose children do not have disabilities.

Our analyses indicate that the transition from the parental home to a nonparental setting is often a planned event, including several steps. Most of the adults with mental retardation 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.

Our research indicates that residential relocation involves an orchestrated set of events, with 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.

Past research has underscored the importance of family relationships for the optimal development and social/psychological well-being of individuals with mental retardation (Hauser et al., 1999; Krauss et al., 1992). Our data show that even when individuals with mental retardation move away physically from the parental home, they do not move out of the zone of influence of the family. One issue to examine in future research is whether family involvement after relocation fosters continued development of new skills in adults with mental retardation, in the same way that warm and involved parents have been shown to have this type of effect on their child with developmental disabilities during the co-resident period (Hauser-Cram et al., 1999).

Another distinctive feature of the family context surrounding the residential relocation of the adults with mental retardation in this sample is the mothers' age. At the time of their son or daughter's initial move out of the home, these mothers averaged 71 years of age. Their personal challenge at this stage of life was to facilitate their adult child's adjustment to a life outside of the family home. By remaining an active source of emotional support for their son or daughter and maintaining a visible presence in his or her new life, these aging mothers fulfilled the oft-stated desire of older parents that before they became ill or died they wanted to see their adult child established in a new residence (Freedman, Krauss, & Seltzer, 1997; Smith, Tobin, & Fullmer, 1995). The increased involvement of siblings may have helped to bolster the mother's confidence in the future, fostering the transmission of caregiving responsibility from one generation to the next.

This research has a number of implications for service providers and policymakers in the field of mental retardation/developmental disabilities. First, the value of planned transitions is highlighted by our findings. Advance planning makes it possible for both the mother and the individual with mental retardation 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 mental retardation 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.

Our findings also confirm the importance of siblings to the quality of life of adults with mental retardation. Siblings' levels of worry about the future mirror those of their mothers, with elevated levels prior to a move and an abatement of worries after. That their level of involvement with their brother or sister with mental retardation 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 mental retardation for years to come and may buffer the stress
of high staff turnover that is characteristic of the contemporary residential service system.

Finally, the findings might be useful in educating service providers about the fidelity of family involvement following lifelong family care. Many agencies that provide services to individuals with mental retardation 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 mental retardation 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.

Our study had several limitations and, therefore, caution is needed regarding the generalization of the findings. First, the samples of mothers and particularly of siblings were quite small, and, thus, there may have been changes that we were not able to detect due to limited statistical power. Second, we examined a postrelocation period lasting 3 to 4 years. Our data do not indicate the extent of longer range patterns of family involvement. Third, the comparison groups differed in critical ways before the adult family member transitioned out of the home, including an elevation in worries about the future for mothers and a lower level of emotional involvement and frequency of contact for siblings of those who moved during the study period. Thus, the between-group comparisons should be interpreted with these differences in mind. Fourth, critical voices in the family were not heard in this analysis, including the fathers and the individuals with mental retardation. Finally, although there was socioeconomic diversity in the sample, it lacked racial and ethnic diversity. Therefore, the rates of family involvement among the European American sample studied here might either underestimate or overestimate the rates of involvement among families of color.

The pattern of continuity of family relationships; sustained emotional and social involvement among parents, siblings, and adults with retardation; and the abatement of concerns about the future for mothers and siblings of adults with mental retardation following a planned and orchestrated relocation of the adult with retardation that we have reported warrants investigation in studies with larger samples. It is also critical that future research include the perspectives of the adults with mental retardation themselves. The limitations of the present study are counterbalanced, in our view, however, by its prospective design, which permitted us to study family interaction patterns before and after the relocation occurred and to contrast those patterns with families in which a relocation did not occur. The low attrition rate in our study, and the inclusion of objective and subjective measures of involvement from both mothers and siblings, also enhance the potential generalizability of our results.

References


Butterworth, J., Steere, D. E., & Whitney-Thomas,


Received 6/5/00, first decision 8/22/00, accepted 9/26/00.

Editor in charge: Steven J. Taylor

This manuscript is based on a paper presented at the annual meeting of the American Association on Mental Retardation, May 27, 1999, New Orleans. Support for the preparation of this manuscript was provided by the National Institute on Aging (Grant No. R01 AG08768) and the National Institute of Disability and Rehabilitation Research through the Rehabilitation Research and Training Center on Aging With Developmental Disabilities at the University of Illinois at Chicago (Grant No. H133B0069).

Authors:

Marsha Mailick Seltzer, PhD, Acting Director and Professor, Waisman Center and School of Social Work (E-mail: mseltzer@waisman.wisc.edu) and Jinkuk Hong, PhD, Assistant Researcher, Waisman Center, University of Wisconsin-Madison, 1500 Highland Ave., Madison, WI 53705-2280. Marty Wyngaarden Krauss, PhD, Associate Dean and Professor, Brandeis University, Heller School, Waltham, MA 02454-9239. Gael I. Orsmond, PhD, Assistant Professor, Boston University, Sargent College, 635 Commonwealth Ave., Boston, MA 02215.