Aging Parents' Residential Plans for Adult Children With Mental Retardation

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Abstract: Future residential plans and placement preferences of 340 mothers of adult children with mental retardation living at home were examined and findings from a 3-year follow-up discussed. Four subgroups of families were compared based upon residential plans and preferences for continued home residence for the next 2 years. Significant group differences were found for background characteristics, maternal psychological well-being, and support systems. Less than 50% had made residential plans, and the majority believed their child would still be at home in 2 years. At 3-year follow-up, 22% of the families with short-term residential plans had achieved a placement compared to 14% among families without a plan who wanted a placement.

Planning for the future is a pervasive concern of aging parents who have adult children with mental retardation living at home. They worry about what will become of their son or daughter when they are no longer able to provide care. Perhaps the most challenging aspect of future planning is to make decisions about where the adult child with mental retardation will eventually live. Smith, Tobin, and Fullmer (1995) characterized residential decisions as the most emotionally laden component of future planning because the parents must acknowledge that their son or daughter may some day not reside in their lifelong home. (p. 487)

Residential planning surfaces unresolved or unspoken concerns of the parents, the son or daughter with mental retardation, siblings, and other relatives, including such concerns as continuing family responsibility, separation, and independence. Making residential plans may signify the beginning of the launching stage for these parents, in which they prepare to relinquish their active parenting role (Carter & McGoldrick, 1989). The launching stage is among the most stressful transitions for parents of adults with mental retardation and is often accompanied by interpersonal turmoil, fluctuations in parental well-being, and disequilibrium in the family (Seltzer, Krauss, Choi, & Hong, 1996; Wikler, 1986).

Either in spite of, or because of, familial concerns, anxiety, and stress about the future, parents of adults with mental retardation often do not make concrete long-term plans (Heller & Factor, 1991; Kaufman, Adams, & Campbell, 1991; Seltzer & Krauss, 1994). Although parents may assume that another child will take responsibility, many parents do not discuss these arrangements with their other children (Goodman, 1978; Heller & Factor, 1991; Kaufman et al., 1991; Krauss, 1990). Similarly, few parents have discussed future plans with their sons or daughters with mental retardation or obtained their preferences for future living arrangements (Heller & Factor, 1994; Smith & Tobin, 1989). Lack of planning creates significant difficulties for family members when a crisis does occur (such as the death or incapacity of a parent) and has repercussions for the service delivery system (Janicki, Otis, Puccio, Rettig, & Jacobson, 1985).

Investigators have examined factors associated with future planning or with families' preferences or requests for out-of-home placement (Black, Cohn, Smull, & Crites, 1985; Black, Molaison, & Smull, 1990; Heller & Factor, 1991; Kaufman et al., 1991; Kobe, Rojahn,
In other studies researchers have investigated the stages or process of future planning (Blacher, 1990; Blacher & Baker, 1994; Pruchno, Michaels, & Potashnik 1990) and have concluded that "placement" is an ongoing process rather than a single discrete behavior, with predictable and ordered stages of decision-making and deliberation occurring prior to the actual placement. Smith et al. (1995) identified five stages in residential planning: no discussion of future residence, early discussion but not serious in nature, alternatives considered without resolution of choices, provisional or tenuous plans made, and definite residential plans established. Researchers have also examined the degree of urgency behind families' placement requests. Families in the Black et al. (1990) study rated the urgency of their requests for community living services, ranging from urgent and in crisis; urgent, but situation stable; services highly desirable; services wanted in the future; and unsure of urgency.

These studies point to the complexities and multidimensionality of residential planning and the variability of families' preferences and decisions regarding future plans. Families' future residential plans are linked to parental hopes and desires for the adult child's future, stage in the planning process, and the perceived urgency of the current circumstances. Factors associated with future planning, placement preferences, and urgency of requests include characteristics of the adult with mental retardation, characteristics of the parents and the family, and formal and informal support system characteristics.

In terms of characteristics of the adult, more severe levels of mental retardation, poorer functional skills, and presence of maladaptive behaviors are related to future planning and placement preferences. For example, maladaptive behavior was identified by Black et al. (1990), Heller and Factor (1991), and Sherman (1988) as a significant predictor of families' urgency of request for community living, preference for out-of-home placement, and decision to place in residential care, respectively.

Mixed results have been reported regarding characteristics of the parents and the family in relation to future plans and preferences. Heller and Factor (1991) found that older caregivers of higher socioeconomic status were more likely to make financial plans, and African American families were less likely than White families to make residential or financial plans. Sherman (1988) found that larger families headed by a single parent and suffering greater disruption of family life were more likely to decide to place a family member in residential care. Black et al. (1990) found that the number of caregiver stressors (e.g., caregiver health problems, financial concerns, other children's care demands) was the strongest predictor of urgency of community living request.

Findings regarding the role of formal and informal support systems in families' future plans also have been mixed. Heller and Factor (1991, 1993) found that increased utilization of formal services and informal supports and high levels of unmet service needs were associated with family preference for out-of-home placement. Smith et al. (1995) found that greater service use and help from other relatives were significant predictors of stage of future planning in families. However, Black et al. (1985) and Sherman (1988) found that low service utilization was associated with out-of-home placement requests and decisions.

To summarize, results of these studies suggest the saliency of maternal, family, and support system characteristics, in addition to those of the adult with mental retardation, in understanding families' future plans and preferences. However, only limited attention has been given to maternal psychological well-being and family functioning as potential factors related to future planning. Heller and Factor (1991) found that caregiver burden was a significant predictor of families' preferences for out-of-home placement. Similarly, Tausig (1985) found that stressors within the family, caregiver burden, and disruption of family relationships contributed to individuals with mental retardation who were over 21 years of age.

Other critical aspects of caregiver and family well-being such as maternal depression, life satisfaction, and perceptions of the family social climate have not been examined in studies of future planning. Given the emotion-laden aspects of residential planning and psychological vulnerability associated with the launching stage (Seltzer et al., 1996; Smith et al., 1995), the relation between families' future plans and preferences and parental psychological and social factors warrant investigation.

In this article we present findings about families' residential plans and placement pref...
ferences based upon a longitudinal study of older mothers caring for adult children with mental retardation. We distinguished families' residential plans along two dimensions: whether the parents (a) have a residential plan and (b) prefer an out-of-home placement for their son or daughter within 2 years. Exploration of these two dimensions yields insights into the prevalence of planning and short-term intentions of parents, thus signaling the immediacy or urgency of their plans and preferences.

We conceptualized four types of families: those who (a) have a residential plan and who prefer that the adult child move out of the home within 2 years; (b) have a residential plan but prefer that the adult remain at home at least for the upcoming 2 years; (c) do not yet have a plan but who prefer placement outside of the home within 2 years; and (d) do not have a plan and who prefer that the adult child remain at home at least during the next 2 years. Our first objective was to explore whether these four types of families differ in their characteristics, functioning, well-being, and formal supports.

Our second objective was to assess the outcomes of families' residential plans and preferences over a 3-year period, based on a follow-up of individuals subsequently placed out of home. We were interested in whether families who had developed plans and preferred out-of-home placement within 2 years were more likely to have achieved these goals at follow-up (3 years later) than were families without plans or preferences for placement outside of the home.

Method

Sample

This analysis is based on an ongoing longitudinal study of 461 families who met two criteria at the outset of the study in 1988: the mother was age 55 or older and had a son or daughter with mental retardation living at home (see Seltzer & Krauss, 1989, for study methodology). Data have been collected every 18 months. Thus far, data have been completed at six time periods. The sample for the present analysis consisted of 340 mothers with sons or daughters who still lived at home in 1991, at the third stage of data collection, during which time extensive information was collected on future planning. Slightly more than half of the families (n = 181) lived in Wisconsin; the other 159 lived in Massachusetts. Excluded from the analysis were (a) 52 families whose adult child by Time 3 of data collection had been placed outside the parental home, (b) 22 cases in which either the mother or the adult with mental retardation had died prior to Time 3, (c) 20 cases in which the mother declined to participate at Time 3, and (d) 27 cases with missing data on residential plans and/or preferences.

At the third time period of data collection, the mothers ranged in age from 58 to 87 years (mean = 68.1, standard deviation [SD] = 6.5). Three fourths (75.6%) rated their health as good or excellent; 18.8%, as fair; and 5.6%, as poor. The majority (61.0%) were married, one third (33.3%) were widowed, and 19 (5.7%) were divorced, separated, or single. Their average family income was $28,538 (SD = $12,986). With respect to education, 15.9% had less than a high school education, 42.4% graduated from high school, and 41.7% had some post-high school education (trade school, college, or graduate school).

Their sons (54.1%) and daughters (45.9%) with mental retardation ranged in age from 18 to 69 years (mean = 36.8, SD = 7.3). Over one third (38.2%) had Down syndrome. Four fifths (80.5%) had mild or moderate levels of mental retardation and one fifth (19.5%) had severe or profound levels. The majority of the adult children (87.9%) were reported to be in either good or excellent physical health.

Data Collection and Measures

At each data point, the mothers participated in a structured interview in their homes and completed self-administered standardized assessments. Residential planning was measured along three dimensions. First, mothers were asked whether they had a specific plan for where their son or daughter would live in the future (coded as 0 = no residential plan and 1 = have residential plan). Second, mothers were asked where they thought their son or daughter would be living 2 years from now (coded as 1 = same place as currently and 2 = in a different setting). Mothers were also asked the kind of setting they ideally wanted their son or daughter to be living in 2 years from now (coded as 1 = same setting as currently and 2 = different setting).

The data used in this analysis included four domains of variables: (a) characteristics of the adult with mental retardation, (b) characteristics of the parents and family, (c) maternal psy-
The specific items from the Questionnaire on Resources and Stress-F that were summed for this subscale were: Item 4 [I worry about what will happen to _____ when I can no longer take care of him/her]; Item 7 [I have accepted the fact that _____ might have to live out his/her life in some special setting, e.g., institution or group home]; Item 12 [In the future, our family's social life will suffer because of increased responsibilities and financial stress]; Item 13 [It bothers me that _____ will always be this way]; Item 32 [I worry about what will happen to _____ when he/she gets older]; Item 43 [I worry about what will happen to _____ when I no longer can take care of him/her]; Item 47 [_____ will always be a problem to us]).

The mean score of mothers was 4.50 (SD = 1.86). Finally, mother's purpose in life (having goals in life and a sense of direction) was measured using the Scales of Psychological Well-Being (Ryff, 1989), which consists of five statements, with response categories ranging from strongly disagree (1) to strongly agree (6) (alpha = .70). The mean score of mothers was 23.82 (SD = 4.55).

Formal support system characteristics of the adult with mental retardation consisted of two measures: the total number of services received by the adult (range from 0 to 16) and the total number of services needed, but not received (range from 0 to 16).

Data Analysis

Two-way analyses of variance were conducted using SPSS-X (SPSS, 1991) to detect significant main and interaction effects in the residential plans (plan, no plan) and placement preferences of families (preference for living in the same place, different place) in terms of the four domains described earlier. In all analyses, an alpha level of at least .05 was used to assess significant effects. We note that the cross-sectional nature of our data preclude making causal inferences from our study's findings.

Results

Description of Residential Plans and Preferences

Less than half (45.3%) of the 340 mothers had a specific plan for where their son or daughter would live in the future, as manifested by putting their name on a waiting list for residential programs such as group homes or apartments, planning for siblings or other relatives...
to take the adult child into their own homes, or planning for siblings to move back to the family home to care for the family member with mental retardation. Further, the vast majority of mothers (94.0%) thought that their son or daughter would still be living at home 2 years hence. However, when asked where they ideally wanted their adult child to be living in 2 years, more than one third (37.9%) indicated that they wanted their child to be living in a different setting. Of the 129 mothers who ideally wanted a different setting in 2 years, only 17 (13.2%) expected that a placement would actually occur within that time frame.

We next examined the relation between families' residential plans and placement preferences in 2 years. Of the 154 parents who had residential plans, 82 (53.2%) ideally wanted their son or daughter to be living at home in 2 years, while the remaining 72 of the planners (46.8%) wanted a different setting in 2 years. For the 186 parents who did not have residential plans, 129 (69.4%) wanted the same setting in 2 years, and the remaining 57 parents (30.6%) indicated that they wanted a different setting for their son or daughter in 2 years. Parents wanting a different setting in 2 years were significantly more likely to have engaged in residential planning than were those who wanted the same setting, \( \chi^2 = 9.28, p = .002 \).

**Comparison by Family Type and Residential Plans**

A key objective was to compare four types of families based upon their future plans and preferences: (a) families with residential plans who prefer out-of-home placement within 2 years (short-term planners); (b) families with plans but who prefer continued home placement for the next 2 years (long-term planners); (c) families who do not have plans but prefer out-of-home placement within 2 years (wishful thinkers); and (d) families who do not have plans and prefer continued home placement for the next 2 years (the status quo). These four groups were compared with respect to characteristics of the adult with mental retardation, maternal/family characteristics, maternal psychological well-being, and support system characteristics (see Table 1). We were particularly interested in examining interaction effects, which indicate a different pattern of results based on specific types of families.

**Table 1**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Residential plan</th>
<th>No residential plan</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Same setting (n=82)</td>
<td>Different setting (n=72)</td>
</tr>
<tr>
<td>Adult with mental retardation</td>
<td>Age 36.70 36.04</td>
<td>Age 36.05 34.92</td>
</tr>
<tr>
<td></td>
<td>Level of retardation 0.87 .85</td>
<td>Level of retardation 0.79 .69</td>
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<tr>
<td></td>
<td>Behavior problems 1.29 1.94</td>
<td>Behavior problems 1.53 2.32</td>
</tr>
<tr>
<td></td>
<td>Decline in health 0.06 .15</td>
<td>Decline in health 0.09 .04</td>
</tr>
<tr>
<td></td>
<td>Decline in skills 0.08 .21</td>
<td>Decline in skills 0.11 .19</td>
</tr>
<tr>
<td>Mother/family</td>
<td>Age of mother 68.38 69.11</td>
<td>Age of mother 67.50 68.00</td>
</tr>
<tr>
<td></td>
<td>Marital status .53 .56</td>
<td>Marital status .64 .72</td>
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<tr>
<td></td>
<td>Decline in health .23 .28</td>
<td>Decline in health .18 .25</td>
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<tr>
<td></td>
<td>Family income (in thousands) 27.83 27.40</td>
<td>Family income (in thousands) 29.69 28.39</td>
</tr>
<tr>
<td></td>
<td>Has other living children .90 .97</td>
<td>Has other living children .96 .93</td>
</tr>
<tr>
<td></td>
<td>Family Relations Index 12.37 11.22</td>
<td>Family Relations Index 12.13 10.88</td>
</tr>
<tr>
<td>Maternal psychological well-being</td>
<td>Burden of care 27.19 31.60</td>
<td>Burden of care 28.79 30.60</td>
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<td></td>
<td>Depression 7.26 11.38</td>
<td>Depression 8.75 10.31</td>
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<tr>
<td></td>
<td>Worry about future* 3.79 5.25</td>
<td>Worry about future* 4.36 4.78</td>
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<tr>
<td></td>
<td>Purpose in life 25.30 23.13</td>
<td>Purpose in life 23.27 23.80</td>
</tr>
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<td>Formal support system</td>
<td>No. of services received by adult with mental retardation 4.60 4.76</td>
<td>No. of services received by adult with mental retardation 4.71 4.86</td>
</tr>
<tr>
<td></td>
<td>No. of unmet service needs of adult with mental retardation 1.00 1.61</td>
<td>No. of unmet service needs of adult with mental retardation .87 1.70</td>
</tr>
</tbody>
</table>

*Note. The n varied between 297 and 340 for the analyses.

*As measured with the Questionnaire on Resources and Stress-F.

*p < .05. **p < .01. ***p < .001.
The analysis yielded five significant interaction effects. Regarding characteristics of the adult with mental retardation, the short-term planners (i.e., families who had residential plans and wanted a different placement in 2 years) were most likely to have a son or daughter who had experienced a decline in health over the past 18 months. In contrast, wishful thinkers (no residential plan and preferred a different setting in 2 years) were least likely to have an adult child who declined in health. In terms of family characteristics, the short-term planners were most likely to have other living children. In contrast, long-term planners (i.e., had residential plans but preferred their child to remain at home in the next 2 years) were least likely to have other living children. In terms of maternal psychological well-being, the short-term planners had the poorest well-being, whereas the long-term planners had the most positive outcomes. Specifically, the short-term planners were most likely to be worried about the future and least likely to experience a sense of purpose in their lives. In contrast, the long-term planners had the highest levels of psychological well-being in these areas.

The families who had no plans (and who preferred either the home setting—the status quo families—or a different setting in the next 2 years—the wishful thinkers) fell between the other two types of families in terms of well-being. That is, both the status quo and the wishful thinker families were less worried about the future and experienced more purpose in life than did the short-term planner families, but they had more worries about the future and less purpose in life than did the long-term planner families.

Analyses of the main effects of residential plans yielded two characteristics that differentiated families who had plans from those who did not: level of mental retardation of the son or daughter and marital status of the mother. Families with residential plans (regardless of placement preference in 2 years) were more likely to have an adult child with moderate or mild levels of mental retardation. Further, mothers in families with residential plans were more likely to be widowed or divorced than those in families without residential plans.

In terms of families' preferences for residential placements in the next 2 years, there were six significant main effects. Families who wanted a different setting in 2 years (regardless of whether they had a residential plan) were more likely to have a son or daughter with behavior problems and declining functional skills than were families who preferred the home setting in 2 years. The families who wanted a different setting also had poorer family relationships, as measured by the Family Relations Index.

Maternal psychological well-being variables were also significant in differentiating families who wanted a different setting in 2 years from families who wanted the same placement. Mothers in families who wanted placement in 2 years were more burdened and depressed than were mothers in families who wanted the same setting. In terms of support system characteristics, families preferring different placements had adult children with higher levels of unmet needs across various types of services.

Follow-Up of Families' Plans and Preferences

By Time 5 of data collection (3 years after the second time period), the vast majority of the adults with mental retardation (n = 29 [85.3%]) still lived at home with their parent. Two adults (0.6%) had died, and no information was available for 6 others (1.8%). Regarding the other families, 42 individuals (12.3%) had been placed outside the home during the intervening 3 years. In order to examine the relation between families' residential plans and preferences as expressed at Time 3 and subsequent placement outcomes at Time 5, we conducted a follow-up analysis of these 42 cases.

At follow-up, 21 adults lived in supervised community residences, 6 were in semi-independent residential programs, 5 were in institutional settings, 3 were in nursing homes, 4 lived with other relatives (typically a sibling), 2 lived in foster homes, and 1 lived independently. Mothers (or the current primary caregiver) described the primary reason for the placement of the adult with mental retardation. According to their report, 12 had been placed because of problems associated with parenting (i.e., fatigue, recognition of the inevitability of a residential change). Ten were placed explicitly due to failing parental health and 10 to increase their independence as adults. Six were placed following the death of their mother.

Three were placed because of increasing stress in the parent–adult child relationship, and the remaining 2 individuals were placed because of their own failing health or problematic behavioral issues.
The four types of families differed in their placement rates. The highest placement rate was among the 72 short-term planner families, in which 16 adults (22.2%) were placed by follow-up. The primary reasons for placement in this group included parental illness (n = 5), parental aging (n = 5), desire for more independence by the adult with mental retardation (n = 3), declining health in the adult with mental retardation (n = 2), or stressful relationship between parent and adult child (n = 1). In contrast, among the 57 wishful thinker families, only 14.0% of their sons or daughters had been placed at follow-up. Placement among these families was attributed to maternal death (n = 2), parental illness (n = 1) or aging (n = 2), desire for more independence by the adult with mental retardation (n = 2), or stressful relationship between parent and adult child (n = 1). These data indicate that among families who preferred an out-of-home setting in 2 years, having a residential plan increased the likelihood of placement considerably (22.2% vs. 14.0%).

Families who preferred that their son or daughter continue to live at home in 2 years (regardless of whether or not they had a residential plan) were least likely to experience a placement. The lowest placement rate (7.3%) was among the 82 long-term planner families. One individual was placed following the mother’s death, 3 because of maternal aging, and 2 in order to increase the adult’s independence. The 12 placements that occurred in the status quo families (who had a placement rate of 9.3%) were attributed to maternal death (n = 3), parental illness (n = 4) or aging (n = 2), stressful parent–adult child relationship (n = 1), and desire for more independence (n = 2).

Maternal death and illness loom large as primary reasons for placement. For the 11 mothers who died between Time 3 and the follow-up period, placements occurred in 6 cases, 5 of whom had no residential plans at Time 3. (One person was placed several months prior to his mother’s death.) Precipitous changes in maternal health, including death, is an obvious catalyst for residential change among adults with mental retardation. In the remaining 4 families in which there was a maternal death during the study period, the care for the adult with mental retardation was assumed by the surviving parent or siblings, but without a change of residential location for the adult with mental retardation.

In order to explore the relation between age of the adult child and out-of-home placement, we compared three age subgroups within our sample in terms of their out-of-home placement rates: age 30 and under (n = 90), 31 to 45 years old (n = 219), and over 45 years (n = 31). The over-45 age group had the highest placement rate of 6 (19%). People age 30 and under had a placement rate of 12.2% (11 individuals), whereas 11.4%, or 25 people, between the ages of 31 to 45 years were placed out-of-home.

Discussion

There are two critical challenges facing families of adults with mental retardation who live at home. First, there is the need to make plans for the future. Second, families need to understand the utility of such plans. We note that these challenges are fraught with uncertainty for families and for the service systems into which adults with mental retardation are placed. Our focus on parental plans and preferences reveals the complexity of the process and the multiple factors associated with the very diverse range of situations in which families exist.

Overall, we found that less than half of the families had made residential plans for their son or daughter with mental retardation, and the vast majority believed he or she would still be living at home in 2 years. Indeed, only slightly more than a third indicated a desire for placement within 2 years. Of those who desired a placement, only 13% believed that a placement would, in fact, occur. These findings alone reveal the durability of family-based care, even when the parents are in the elder years. Despite the increased emphasis within the service systems to engage in person-centered planning (Bradley, Ashbaugh, & Blaney, 1994), and for parents and adults with mental retardation to be active participants in such planning (Dybwad, 1990), there appears to be substantial reluctance among caregiving families to alter or plan for a change in residential setting.

Based on parental plans (or no plans) and desire for out-of-home placement within 2 years (or no such desire), we identified four types of families. The group that had the greatest propensity for placement (i.e., the short-term planners who had a residential plan and wanted a placement within 2 years) had the poorest wellbeing. They were most likely to have a son or daughter in declining health, to have mothers
with greater worries about the future, and to have mothers with a lower sense of purpose in life. They were also the most likely to achieve their goal, as 22.2% had secured a placement at the 3-year follow-up. Although parental illness or concerns about aging were the reasons for 10 of the 16 placements, none occurred because of maternal death.

In contrast, the long-term planners (i.e., those with residential plans but not seeking placement) had the most positive well-being among the four groups and had the lowest placement rate (7.3%) at follow-up. The mothers in these families had the lowest level of worries about the future and the highest levels of sense of purpose in life.

More than a third of the families (37.9%) were characterized as status quo families, meaning they had no residential plans and did not desire an out-of-home setting within 2 years. These families were similar to, but slightly less well-off in terms of functioning and well-being than were the long-term planners. Despite their satisfaction with their present arrangements, at follow-up we found that 9.3% of the adults with mental retardation in these families were in an out-of-home setting. Most of these placements were attributed to maternal factors, including death, illness, or aging concerns. Indeed, of the 6 mothers whose death resulted in an out-of-home placement, 3 had been classified in the status quo group.

The wishful thinkers were the smallest of the four groups, but perhaps the most problematic. These families had no residential plans but wanted a placement within 2 years. Even so, however, 14% achieved a change in residential setting at the 3-year follow-up, primarily due to maternal factors, including death, illness, or concerns with aging. Both in terms of maternal well-being and family functioning, the profiles of these families were similar to (although slightly better off than) those of the short-term planners.

The results suggest that having a residential plan results in a greater probability of placement than does not having a residential plan, a finding confirmed in other analyses of these data (Essex, Seltzer, & Krauss, in press). It does not, however, guarantee a placement, and the absence of a plan is not a singular barrier to placement, particularly when parental death or illness occur (Gordon, Seltzer, & Krauss, 1997).

We suspect that the motivation to plan (regardless of motivation to place) is affected by multiple factors, some of which are internal and unique to the families, some of which are external and affected by federal and state policies. With respect to the family-based factors, we found that planning was more likely among mothers who are no longer married and may feel more pressure as single parents to articulate their expectations for their dependent offspring. We also found that having a son or daughter with mild or moderate retardation associated with having a residential plan. Parents may perceive more variety in residential options for dependents with more capabilities and may thus be willing to articulate plans.

With respect to the external factors, we may affect the motivation to plan, there currently tremendous residential waiting lists virtually every state in the country. It is stated that there are 78,700 individuals with mental retardation in need of residential services (Hayden, 1992). Families may be aware of the arduous process and intense required to secure highly sought after and so openings in publicly financed residential homes. Indeed, we found that among those who wanted a placement within 2 years there were exceptionally low expectations it would occur. We also noted that parer adults with severe or profound levels of retardation were less likely to make reside plans than were parents of adults with abilities. These types of families are acutely aware of the constraints in service availability. Although many states have placed special emphasis on reducing the size of ing lists, short-term resolution is elusive in of the uncertainties confronting every state regarding potential caps in Medicaid funds, diminished state resources for human services.

Despite the discouraging prospect of achieving a residential placement in the term, our findings suggest that active plan by families can make a difference—22% of families with a short-term plan achieve placement within 3 years compared to 14% of those who wanted a placement but did not have a plan. Further, our data reveal that among who wanted a placement and had taken to achieve it (the short-term planners) mothers were reporting greater worry about future, a diminished sense of purpose in life declining health in their adult dependent. We also found that placement was more
to occur among the oldest age cohort in the sample of adults with mental retardation, those ages 45 and over. We cannot infer from our research that these factors caused the planning to occur, but our findings suggest that greater vulnerability in maternal well-being and health problems in adults with mental retardation may prompt the family to confront and act on the task of residential planning.

We also found that among those who want a residential placement in the near future (even if they have taken no steps to achieve it), there are a cohesive set of “risk” factors. These families were more likely to have a son or daughter with behavior problems, declining functional skills, and greater unmet service needs. The families were also in more turmoil as suggested by elevated levels of caregiving burden and depressive symptoms among the mothers.

There is great fear among families about what will happen to their son or daughter with mental retardation when the parents can no longer sustain active caregiving. The reluctance to plan for this inevitability is surprising, particularly considering the investment they have already made in securing the well-being of their loved one. The challenge for families and for the service providers with whom they interact is to marshal the energy and vision to engage in planning for the future. To take a “why bother” approach—either because of realistic appraisals of the bottlenecked service system or because of false hope for immortality—is a risky approach for parents because it invites abrupt and often major disruption in the lives of adults with mental retardation who are precipitously launched into the service system because of parental death or incapacitation (Gordon et al., 1997). To take a careful and personal look at the options available may provide a measure of comfort to families and a promise of easier transitions for adults with mental retardation who have always lived with their families, but whose future is dependent on the quality and capacity of the community-based service system.

References


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