Residential Transitions of Adults With Mental Retardation: Predictors of Waiting List Use and Placement

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Predictors of residential planning and placement among 461 families of adults with mental retardation living at home were examined prospectively over a 4.5-year period. Factors predicting whether an adult's name would be put on a waiting list for residential placement were a diagnosis of Down syndrome, higher unmet service needs, smaller parental support networks, and better maternal health. Predictors of residential placement were being on a waiting list, poorer maternal health, and older age of the adult child. Results from qualitative analyses of parental reasons for use of the waiting list or of placement were also presented. Findings were interpreted using stress and coping, family life cycle, and postponed launching models.

In the last 10 years, there has been increasing interest in the complex factors associated with how older parents of adults with mental retardation who live at home plan (or do not plan) for the future (Freedman, Krauss, & Seltzer, 1997; Heller & Factor, 1991; Kaufman, Adams, & Campbell, 1991; Smith, Tobin, & Fullmer, 1995). The importance of this issue is derived from three phenomena. First, family-based care is the dominant residential arrangement for persons with mental retardation (Fujiura & Braddock, 1992), resulting in a sizable population of families who must eventually decide how their son or daughter with mental retardation will be cared for after parental decline or death. Second, most individuals with mental retardation are now expected to outlive their parents (Seltzer & Krauss, 1994), resulting in a sizable population who may enter the formal residential service system for the first time well into their 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.

Despite the obvious need for planning for the future, many older families do not profess concrete residential, financial, or legal plans (Freedman et al., 1997; Heller & Factor, 1991). Investigators have also found that planning is a process, not a discrete event, and that the process can be protracted, vary with respect to the specificity and feasibility of different options, and be subject to change (Blacher & Hanneman, 1993). Moreover, there is growing acknowledgment that the forces propelling families to plan differ depending on the stage of the family life cycle (Tausig, 1985).
The reluctance of older families to plan may be partially explained by their satisfaction with the current living arrangement. Most older families who have provided life-long care to their son or daughter have done so voluntarily and are reluctant to relinquish their parental roles (Krauss & Seltzer, 1993). Families' efforts to engage in planning for the future may confront their deep-seated ambivalence and fear of the unknown.

The present study was designed to examine the dynamics of one aspect of planning among a sample of older families of adults with mental retardation who live at home, namely, placement of the son or daughter's name on a waiting list for residential services. This specific action constitutes a behavioral or objective indicator of family planning that may be part of a larger set of future planning activities. It does not necessarily constitute a decision to seek residential placement immediately, although it is generally viewed as a precursor or component of the placement process (Blacher & Hanneman, 1993). We also examined the dynamics of placement, namely, the factors that predict the residential relocation of an adult with mental retardation from the family home to a licensed residential setting.

A particular advantage of this dual focus is that in most of the extant literature on the predictors of planning, investigators draw their conceptual and analytic models from the results of studies on the predictors of residential placement. We view these processes as potentially distinct and subject to different or unique influences. Indeed, researchers have examined correlates and/or predictors of various facets of planning and placement including having plans (Heller & Factor, 1991; Kaufman et al., 1991), stage of planning (Smith et al., 1995), future intentions to place (Cole & Meyer, 1989), preferences for formal residential placement (Grant, 1989; Heller & Factor, 1991), requests for residential placement (Tausig, 1985), urgency of placement requests (Black, Molaison, & Smull, 1990; Kobe, Rojahn, & Schroeder, 1991), and actual placements (Black, Cohn, Smull, & Crites, 1985; Sherman, 1988). Other researchers have examined barriers and motivations for planning (Campbell & Essex, 1994), typologies of planners and nonplanners (Freedman et al., 1997), and timing of adults' moves from the family home (Gordon, Seltzer, & Krauss, 1997).

Authors in the family development literature have identified a central task in families: the launching of children from the home (Carter & McGoldrick, 1989). For most parents, the launching of a young adult son or daughter is an expected event with positive implications, marking the child's successful negotiation of adult roles (e.g., marriage, employment) and allowing the parents more freedom and resources for self-development (see Aquilino, 1991). According to this perspective, some parents of adults with mental retardation may view residential placement of their adult son or daughter as an opportunity for increasing independence and personal growth for both their child and themselves.

However, the most commonly used model for understanding how change occurs in families who face challenging circumstances is the stress and coping model (Pearlin, Mullan, Semple, & Skaff, 1990). Briefly stated, the model posits that internal and external resources are activated by stressful situations and that the utilization of such resources modifies the impact of the stressor. In the present study, we used a stress and coping model to guide our analyses because of our interest in understanding the forces that propelled a cohort of families who have provided in-home care for their adult child with mental retardation for, on average, over 30 years, to take steps that would change their current pattern of living. The two steps we examined were putting the adult child's name on a waiting list and actual placement in a residential setting.

Our use of the stress and coping
model as a conceptual (and analytic) framework is based on three primary factors associated with planning and with placement: background characteristics of the son or daughter with mental retardation and of the mother, caregiving stresses, and caregiver resources. Regarding background characteristics, results of past research suggest that older age of both the caregiver and the adult with mental retardation increase the probability of planning and of placement (Black et al., 1985; Borthwick-Duffy, Eyman, & White, 1987; Heller & Factor, 1991; Sherman, 1988). Kaufman et al. (1991) found that parents are more likely to plan when the adult child is female. Although Grant (1989) and Kaufman et al. (1991) found that higher income or social class was associated with planning or placement, Black et al. (1985, 1990) found the reverse.

With respect to caregiver stressors, previous researchers have found that certain functional and behavioral characteristics of the family member with mental retardation are sources of stress that strain the family's caregiving capacity. Specifically, families who have a son or daughter with more significant caregiving needs and limitations (e.g., greater behavioral problems, greater severity of mental retardation, poorer functional skills, and more medical needs) are more likely to consider residential placement, particularly families of younger persons with mental retardation (Black et al., 1990; Borthwick-Duffy et al., 1987; Cole & Meyer, 1989; Sherman, 1988; Tausig, 1985). However, this pattern may be different when the parents are older. In studies of older families, Freedman et al. (1997) and Kaufman et al. (1991) found that planning for future placement is more likely when the son or daughter has less severe disability. Thus, the stage of the family life course may alter the extent to which the level of disability of the family member with mental retardation strains the family's caregiving capacity.

Results of several longitudinal studies have shown that parents' perception of high unmet formal service needs predicts out-of-home placement of the son or daughter with mental retardation (Freedman et al., 1997; Heller & Factor, 1994). Although family support programs to assist caregiving families have proliferated in recent years (Bradley, Ashbaugh, & Blaney, 1994), it is still widely acknowledged that placement in a residential setting increases the range of services provided (Gordon et al., 1997). Unmet needs for services may well propel families to consider residential placement.

According to proponents of stress process models, the availability of resources can reduce the effects of stress. Several investigators have suggested that the parental resources of good health (Black et al., 1985; Smith et al., 1995) and psychological well-being (Freedman et al., 1997; Grant, 1989) are associated with less of a desire to seek residential placement for their family member with mental retardation. Research on the effect of external resources has yielded mixed results. Informal social support from family and friends has been found to mitigate against residential planning and placement (Freedman et al., 1997; Heller & Factor, 1991). However, Smith et al. (1995) reported that help from adult children was associated with an increase in planning by mothers, whereas Grant (1989) found that help from neighbors and friends was associated with caregivers' preferences for out-of-home residential care, but help from kin had the opposite effect.

Use of formal services may also move families closer to (or farther from) residential placement. Sherman (1988) distinguished between services to the individual with mental retardation and services to the family and found that the former decreased the probability of placement whereas the latter increased it. It may be that family-focused services, such as respite, increase the family's familiarity and trust in the service system as well as their acceptance of the possibility of nonfamily care (Heller & Factor, 1994).

Taken as a whole, these studies
provide partial support for a stress process explanation of family decisions regarding planning and placement. However, the research has methodological and theoretical limitations that temper the conclusions that can be drawn. Most of the studies are cross-sectional or retrospective, thus limiting the ability to specify temporal ordering of predictors and consequences. In many of these studies, the investigators grouped together families at many different stages of the life course rather than differentiating factors prevalent in childhood versus adulthood (Tausig, 1985). Finally, there is little attention in the literature with regard to how the various aspects of the planning and placement process are associated with each other.

In this analysis, we examined the dynamics of residential planning and placement based on a longitudinal study of older families of adults with mental retardation. We focused on one specific indicator of planning: putting the name of a son or daughter on a waiting list for residential services. To deepen our understanding of waiting list and placement processes, we coupled qualitative and quantitative analyses. In contrast to the many cross-sectional studies found in the literature, we used a “long lens” to investigate how family characteristics in 1988 predicted whether the adult would be on a waiting list for or placed in a nonfamily setting 4.5 years later. Consistent with previous researchers, we based our hypotheses on a stress process model. However, we also considered the possibility that normative processes of separation and independence of adults from their parents may be affecting family decisions.

We posed four research questions. The first was, What are parents’ reasons for either adding their son’s or daughter’s name to a waiting list for residential placement or not putting their child’s name on a waiting list? Our intention in considering this question was to gain an understanding of parents’ perceptions of the factors that propel them to plan via the waiting list or to refrain from using this mechanism. We hypothesized that the majority of families who put their son’s or daughter’s name on a waiting list would give reasons suggesting a stress process model.

Our second question was, What variables predict the family’s decision to place the name of the adult with mental retardation on a waiting list for residential placement? Based on a stress process model, we hypothesized that stressors associated with caregiving (more severe mental retardation, poorer health status, and greater number of unmet service needs of the adult with mental retardation) would increase the probability that the family would use the waiting list, whereas greater resources available to the mother (i.e., better health, a greater number of children in the family, larger social support network, and greater number of services provided to the adult with mental retardation) would decrease the probability.

Our third research question was, What are the parents’ reasons for placing their adult child with mental retardation in a nonfamily residential setting? Our hypothesis concerning parents’ reasons for placement parallels our hypothesis about families’ reasons for using a waiting list. We predicted that most families would give reasons for placement suggesting a stress process model.

Our fourth research question was, What variables predict the placement of the adult with mental retardation in a nonfamily residential setting? Our hypotheses again parallel those we made concerning the decision to turn to a residential waiting list, namely, that caregiving stressors would increase the probability of placement whereas caregiver resources would decrease this probability. In addition, we hypothesized that having the son’s or daughter’s name on a waiting list for residential services would increase the likelihood of placement.
Method

Sample

The analyses presented in this paper were based on an ongoing longitudinal study of 461 families who met two criteria when the study began: (a) the mother was age 55 or older and (b) a son or daughter with mental retardation lived at home with her. The mother was the primary study participant. Half the families lived in Massachusetts and half lived in Wisconsin. Identical recruitment procedures were used in the two states. The majority of participants were recruited through the assistance of the Massachusetts Department of Mental Retardation, the Wisconsin Office of Developmental Disabilities, and the Arc and Senior Centers in both states. Other families were recruited through media announcements or referrals by participating family members.

Mothers were first interviewed in 1988. Subsequently, data have been collected every 18 months. At each point of data collection, the mother is interviewed and completes a set of self-administered measures. In a small but growing number of families, the mother has died or become too ill to participate. In these cases, another family member has become the main study participant, most often the father or a sibling. For the present study we used data from the first point of data collection and the fourth point (4.5 years later), hereafter referred to as Times 1 and 4. We did not track changes in sample characteristics over time but, rather, examined whether characteristics at Time 1 predicted planning and placement at Time 4.

Virtually all of the sample members (98.3%) were White. The average family income at Time 1 was $23,936. The mean age of the mothers at Time 1 was 65.5 years (standard deviation [SD] = 6.47). Nearly two thirds (66.4%) were married. Over one fourth were widowed (27.5%), and the remainder (6.1%) were single, separated, or divorced. A large majority of the mothers (76.8%) rated themselves in good or excellent health. The mothers had an average of 4 living children, with a range from 1 (the son or daughter with mental retardation) to 9. They reported an average of 7.4 people in their social support networks, which ranged from 0 to 20 people.

The mean age of the sons (53.8%) and daughters (46.2%) with mental retardation at Time 1 was 33.6 years (SD = 7.61). Over three fourths (78.4%) had mild or moderate mental retardation, and 37.3% had a diagnosis of Down syndrome. Most of the sample (87.6%) were in good to excellent health, and had some sort of work or day activity program (89.8%). According to the mothers, the sons and daughters received an average of 3.4 services (range = 0 to 10) and had an average of 1.6 unmet service needs (range = 0 to 10). Over one fourth (27.6%) were on a waiting list for an out-of-home residential placement at Time 1.

Subsamples. Four subsamples were used for the analyses presented in this paper, one each for the four research questions. For the first question, which addressed the reasons parents did or did not have their adult child’s name on a waiting list as of the Time 4 point of data collection, the subsample included 322 families whose son or daughter was still co-residing with the mother at Time 4. In total, 139 families were excluded from this first subsample: 71 families where the son or daughter had moved away from the parental home prior to Time 4 (67 to a nonfamily setting and 4 to the home of a sibling) and 68 families for whom there was missing data on at least one study variable. These 68 families differed from those with complete data on four characteristics: The mothers and their sons or daughters with mental retardation were older (means for mothers = 67.22 and 64.82, respectively, $t = 2.88, p = .004$; means for sons or daughters = 35.90 and 32.86, respectively, $t = 3.07, p = .002$), had lower incomes (means = 19,704 and 24,683, respectively, $t = 2.68, p = .008$), and the
mothers had smaller social support networks (means = 6.15 and 7.62, respectively, t = -2.79, p = .005).

To address the second research question, which we hypothesized would identify factors that predict the transition to the waiting list, we analyzed a subsample of 257 families. For this analysis, we excluded the 139 families eliminated from the first subsample as well as those who were already on a waiting list at Time 1 (65 families). The reason we excluded those on a waiting list at Time 1 was that these adults had already made the transition we were aiming to predict (i.e., the transition to the waiting list). If these families had been retained for this second research question, the temporal ordering of effects would have been unclear, and, thus, they were not included in this analysis.

To address the third research question, which was framed to elicit the parents' reasons as to why their adult child moved to a nonfamily placement, we formed a subsample that consisted of the 67 families for whom such a placement occurred after Time 1 but before Time 4.

To address the fourth research question, which was designed to investigate the factors that predict placement, we used a fourth subsample (n = 389). This subsample excluded the 68 families with missing data and the 4 families in which the adult with mental retardation lived with a sibling as of Time 4. The latter 4 families were excluded because our purpose in this analysis was to identify the factors that predicted a move to a nonfamily residential placement.

The mother was the respondent in all cases at Time 1. By Time 4, however, 11 mothers had died or became incapacitated. In these cases, the father, sibling, other relative, or guardian provided the needed information about waiting list and residential status.

**Measures**

The two dependent variables were (a) waiting list status of the son or daughter with mental retardation at Time 4 (coded 0 if the son or daughter was not on a waiting list for residential placement at Time 4 and 1 if he or she was on a waiting list at that time) and (b) placement status of the son or daughter with mental retardation at Time 4 (coded 0 if the son or daughter co-resided with a parent at Time 4 and 1 if the son or daughter lived in a nonfamily setting at that time).

The independent variables, based on data collected at Time 1, were organized into three domains: background characteristics of the son or daughter with mental retardation and of the mother (included as control variables), caregiving stressors, and caregiver resources. The analysis of predictors of placement also included residential waiting list status of the son or daughter at Time 1 as an independent variable.

The background characteristics of the son or daughter included age (in years), gender (0 = male, 1 = female), and diagnosis (1 = Down syndrome, 0 = other). We included diagnosis as a control variable because in our past research, we found that parents of adults with Down syndrome have better well-being, which may affect their caregiving capacity (Seltzer, Krauss, & Tsunematsu, 1993). Marital status of the mother (0 = not married, 1 = married) and family income (in dollars) were also included as control variables. Because of the high correlation with age of the adult with mental retardation, age of the mother was not included in the analyses.

Caregiving stressors included measures of three potential sources of stress: the level of mental retardation of the son or daughter, based on maternal ratings or agency reports, was rated on a scale from 0 (profound) to 3 (mild). Physical health status of the son or daughter was measured on a 4-point scale, ranging from 0 (poor) to 3 (excellent) (Duke University Center for the Study of Aging and Human Development, 1978). Unmet service needs of the son or daughter was a count of up.
to 13 formal services needed but not received.

Caregiver resources included four measures of maternal personal and social resources. Maternal health was self-rated using the same 4-point scale just described. Number of children was a count of the number of the mother’s living children. The size of the social support network, based on Antonucci’s (1986) measure of social support, was a count of the number of people with whom the mother reported that she feels a special bond. The number of services provided to the son or daughter was a count of up to 13 services provided to the son or daughter with mental retardation. Waiting list status at Time 1 was measured by a dichotomous variable (0 = not on a waiting list for residential services, 1 = on a waiting list).

A correlation matrix of all study variables is found in Table 1. Above the diagonal are the data based on the 257 families in the waiting list sample; the data below the diagonal are from the 389 families in the placement sample. Means and SDs for all study variables are also provided.

For the descriptive analyses, we used the respondents’ answers to open-ended questions regarding their reasons for having or not having the name of their son or daughter on a residential services waiting list and their reasons for having their son or daughter move to a residential placement. These questions were posed to all respondents, whose answers were recorded in writing by the interviewers. When the adult with mental retardation was living away from the parental home, respondents also provided information about the new kind of living arrangement (e.g., group home, fully staffed apartment, nursing home). Based on a content analysis we conducted, we were able to identify broad categories of reasons. For all but a handful of cases, the respondent’s reason could be classified under one category. In the few exceptions, we determined the main category for each case by reading all relevant materials.

**Data Analysis**

For our first research question, we divided the families into four groups reflecting change or stability in waiting list status over time: Group 1—continuously on a waiting list (the son or daughter was on a waiting list at Time 1 and remained on the waiting list continuously through Time 4); Group 2—transition off the waiting list (the son or daughter was on a waiting list at Time 1 but by Time 4 was no longer on a list); Group 3—persistently off the waiting list (the son or daughter was not on a waiting list either at Time 1 or at Time 4); and Group 4—transition onto the waiting list (the son or daughter was not on a waiting list at Time 1 but was on at Time 4). We then analyzed parents’ answers to open-ended questions about reasons for their son’s or daughter’s waiting list status and classified their reasons for using the waiting list as either normative or nonnormative. Normative reasons were not linked with either the disability of the adult or the aging of the parent but, rather, were based on the hope for growing independence of the adult or the normative separation of parent and adult child. Nonnormative reasons related to either the disability of the adult with mental retardation or the aging of the parents. All responses were double checked to assure reliability of classification and instances of disagreement were discussed and resolved.

For our second research question, which addressed the factors predictive of the transition to the waiting list, we conducted a logistic regression analysis. The dichotomous dependent variable (on a waiting list or not on a waiting list at Time 4) was regressed on the three domains of Time 1 variables (background characteristics, caregiving stressors, and caregiver resources).

For our third research question, which was designed to elicit responses describing parents’ reasons for placement, we classified their reasons into two types: normative and nonnormative (as defined
| Variable                  | 1  | 2  | 3  | 4  | 5  | 6  | 7  | 8  | 9  | 10 | 11 | 12 | 13 | 14 | 15 | Mean | SD  |
|---------------------------|----|----|----|----|----|----|----|----|----|----|----|----|----|----|-----|------|
| Age of son/daughter       | .14| -.21| -.31| -.20| .21| -.14| .06| -.14| -.19| -.19| -.18|    |    |    | -.12| 3.21 | 7.59 |
| Gender of son/daughter    | .12| -.14| -.12| -.16| .09| .04| .01| -.01| .01| .01| -.02|    |    |    | -.03| .46  | .50  |
| Diagnosis (DS)*           | -.23| -.12| .03| -.03| -.11| .07| -.20| .10| .07| .11| .06|    |    |    | -.09| .37  | .48  |
| Mother's marital status   | -.26| -.10| .06| .45| -.15| .23| -.16| .24| .10| .16| .04|    |    |    | .06  | .67  | .47  |
| Family income             | -.19| -.07| .00| .43| -.01| .31| -.15| .37| .04| .21| -.07|    |    |    | .10  | 25.57 | 14.19 |
| Level of MF*              | .12| .01| -.10| -.09| -.05| .01| .05| -.05| -.06| -.02| -.05|    |    |    | -.06| 2.11 | .86  |
| Health status of son/daughter | -.12| .02| .03| .17| .23| .04| -.11| .40| .12| .20| -.04|    |    |    | -.04| 2.35  | .74  |
| No. of unmet needs        | .03| .03| -.17| -.12| -.04| -.15| -.23| -.12| -.05| -.20|    |    |    | -.11| 1.49  | 1.75 |
| Maternal health           | -.18| .00| .11| .22| .35| -.07| .34| -.22| -.02| .20| .04|    |    |    | .09  | 2.02  | .74  |
| No. of children           | -.18| -.00| .12| .06| .01| .03| .11| -.10| .03| .29| .00|    |    |    | .01  | 4.08  | 1.92 |
| Size of social support network | -.13| -.01| .09| .15| .23| -.01| .17| -.08| .16| .26| .05|    |    |    | -.11| 7.96  | 4.15 |
| No. services              | -.12| -.03| .01| .08| -.04| -.07| -.03| -.16| .04| -.03| .03|    |    |    | -.00| 3.20  | 1.80 |
| Waiting list (Time 1)     | -.05| -.05| .09| .02| -.09| -.02| -.02| .08| -.01| -.05| -.13|    |    |    | -.16|      |      |
| Waiting list (Time 4)     |      |      |      |      |      |      |      |      |      |      |      |      |      |      |      |      |
| Placement status (Time 4) | .10| -.04| .04| -.00| .00| -.01| .03| .01| -.13| -.03| .01|    |    |    | .06| 3.44  |      |
| Mean                      | 33.23 | .47 | .39 | .67 | 24,700 | 2.12 | 2.35 | 1.53 | 1.97 | 4.02 | 7.60 | 3.41 | 27 |    |      |      |
| SD                        | 7.58 | 50 | .49 | .47 | 14,480 | .85 | .72 | 1.71 | .75 | 1.94 | 4.00 | 1.86 | 44 |    |      |      |

Note: The upper diagonal presents data from the waiting list sample (n = 257). For this sample, correlations greater than .13 are significant at the .05 level. The lower diagonal presents data for the placement sample (n = 389). For this sample, correlations greater than .10 are significant at the .05 level.

*DS = Down syndrome. *Mental retardation.
earlier). Again, all reasons were coded by two independent raters.

For our fourth research question, through which we sought to identify predictors of placement, logistic regression was again the method of data analysis. Time 4 placement status (placed or not placed) was regressed on the same Time 1 variables as investigated for Research Question 2 (background characteristics, caregiving stressors, and caregiver resources). In addition, waiting list status at Time 1 was included as an independent variable in the prediction of placement as of Time 4.

For the two multivariate analyses (Research Questions 2 and 4), we used the .05 level of significance, although trends (up to $p = .07$) were also noted. The statistical package was SPSS (SPSS, 1991).

Results

Dynamics of the Waiting List

Reasons for Waiting List Use. For our first research question, we examined parents’ reasons to either add their son’s or daughter’s name to a waiting list or not to use this mechanism for future planning. As described previously, we divided the sample into four groups reflecting the family’s waiting status at both Time 1 and Time 4.

Group 1: Continuously on the waiting list. This group consisted of 53 families (16.5% of the 322 families included in this analysis) whose son or daughter was on a list at Time 1 and still on at Time 4. Almost all parents in this group explained that they added their son’s or daughter’s name to the waiting list because of the recognition that they were aging and, thus, their child would eventually need placement. There was variability with respect to the urgency these parents felt for placement. For some, a rapid placement was desired, whereas for others the anticipation of future needs motivated these families to make longer-range plans.

Some parents expressed regret about the decision to add their son’s or daughter’s name to a waiting list and about the inevitability of future placement. Although they preferred that the adult continue to live at home, they added his or her name to the list to have a back-up in case of future emergencies (e.g., their own failing health or death). Others noted the influence of service providers who had encouraged the family to put the name of the son or daughter on a waiting list.

Only 4 of the 53 mothers in this group gave reasons for waiting list use that suggest the normative separation of parents and adult children. These mothers anticipated placement as an opportunity for increased independence for their son or daughter and for themselves.

Group 2: Transition off the waiting list. There were only 12 families (3.7%) whose son or daughter was on a waiting list at Time 1 but not at Time 4. There is great diversity in the reasons why these parents removed their son’s or daughter’s name from a waiting list. For example, one mother removed her son’s name from the waiting list of a private residence because she realized that she would not be able to afford the fee. The residence another family chose formally changed the eligibility criteria, and the daughter did not fit the new eligibility profile. In yet another instance, in which the daughter had a dual diagnosis, the parents felt that the recent increase in the seriousness of her mental illness would interfere with the success of a placement, and, therefore, they removed her name from the waiting list. Other mothers felt that their children would receive inadequate care in a residential placement. Finally, some mothers noted a change in previously made plans (i.e., a sibling was now expected to take over primary caregiving when the parents were no longer able to provide care).

Group 3: Persistently off the waiting list. These families, whose son or daugh-
name from a waiting list after a brief period of time. 

Group 4: Transition onto the waiting list. This group of 51 families (15.8%) did not have the name of the son or daughter on a waiting list at Time 1 but did by Time 4. The reasons provided by these parents were virtually identical to those expressed by the families in Group 1, namely, that the parents recognized that they were growing older and that sometime in the future there would be a need for the son or daughter to live in an out-of-home residential option. For some, this may be an “insurance policy” against a need anticipated but not yet felt, whereas for others health problems and the manifestations of aging had already been experienced. Again, only a handful of mothers described the waiting list decision in terms of normative parent–child separation. Most mothers noted that the son or daughter wanted to be more independent, whereas one mother noted her own desire for the adult child to become more independent.

Multivariate Analysis of Predictors of Waiting List Status. For our second research question, we examined the factors that are predictive of being on a waiting list for residential placement. Included in this analysis were only those families who were not on the waiting list at Time 1 (Groups 3 and 4 as described previously). We examined whether the following variables predicted whether parents would add an adult’s name to a waiting list during the subsequent 4.5 years or would not use this mechanism for future planning: demographic characteristics (age, gender, and diagnosis of the son or daughter, maternal marital status, and family income), caregiving stressors (level of retardation, adult’s health status, and number of unmet needs), and caregiver resources (maternal health status, number of children in the family, size of the mother’s social support network, and the number of services provided to the son or daughter).

The multivariate model predicting waiting list status at Time 4 was signifi-
cant, $\chi^2(12) = 29.02, p = .004$ (see Table 2). The model was examined for overall fit as well as the significance of individual betas based on the Wald statistic. A significant beta can be interpreted as the change in the log odds of being on the waiting list associated with an increase of one unit of the specific independent variable.

As shown in Table 2, of the background variables, having Down syndrome was a significant predictor of transitioning to a waiting list between Time 1 and Time 4. There was also a trend for higher family income to predict transitioning to a waiting list.

**Table 2**
Regression of Time 4 Waiting List Status on Time 1 Predictors ($n = 257$)

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Beta</th>
<th>Standard error</th>
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</thead>
<tbody>
<tr>
<td><strong>Background characteristics</strong></td>
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<td></td>
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<td>Age of son/daughter</td>
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<td>Gender of son/daughter</td>
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<td>Family income</td>
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<td>.014</td>
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<td><strong>Caregiving stressors</strong></td>
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</tr>
<tr>
<td>Level of MR*</td>
<td>.364</td>
<td>.223</td>
</tr>
<tr>
<td>Health status of son/daughter</td>
<td>-.477</td>
<td>.263</td>
</tr>
<tr>
<td>No. of unmet needs of son/daughter</td>
<td>.298*</td>
<td>.103</td>
</tr>
<tr>
<td><strong>Caregiver resources</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternal health status</td>
<td>.608*</td>
<td>.279</td>
</tr>
<tr>
<td>No. of children</td>
<td>.096</td>
<td>.098</td>
</tr>
<tr>
<td>Size of social support network</td>
<td>-.133*</td>
<td>.049</td>
</tr>
<tr>
<td>No. of services provided to son/daughter</td>
<td>.047</td>
<td>.097</td>
</tr>
</tbody>
</table>

*1 = DS (Down syndrome), 0 = other. *Mental retardation. 
*p < .05. **p < .01. *p < .07.

Of the variables we conceptualized as caregiving stressors, one was a significant predictor of being on a waiting list at Time 4. As we hypothesized, the larger the size of the mother’s social support network at Time 1, the less the likelihood that her adult son or daughter would be on a waiting list 4.5 years later. Counter to our hypothesis, however, good maternal health appeared to increase the likelihood of waiting list use.

To summarize, an adult was more likely to be added to a waiting list for a residential placement if he or she had Down syndrome, had a relatively high level of unmet service needs, and if his or her mother had a smaller social support network and was in better health. Poorer health of the adult with mental retardation and higher family income may also increase the likelihood of a family’s turning to a waiting list for long-range planning.

**Dynamics of Placement**

Four and a half year after the study began, 67 adults with mental retardation had moved from the parental home to a formal residential placement. As shown in Table 3, these adults were living in a variety of types of residential settings at Time 4. More than half lived in fully staffed community-based settings or foster homes. About another fifth lived in nursing homes or institutions. Approximately 15% lived either independently or semi-independently. All of the adults had continued contact with their families after moving away from the parental home, most (72.4%) on a weekly basis or more often.

**Table 3**
Types of Residential Placements ($N = 67$)

<table>
<thead>
<tr>
<th>Type of placement</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community residence</td>
<td>37</td>
<td>55.2</td>
</tr>
<tr>
<td>Semi-independent living</td>
<td>8</td>
<td>11.9</td>
</tr>
<tr>
<td>Nursing home</td>
<td>8</td>
<td>11.9</td>
</tr>
<tr>
<td>Institution</td>
<td>7</td>
<td>10.4</td>
</tr>
<tr>
<td>Foster home</td>
<td>5</td>
<td>7.5</td>
</tr>
<tr>
<td>Independent living</td>
<td>2</td>
<td>3.0</td>
</tr>
</tbody>
</table>

**Reasons for Placement.** For our third research question, we examined the reasons why these 67 adults moved from the parental home to a different living arrangement. For 12, the reasons could be
characterized as normative. In 2 of these instances, the mother viewed placement as the natural next step in the family life course and looked forward to more free time for herself. In the other 10 families, the theme of independence for the son or daughter was said to be the prominent reason for placement. The placement was viewed as a positive achievement because the son or daughter could be more independent in that context.

However, the majority of the placements were made for nonnormative reasons (i.e., reasons related to the disability of the adult or the aging of the parent caregivers). For 38 families, the reason for placement was actual or anticipated changes in the health of the parents. In 17 of these families, the mother recognized that she and/or her husband were aging and she wanted to facilitate the transition to a new living arrangement before their own health worsened and created a crisis. In another 17 of these cases, the mother and/or father already were ill, and the mother felt that she could not manage to care for her son or daughter any longer. In yet another 4 of these families, placement followed the death of the mother.

The changing needs of the son or daughter motivated the placement in 17 families. In 9 of these, the son or daughter became ill, could no longer be cared for by the parents, and, hence, needed to be placed. In another 7 of these families, the placement was caused by the problematic behavior of the son or daughter, who no longer could be managed at home. Such behavior problems included aggression toward or abuse of the parent by the adult with mental retardation, behavioral changes due to suspected Alzheimer’s disease, depression secondary to medical problems, and unpredictable and disturbing behavior. In one case, a service provider suggested that the son needed to be placed at this time.

We contrasted the ages of the 12 adults who were placed for normative reasons with the 55 adults who were placed for nonnormative reasons. Pre-

sumably, placement for normative reasons should come earlier in the life course than placement for nonnormative reasons. In fact, adults placed for normative reasons were about 5 years younger than adults placed for nonnormative reasons (means = 30.75 vs. 35.87 years, \( t(65) = -1.95, p = .055 \)) as were their mothers (means = 63.08 vs. 67.89 years, \( t(65) = -2.15, p = .036 \)), supporting this life course interpretation.

Multivariate Analysis of Predictors of Residential Placement. For our fourth research question, we examined the predictors of out-of-home residential placement (see Table 4). The model predicting placement status was significant, \( \chi^2(13) = 59.72, p < .001 \).

Table 4
Regression of Time 4 Placement Status on Time 1 Predictors (n = 389)

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Beta</th>
<th>Standard error</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background characteristics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of son/daughter</td>
<td>.058*</td>
<td>.022</td>
</tr>
<tr>
<td>Gender of son/daughter</td>
<td>-.427</td>
<td>.307</td>
</tr>
<tr>
<td>Diagnosis (DS) of son/daughter</td>
<td>.332</td>
<td>.326</td>
</tr>
<tr>
<td>Marital status of mother</td>
<td>-.122</td>
<td>.359</td>
</tr>
<tr>
<td>Family income</td>
<td>.023</td>
<td>.012</td>
</tr>
<tr>
<td>Caregiving stressors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of MP</td>
<td>-.028</td>
<td>.181</td>
</tr>
<tr>
<td>Health status of son/daughter</td>
<td>.050</td>
<td>.222</td>
</tr>
<tr>
<td>No. of unmet needs of son/daughter</td>
<td>-.047</td>
<td>.095</td>
</tr>
<tr>
<td>Caregiver resources</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternal health status</td>
<td>-.633*</td>
<td>.226</td>
</tr>
<tr>
<td>No. of children</td>
<td>.013</td>
<td>.078</td>
</tr>
<tr>
<td>Size of social support network</td>
<td>.031</td>
<td>.041</td>
</tr>
<tr>
<td>No. services provided to son/daughter</td>
<td>.036</td>
<td>.080</td>
</tr>
<tr>
<td>Waiting list (Time 1)</td>
<td>2.031**</td>
<td>.325</td>
</tr>
</tbody>
</table>

*1 = DS (Down syndrome), 0 = other. **Mental retardation.
*p < .01. ***p < .001. \( t < .07 \).

As shown in Table 4, having the son’s or daughter’s name on a waiting list is the strongest predictor of residing away from the parental home at Time 4. This is not surprising because 59.7% of those who were placed had been on a waiting list at Time 1.

There were two other significant variables in this model. As we hypothesized, poorer maternal health at Time 1 increased the likelihood of living away from the parental home at Time 4. Also,
the older the son or daughter, the greater the likelihood he or she had moved away from home by Time 4. As with the waiting list model, there was a trend for family income to predict residential placement.

One possible explanation for the small number of predictors in this model could be that the waiting list variable was masking the effect of other variables on placement status. To explore this possibility, we again ran the placement model, but this time we excluded the waiting list variable. The overall relations did not change: age of the son or daughter and maternal health were the only significant predictors in the model. Thus, including waiting list in the model does not appear to limit the effects of other variables, and it increases the explanatory power of the model considerably.

Behavior Problems

The literature suggests that behavior problems of a family member with mental retardation can be a major source of stress for the caregiver and a predictor of residential preference and placement (Black et al., 1990; Freedman et al., 1997; Grant, 1989; Heller & Factor, 1991; Sherman, 1988; Tausig, 1985). Unfortunately, we did not have a measure of behavior problems at the Time 1 point of data collection and, thus, did not include this potential stressor in our models.

However, at Time 2 we did have a measure of behavior problems (Bruijninks, Hill, Weatherman, & Woodcock, 1986), which was a count of up to eight behavior problems manifested by the adult with mental retardation (hurtful to self, manifested by 17.1% of the sample; hurtful to others [9.6%]; destructive to property [7.9%]; disruptive behavior [24.4%]; unusual habits [49.2%]; socially offensive behavior [22.2%]; withdrawn or inattentive behavior [28.4%]; and uncooperative behavior [26.7%]). To explore the possible association of behavior problems with the dependent variables, we re-ran the models presented in Tables 2 and 4, but this time we included our measure of behavior problems. Because the behavior problems measure was taken at Time 2, all of the independent variables included in these analyses were from Time 2, whereas the dependent variables were again from the Time 4 point of data collection. We found that number of behavior problems was not a significant predictor of being on a waiting list or of out-of-home placement. (These data are available upon request to the authors.)

Note that we chose to use the Time 1 data for our main analysis even though the data set did not include the behavior problems variable because the sample included in the Time 2 data set was considerably smaller because families who had added their son’s or daughter’s name to the waiting list or were placed at Time 2 would have necessarily been excluded.

Discussion

The purpose of our analysis was to provide a deepened understanding of residential planning and placement processes in older families of adults with mental retardation. We coupled qualitative with quantitative data and based our analysis on a stress process model. The findings of our study add to the relatively new body of literature on residential planning and placement processes specific to older families of adults with mental retardation and build on prior work that was focused on these processes in younger families (Blacher & Hanneman, 1993).

Regarding families’ reasons for putting the son’s or daughter’s name on a waiting list and their reasons for placement, we identified three distinct profiles. The first of these was characteristic of only a small number of families, who gave reasons that suggest a normative launching process, similar to that observed in the general population. These families viewed placement as a means to enable greater independence for their son or daughter and/or for the parents.

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A larger group of families turned to the waiting list or placed their son or daughter as a result of failing parental health, age-related changes in the son or daughter that resulted in new caregiving challenges the parents were unable to meet, or the death of the mother. These reasons suggest a stress process model.

A third group of families decided to add their son's or daughter's name to a waiting list or to place him or her in a residential setting not because of specific difficulties but, rather, because of their wish to ensure a secure residential future after they were no longer the primary caregivers. This explanation suggests neither a normative launching nor a stress process model but, rather, a third process: anticipatory planning for the son's or daughter's future needs. Although they were launching their son or daughter well past the normative age for this transition, these mothers were behaving proactively rather than reacting to increasing burdens or stresses.

Thus, our results suggest three different kinds of family explanations for planning and placement processes. These include two patterns evident in prior research, namely, a stress process model that is consistent with reasons for planning and placement in younger families with a child who has mental retardation and a normative launching process that is consistent with reasons for the young adult's transition in the general population. In addition, we identified a third process possibly unique to families in the later years of the family life course who are faced with the continuing challenge of caring for a member with mental retardation. This model suggests postponed launching associated with anticipatory planning and proactive placement.

In addition to these families who have made advance plans, we found that a large number of families—the majority in our sample—avoided planning. Most families whose adult with mental retardation was not on a waiting list expressed a strong preference for keeping him or her at home as long as possible. However, some noted that they may look into residential services in the future. Although there are some families who never will place their son or daughter into a nonfamily setting, we expect to see more and more of the families who have not yet made plans turn to the waiting list as a bridge to their son's or daughter's future away from the family. Thus, from a policy perspective, the size of the waiting list is undoubtedly an underestimate of the true magnitude of the need for residential services.

The parents' explanations aid in the interpretation of the patterns revealed in our multivariate analyses. We found, consistent with a stress process model, that when the adult with mental retardation had a higher number of unmet service needs and poorer health, and when the mother had a smaller social support network, a family was more likely to decide to put the son's or daughter's name on a waiting list for residential placement. These families may be taking realistic stock of their circumstances, as the specialized health care and unmet service needs of the son or daughter and the limited number of people the mother can draw on make a crisis situation more likely should the parents become incapacitated.

The quantitative data also revealed indicators of a normative launching model because families with higher incomes and those in which the mother had better health were more likely to add their son's or daughter's name to a waiting list for out-of-home placement. Mothers with good health and greater financial means may have more to gain from the launching of their son or daughter because they have the resources to enjoy their freedom from primary caregiving. There is evidence that families in the general population who have higher incomes are more apt to emphasize norms of independence and self-development, whereas families with more limited incomes are more likely to stress patterns of interdependence among family members (Aquilino, 1991). By begin-
ning the launching process through a residential waiting list, higher income parents of adults with disabilities may be conforming to similar norms. An alternative explanation of these findings, in the context of the postponed launching pattern described earlier, is that mothers in good health may use the waiting list as a means of proactive planning before their own aging causes a caregiving crisis. Families with higher incomes may feel more likely to reap benefits from this form of planning because they can access more expensive private facilities.

The finding that families of adults with Down syndrome are more likely to add their son's or daughter's name to a waiting list may reflect a high degree of trust in and familiarity with the service system and, possibly, a greater responsiveness of the service system to these families. Families of adults with Down syndrome tend to be more connected with services and support groups than are families of children with other diagnoses (Seltzer et al., 1993). As a result, these parents may feel more comfortable with the idea of using formal residential services.

Our findings based on the multivariate analysis of placement highlight the importance of residential waiting lists in the placement process because the waiting list was the primary entry point to residential placement. In addition, placement was more likely to occur when the mother was in poorer health and the adult son or daughter was older. It is noteworthy that although better health of the mother predicted using the waiting list to plan, poorer health of the mother predicted placement. Thus, a downturn in maternal health emerges, not surprisingly, as one of the factors that propels an adult from the waiting list to actual placement. Together, these predictors suggest two routes to placement: via planning and in response to a crisis. However, the absolute number of placements was surprisingly low, reflective of the scarcity of residential placements even when need is great.

A limitation of our data was that there was no measure of behavior problems available at Time 1, the point at which the predictors of waiting list use and placement were measured. However, in our exploratory analyses based on Time 2 data with a smaller sample, we found that this variable was not a significant predictor of either waiting list use or placement. In our qualitative analysis, no parents cited behavior problems as the reason they turned to the waiting list, and only 7 of the 67 families who placed their son or daughter during the study period noted behavior problems as a reason for placement. However, for some of this latter group, the behavior problems were linked with age-related changes (e.g., dementia), so that increasing age of the son or daughter may have been a more important determinant of these parents' placement decisions. Behavior problems may be a less important predictor of placement in older than in younger families. In two other studies, having behavior problems was not predictive of planning for placement by older families (Heller & Factor, 1991; Tausig, 1985).

Our findings are tempered by a number of other limitations. First, the use of a nonprobability sample limits the generalizability of the findings. Second, our analyses were based on a specific time frame of 4.5 years of an ongoing process that continues to unfold. Further, we did not examine the effect of changes in predictor variables during the 4.5-year period, but, rather, we considered whether prior states predicted subsequent planning and placement outcomes. Third, almost all of our data were provided by mothers. We, therefore, lacked the perspectives of other family members, including fathers, siblings, and, especially, the adult son or daughter with mental retardation.

Finally, although parents' explanations informed our multivariate analyses, the reasons given by parents for planning...
and placement did not always correspond neatly to the results of the quantitative analyses. Parents’ attributions for family decisions are affected by a number of subjective processes, including the need to create a “story” that is consonant with personal beliefs and values. How and why these older parents form post-hoc explanations of their decision-making have important implications for their own well-being and the well-being of their adult children with mental retardation. The juxtaposition of objective and subjective processes in unraveling parental decision-making during the later years of the family life course involves complex theoretical and methodological questions—fertile ground for future research.

References


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