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The Aftermath of Parental Death: Changes in the Context and Quality of Life

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This chapter examines the aftermath of parental death for adults with mental retardation who have lived at home throughout their lives. For many parents of persons with mental retardation, the most difficult issue they face is what will happen to their son or daughter when they are no longer alive or able to provide care. Questions that haunt them include: "Where will my daughter live?" "Who will take care of him?" "How can the quality of her life be maintained?" "Will my other children be able to help their brother (or sister) with everyday life?" These persistent and nagging questions affect parents, other children in the family, the family member with mental retardation, and the service systems in every state.

It has not always been so. As recently as 40 years ago, it was common for persons with mental retardation to predecease their parents. The dramatic increase in the expected life span of the current generation of adults with mental retardation is attributed to advances in medical and human service systems that have extended the quality and quantity of life of persons with mental retardation.
(Carter & Jancar, 1983; Eyman & Bourdette-Duffy, 1994; Thase, 1982). Consequently, many adults with mental retardation can now anticipate several decades of life after their parents have died. Understanding the consequences of parental death with respect to the life circumstances and quality of life of adults with mental retardation is now a topic of considerable importance from both service systems and family policy perspectives (Edgerton, 1994; Heller & Factor, 1991).

Parental death is not an inconsequential event with respect to the service delivery system for persons with mental retardation. It is increasingly recognized that the most common provider of long-term support for persons with mental retardation is the family. Estimates, though imprecise, suggest that close to 85% of the population with mental retardation live with or under the supervision of their families throughout their lives (Fujii & Bradlock, 1992). Acceptance into the publicly financed residential service system is, indeed, rare for the majority of persons with mental retardation. The family, particularly mothers and fathers, is the durable and steady support system for most persons with mental retardation. The family creates and sustains the quality of daily life and is responsible for articulating future care arrangements that will play out when the parents are no longer alive or able to manage day-to-day care (Seltzer & Krauss, 1994).

The twin forces of the increased life span of persons with mental retardation and the prevalence of family-based care well into adulthood emphasize the need to understand what happens to adults with mental retardation when one or both parents die. The published literature on this topic is meager. Little is known about how individuals with mental retardation understand and respond to death, and how best to help them through the bereavement process (Seltzer, 1985). Although it is widely assumed that parental death will be a catalyst for placement into a licensed residential program, there is nothing in the literature that tests the accuracy of that assumption. Indeed, our knowledge of how persons with mental retardation cope emotionally and psychologically with parental death, and how parental death alters their residential, social, legal, and service profile is woefully inadequate.

For adults with mental retardation, the experience of parental death and subsequent grieving is complicated by their particular life experiences, cognitive and verbal skills, and the ability of surviving family members and friends to recognize and attend to their possibly atypical manifestations of grief (Kloeppe1 & Hollins, 1989; Lipe-Goodson & Goebel, 1983; Mandorf & Ben-David, 1986; Wadsworth & Harper, 1991).

Adults with retardation who live at home with their parents are generally much more emotionally and instrumentally dependent on their parents than their nondisabled siblings and peers are. The death of a parent can be profoundly disturbing to all aspects of their lives. If parental death results in a residential relocation for the surviving adult child, it may also trigger a change in day or work programs, disrupt access to familiar friends and family members, and result in service changes (Wadsworth & Harper, 1991). Those with mental retardation are at greater risk for mental health problems due to the lack of support they receive in the grieving process (Wadsworth & Harper, 1991). One study reported that 50% of the clients with mental retardation with sudden emotional or behavioral changes had recently experienced a death or loss (Emerson, 1977).

Thus, parental death is a major life event, often unleashing a host of emotional reactions that are conditioned, in part, by the quality and intensity of the relationship between parent and child. For persons with mental retardation, particularly those who were residing with their parent(s) prior to the mother’s or father’s death, the loss of a parent may also set in motion major alterations in the fundamental structures that determine the adult’s quality of life—where he or she lives, works, or spends the days, and who provides or supervises his or her daily care.

This chapter explores these issues in detail. Since 1988, we have followed 461 families in which the mother was at least 55 years of age and had a son or daughter with mental retardation living at home with her when the study began. Over the past eight years, a parental death has occurred (of either the mother, the father, or both parents) in 66 of these families. The design of our study has permitted us to collect information on the aftermath of parental death and to address a number of research questions. First, what are the living arrangements and levels of family involvement for adults with mental retardation following parental death? Second, what life-style changes occur with regard to day or work program, social activities, and formal services? Third, how is the well-being of the adult with mental retardation affected by parental death with respect to activities of daily living skills, health, and behavior problems?

The next section presents a description of the study and discusses some of the methodological challenges and constraints that affect our research and findings. We then present descriptive data profiling the quality of life of adults who have experienced the loss of a mother, a father, or both. Next we report the results of analyses designed to answer three major questions. We conclude with implications for practice suggested by our results.

**Methods**

All of the 461 families in our study met two criteria when the research began in 1988: The mother was between the ages of 55 and 85 and an adult son or daughter with mental retardation lived at home with her. Our purposes are to examine the later stage of the family life course in families who have atypical caregiving challenges and to describe the natural history of the transition from parental to nonparental care.

We collect data from each family every 18 months. At each point of data collection, the mother is interviewed and completes a set of self-administered measures. We have collected supplemental data from the father at each of the points of data collection. We also have collected data at different times from adult siblings in these families and from the adult with retardation. In some cases, the adult with retardation has moved to a residential placement during the course of the study. In these instances, we collect data from the primary care provider in the residential setting, as well as continuing to interview family members. We treat the family as the unit of analysis for data collection purposes.

In cases in which a mother has died, we turn to the “successor caregiver” and conduct a special interview with him or her. This interview contains all of the questions we ordinarily ask about the son or daughter (e.g., questions about his or her functional abilities, health, behavioral problems, social activities, services, etc.) and questions about the family (e.g., changes in family composition, sources of care for the adult with mental retardation, etc.), as well as special questions about the circum-
CHAPTER 2

stices of the mother’s death, the reaction of the adult to this loss, sources of support in the family and the adult during their time of grief, and changes in living arrangement or services that have resulted from the inevitable reorganiza
tion of the family following the mother’s death. If there is a surviving father, he is the respondent for these interviews. In instances in which the father has died during the course of the study and the mother is still alive, we conduct a paral
el interview with the mother about the father’s death. In cases in which the mother and father have both died, a sibling is interviewed. When there is no surviving family we have turned to a service provider or a friend, who be
comes the primary respondent. Thus, for all 66 adults who have lost either a mother or a father (or both) since our study began, we have a description of their reactions to this loss and their current quality of life. We also have longitudinal data on their functional abilities, health, and behavior problems so we are able to construct comparisons between their situations prior to and after the death of the parent.

An obvious consequence of the data collection strategy of interviewing the primary caregiver is that in some cases, the respondent changes over time. A change in respondent occurs in two types of instances: 1) when the mother has died and the father, sibling, or other care provider becomes the primary respondent, and 2) when the adult with retardation has moved to a nonfamily residential setting and a care provider becomes a respondent in addition to a surviving family member. Our strategy is to interview the persons with the most up-to-date information about the individ
al with retardation. Although we believe this is the best approach (and it is the only approach when the mother has died), it has the limitation of intro
ducing yet another source of variance into an already complicated situation. In the analyses presented in this chapter, which are based on a sample of 132 families (66 families in which a parent has died and 66 randomly selected compari
sion families in which both parents are still alive), a change in reporter occurred in 52 families, either as a result of placement (11 families), death of a parent (15 families), or both (26 families).

In 11 families, the mother in fact is not deceased, but rather has become totally incapacitated, generally as a result of dementia. In these families, the responsibility for caregiving is no longer the mother’s and has clearly shifted to another family member. For the present analysis, we included these families in the same group as those in which a death has occurred because there are minimal differences in the family caregiving arrangements between families in which the mother is deceased and families in which the mother is no longer in the caregiving role (and often in a nursing home) due to dementia.

For this analysis, we are contrasting four subgroups of our sample. Group 1 consists of 35 families in which the father died at some time after Time 1 date collection, but the mother is still alive. Group 2 consists of 12 families in which the father has survived but the mother died (in 9 of the 12 families) or became totally incapacitated (in 3 families) at some point after Time 1. Group 3 consists of 21 families in which both mother and father are deceased (in 13 of the 21 families) or the father is deceased and the mother became inca
cipated (in 8 of the families). In all of the Group 3 families, the mother died or became incapacitated after the Time 1 point of data collection. In 7 of these families the father also died during the study period, but in the remaining 14 families in Group 3, the father died before the study began. Group 4 is a comparison group of families in which both mother and father were still alive at Time 5 data collection. Of the 208 families in our sample who met the criterion for inclusion in Group 4, we randomly selected 66 families—the same number as the families in which a parental death or incapacitation oc
curred (Groups 1, 2, and 3 combined)—to include in this analysis. The character
cistics of the adults with retardation in the four groups, and the characteristics of their mothers and fathers at Time 1, are described below. In some instances, the groups and subgroups are quite small. We report the data nonetheless, with the awareness that these are necessarily preliminary estimates that warrant confirmation in larger-scale studies. Note that in the tables in this chapter, only the differences that were significant are reported.

The timing of the parental death or incapacitation varied considerably (32 at Time 2, 15 at Time 3, 14 at Time 4, and 14 at Time 5). Our purpose in this chapter is to describe the initial reac
tions of the adult following the death of his or her parent(s) and the changes in his or her quality of life in response to this loss. Our primary strategy is to use data from the first point of data collection after the death or incapacitation occurred (which, in this chapter, we term ‘Wave 2’). For many of our analyses, we compare the situation as it was at the beginning of our study (which we term ‘Wave 1’), with the first point of data collection after the death or incapacitation of the parent (i.e., Wave 2). In other analyses, we compare the four groups at Wave 2.

Qualitative Findings

Profiles of Subgroups

Group 1: Father deceased and mother alive. Group 1 consists of 35 families in which the father died after the study began and the mother is alive. The sons (55%) and daughters (45%) in this group were between 21 and 58 years of age when the study began (mean = 33). At that time, they were in excellent or good health (94%); only 6% were consid
ered to be in fair or poor health. Most had moderate (32%) or mild (40%) retardation, 18% are classified as having severe retardation, and no one is classified as having profound retardation in this group. Most of these adults (76%) continued to live at home with their mother at the Wave 2 point of data collection.

When the study began (prior to the death of the father), the mothers of adults in Group 1 averaged 66 years of age (range 55-85). Most were in excellent or good health (92%), although 18% were in fair or poor health. At Wave 1, their husbands were somewhat older (mean = 71 years) and were in poorer health than the wives—only 8% were in excellent or good health and 32% were in fair or poor health.

Although there was considerable variability in this group, a dominant theme was the need for both the adult with retardation and the mother to adapt to the loss of the father. We have found in our past research that the mother is clearly the primary caregiver for the adult with retardation. However, the

1 It is important to note that the amount of time that elapsed between Wave 1 and Wave 2 in this analysis is not constant across all cases. To investigate the possible confounding effects introduced by having Wave 2 be at varying lengths of time after Wave 1, we conducted a series of preliminary analyses in which we controlled for the amount of time between Wave 1 and the death (or incapacitation) and Wave 2. In none of these analyses was either time variable significant, suggesting that the point in time and the duration of the death (or incapacitation) occurred was not related to patterns of shorter-term adaptation and quality of life. Although these preliminary analyses suggest that there is no systematic bias introduced by allowing for variation in the length of time between Wave 1 and Wave 2, it remains a potential limitation in our study. Note that for Group 4, Wave 2 was the fifth point of data collection in all instances.
father plays an important secondary role, providing emotional and instrumental help to the mother (Essex, Seltzer, & Krauss, 1993) that is related to maternal well-being. Thus, even though the primary caregiver remains constant in this group, the family is in flux after the death of the father.

**Group 2: Mother deceased and father alive.** Group 2 consists of 12 families in which the mother died or became incapacitated after the study began and the father is alive. Of these 12 adults, 10 continued to live at home with the father; the other two had moved to a nonfamily living arrangement. The sons (58%) and daughters with retardation (42%) averaged 34 years of age when the study began in 1988 (range 18-51). At that time most were in excellent or good health (83%), but 17% were in fair or poor health. Most were classified as having mild (36%) or moderate (27%) retardation, and the others as having either severe (18%) or profound (18%) retardation.

When the study began, their mothers averaged 67 years of age (range 55-79). Their health status was classified as either excellent or good (67%) or fair or poor (33%). In contrast, their husbands who survived them averaged 68 years of age at the beginning of the study and were in better health—82% in excellent or good health and only 18% in fair health (none classified as poor health). Although this group of families was highly variable, one notable feature was the reciprocity of care exchanged between the adults with retardation and their fathers, who are now in a new role of primary caregiver.

**Group 3: Both parents deceased.** Group 3 consists of 21 families in which the father is deceased and the mother is deceased or totally incapacitated. In all of these families, the death or incapacitation of the mother occurred after the study began. As noted earlier, in 7 of these families, the father also died during the study period, while in the other 14 families in Group 3 the father's death preceded the beginning of the study. The adults with retardation in these families were nearly evenly split between sons (52%) and daughters (48%). Most were in excellent or good health (91%) when the study began, with the remaining 9% in poor or fair health. The majority were classified as having mild (53%) or moderate (37%) retardation, with fewer classified as having severe or profound retardation (5% each).

When the study began, their mothers averaged 70 years of age (range 57-82), the oldest group of mothers in this study. Most were in excellent or good health (62%), but fully 38% were in fair or poor health when the study began. Their husbands averaged 73 years of age (range 67-82), again the oldest group in this study. Their health was similar to their wives at Wave 1—60% in excellent or good health and 40% in fair or poor health. Forecasting their future mortality, the health of these parents at Wave 1 was the most impaired of all parents in the study.

The adults who have lost both parents experienced significant changes in their quality of life, often resulting in a placement in a nonfamily setting (76%). Some of them experienced multiple placements before a satisfactory arrangement was found. In 17 of the 21 families in Group 3, a sibling (8 brothers and 9 sisters) is now responsible for either overseeing the care provided to the brother or sister (in 12 of the families) or providing the direct care (in the 5 cases in which they live together in the same household). In 1 family, a cousin is now the primary person responsible for overseeing the care of the adult, while in another 3 families, this role is filled by a nonfamily guardian.

**Group 4: Both parents alive.** For context purposes, we also include in this analysis a group of 66 families who were randomly selected to represent the families in our study in which both mother and father are still alive at the fifth point of data collection. The sons (58%) and daughters (42%) in these families mainly continued to live with their parents (85%), although 17% have moved to a nonfamily residential setting.

At the beginning of the study, these adults were in excellent or good health (92%), with only 8% in fair or poor health. Like the other groups of adults, they tend to have mild (29%) or moderate (42%) retardation. This group has the highest percentage of those classified as having severe retardation (23%) and another 7% are classified as having profound retardation. At the beginning of the study they averaged 32 years of age (range 15 to 47).

Their mothers averaged 63 years of age (range 55-77) when the study began, the youngest mothers in this study. They were in excellent or good health for the most part (83%), with only 17% in fair or poor health. Their husbands also were young relative to the other groups in the study, averaging 64 years of age when the study began (range 55-77). Their health was also excellent or good (81%) much more often than fair or poor (19%).

**Reactions of Adults with Mental Retardation to Parental Death.**

In our interviews with primary respondents following the death or incapacitation of a parent, we asked them to characterize how the adult with retardation coped with his or her loss. These qualitative data offer insight into the range of reactions of adults with retardation to this life transition.

Although the details of each person's reaction to the death of the mother were highly individualized, several broad patterns were suggested. Some adults were described as able to talk about the mother's death and to express emotion along with other family members. A sister told us, "She did fantastic. She took cues from us. If we cried, she cried. But she bounced back from it."

Others were described as coping well because they relied on their religious beliefs, permitting the use of prayer and attendance at religious services to calm themselves, and adopting explanations of death, such as their mother went to live with the angels or was reunited with other deceased family members. Many were described as having participated in the rituals of death—going to the hospital towards the end of the mother's life, being part of wakes and funeral services, and visiting the cemetery.

Other adults were described as not fully understanding the reality of parental death or as not seeming to comprehend that the mother had died. In several situations, surviving siblings confessed that they were unsure what impact their mother's death has had on their brother or sister with retardation or how aware of the death he or she was.

Only a few were described as being (and remaining) agitated, nervous, and depressed over the death. Several received psychiatric counseling or relied heavily on the outpouring of support from family, friends, or service providers who offered explanations of what death
means. Many were described as having delayed reactions, such as erupting into tears for the first time months after the father's death. Others were described as keeping their father's memory alive by continuing to look at family photographs, reminiscing about pleasant family events, and expressing warm feelings and longing for their deceased father.

Quantitative Findings

**Impact of Parental Death on Quality of Life**

We turn now to our quantitative analyses, which address our three research questions. (a) What are the living arrangements and levels of family involvement for adults with mental retardation following parental death? (b) What lifestyle changes occur after parental death with respect to day or work program, social activities, and family services? (c) How is the well-being of the adult with mental retardation affected by parental death, with respect to health status, activities of daily living (ADLs), instrumental activities of daily living (IADLs), skills, and behavior problems?

**Current Living Arrangements**

We found that there was an elevated likelihood of out-of-home placement following the death or incapacitation of both parents ($F = 12.21, p < .001$). The highest rate of placement is in Group 3, when both parents have died, in which 76% of the adults have moved to a residential placement. Residential placement is considerably less likely when at least one parent is alive. Interestingly, maternal death with a surviving father (Group 2) is less likely to precipitate a placement than paternal death with a surviving mother (Group 1). Specifically, 24% of the adults who experienced the death of their father have been placed even though their mother is still alive. The rate of placement in adults whose mother has died and who have a surviving father is only 17%, which is equivalent to the placement rate in Group 4, the contrast group. Overall, it appears that the death or incapacitation of both parents sharply increases the likelihood of residential placement in comparison to the death of one parent.

Of the 66 adults who experienced the death or incapacitation of a parent, 26 have moved to a nonfamily living arrangement. These adults now live in a variety of settings. Half (13) live in community residences, including group homes, community-based ICFs-MR, and fully staffed apartments. Another 3 adults live in foster homes and one lives in a semindependent apartment (with less than full staff coverage). Two of the adults live in nursing homes, while another 7 live in institutional settings. Of those living in institutions, 5 live in private institutions, 1 lives in a county home, and 1 lives in an institution for persons with mental illness.

In the other 40 families in which there has been a parental death or incapacitation, the adult with retardation still lives with family. In Group 1, all 25 adults who still live with family live with their mother. In Group 2, all 10 adults who still live with family live with their fathers. In Group 3, all 5 adults who still live with family live with their siblings.

Although the majority of adults who have experienced parental death continue to live with their families, the durability of this arrangement is unknown, and the possibility of future residential placement remains. In some instances, the adult's name has been added to a waiting list for residential placement. However, we found no increased likelihood of being on a waiting list among adults who had experienced the death or incapacitation of a parent as compared with the contrast group in which both parents were still alive. Overall, less than one-third of the adults who still lived with family were on a waiting list for residential placement, suggesting the presumption of continued family-based care or, alternatively, the reluctance of surviving family members to address future care planning.

Although there was great variability in the sample with respect to their living arrangements following parental death, these placements were generally guided by the mother's preferences. At the beginning of the study, when all mothers were alive and functioning as the primary caregiver for their adult son or daughter with mental retardation, we asked each mother to indicate her preferences regarding where her adult child would live after she and her husband are no longer able to provide care. Focusing only on the 33 families in which the mother subsequently died or became incapacitated (Groups 2 and 3), we found that in 11 families, the mother's plan was implemented. For example, one mother both named a "successor caregiver" (her daughter) and indicated that she hoped her son with retardation would eventually move to a group home. Following the mother's death, the sister took over responsibility for overseeing her brother's care as planned, and the brother moved to a placement fitting the mother's description. In another 5 of the 33 cases, the mother's plan was partially implemented. For example, a mother named a "successor caregiver" (again, a daughter) and hoped for placement of her child with retardation into an apartment. After the mother's death, the sister did assume responsibility but the adult moved in with the sister, representing a partially implemented plan.

In only 2 of the 33 families was the mother's preference not implemented at all. For example, a mother named her son to be the successor caregiver for her daughter with retardation, and added her daughter's name to a waiting list for a group home. Following the mother's death, the son refused to take responsibility for his sister and cut off all contact with her. A different sibling assumed responsibility for her care and arranged for her to move into an apartment. Thus, neither part of the mother's plan was implemented.

In another 5 families, there was no plan articulated by the mother prior to her death. Finally, in the remaining 10 cases, the father is still alive and residing with the son or daughter, so it is premature to assess whether the plan has been implemented. Thus, in 16 of the 18 families in which a plan for the future care of the adult with retardation could have been implemented, the living arrangement of the adult at Wave 2 is either fully or partially consistent with the mother's prior plan.

To summarize, there is an elevated likelihood of residential placement following the death of both parents. In nearly one-quarter (23.8%) of these families, the adult moved in with his or her sibling. When one parent survives, there is an impressive amount of continuing family involvement with the adult with retardation.

**Continued Family Involvement in Caregiving**

Table 2.1 portrays the sources of direct care provided to the adult with retardation. The entries in the table indicate the average number of tasks (maximum = 27) for which the mother, father, sibling/other relative, or paid helper provided care to the adult with retardation. For any of the 27 tasks (e.g.,
dressing, setting the table, shopping), and multiple sources of help could be counted. For example, if the adult received help in dressing from both the mother and the father, both were "credited" with providing help.

As shown in Table 2.1, at Wave 1 the mother was the primary caregiver in all groups. The highest rate of direct care from the mother was in Group 4, in which both mother and father were alive. The father was in a secondary caregiving role at Wave 1, while the siblings and paid helpers played an incidental role. At Wave 2, the supportive "cast" changed. In the case of Group 1 (in which the father had died between Wave 1 and Wave 2), there was an increase in care provided by siblings and paid helpers, although the absolute magnitude of their help remained very low. In the case of Group 2 (in which the mother had died or became incapacitated between Wave 1 and Wave 2 and the father was still alive), the role of the father increased dramatically (assisting with 5 tasks at Wave 1 and nearly 11 tasks at Wave 2, on average). Also, the contributions of siblings and paid helpers increased, although again the absolute level of their assistance was small. In the case of Group 3 (in which both parents had died or became incapacitated before Wave 2), the siblings' assistance became prominent (increasing from virtually zero contribution to helping with 12 tasks), primarily as a result of co-residence with the adult with mental retardation. Finally, Group 4 provides an estimate of the distribution of caregiving when both parents are alive. Here we see that the number of tasks for which help was given by both mother and father declined, possibly reflecting their aging and increasing frailty. Although siblings did not emerge as important sources of assistance when both parents were still alive, paid helpers made an increasingly large contribution.

Table 2.1 also portrays similar data with respect to adults who were placed in a residential setting between Wave 1 and Wave 2, and we see both similar and distinct patterns. The primary difference concerns the role of paid helpers. Not surprisingly, following the placement, paid helpers were the primary source of direct care assistance to adults with mental retardation, and the role of surviving mothers and fathers, and of siblings diminished considerably.

These data suggest that there is a substitution process governing which family members will provide care to an adult with retardation and when they will be called on to do so. That is, when the mother is alive, she is the primary caregiver. If the mother dies or becomes incapacitated and the adult continues to live in the parental home, the contribution previously made by the mother is taken on by the father. It is only when both parents are deceased that the sibling becomes an important source of direct care, and only in those instances in which the adult lives with a sibling. However, this pattern is markedly different following a placement. At that point, direct care from relatives becomes minimal, and paid staff provide the care. Note, however, that the level of care provided by paid staff at Wave 2 is considerably lower than the level provided by the mother at Wave 1, prior to placement.
probably reflects the fact that some services provided by parents (e.g., transportation, social activities) are not "counted" as discrete services, whereas comparable supports provided in residential programs are viewed as discrete and "countable" services. Interestingly, at Wave 2, among all those who were placed in a nonfamily living arrangement, adults whose mother and father were both deceased (Group 3) received the fewest services. In contrast, among all those who continued to live with family, adults in Group 3 received the largest number of services.

The Well-Being of Adults with Retardation

Adults with retardation who experience the death of their parent may be at increased risk for poor health, decline in ADL/IADL skills, and increased levels of behavior problems. We examined the extent to which each of these indicators of poor quality of life was evident in our sample. As shown in Table 2.4, there was a general decline in the health of the adults in our study, regardless of parental mortality or changes in residential arrangement. These changes may reflect age-related health problems. Note that adults whose parents were alive (Group 4) showed virtually the same pattern of declining health status as adults whose father had died (Group 1), whose mother had died (Group 2), or those who had lost both parents (Group 3).

The pattern with respect to ADL/IADL skills is quite different. In this case, we see evidence that adults whose parents were both alive (Group 4) acquired new skills between Wave 1 and Wave 2, a pattern not evident in any of the other groups. This increase parallels the finding reported earlier that Group 4 adults received less help from parents, siblings, or paid helpers at Wave 2 than at Wave 1. Thus, there was an increase in independence in the adults in Group 4 that might have been prompted by the parents’ age-related declining abilities and decreasing caregiving assistance. Adults in Group 4 who were placed between Wave 1 and Wave 2 showed a particularly marked increase in skills. This increase may be the result of new opportunities for independence provided by the residential setting, coupled with the support of their parents as these adults made the transition from home to a residence. In contrast, adults who had lost a parent showed a pattern of either declining skills or no change between Wave 1 and Wave 2.

Finally, we analyzed data regarding the behavior problems of adults with retardation at Wave 2. Those adults who continued to live with family at Wave 2 had significantly fewer behavior problems than adults who had moved to a nonfamily residential placement ($F = 6.13, p = .015$). There is no difference, however, in the number of behavior problems manifested by those who experienced the death or incapacitation of a parent as compared to those for whom both parents survived. It is possible that a high level of behavior problems is a precipitant rather than a consequence of placement. As no data on behavior problems were available in the Wave 1 data set, it is not possible to fully describe the change process.

Implications for Practice

To conclude, the quality of life of adults with retardation following parental death is dominated by an extraordinary...
nary amount of change. The sadness and loss that is a universal reaction to parental death is magnified in this instance because of the prior dependence of adults with retardation on their parents, for care, for emotional support, and for a shared social world. Little is known about the long-range pattern of adaptation by these adults to the loss of their parents, but in the short term their quality of life is altered pervasively. In addition to these general conclusions, our study points to a number of implications for practice.

From what we have observed to date, living with family over the long term is not the norm once both parents are deceased. Fully three-fourths of the adults who have lost both parents live in a nonfamily residential setting. In contrast, those families in which only one parent has passed away (Groups 1 and 2) have a relatively low rate of residential placement, at least in the immediate or short-term period following parental death.

When the adult continues to live with family, there is a hierarchy of care provision. Responsibility shifts from the mother, who is generally the primary caregiver or overseer for these adults as long as she is able to provide this care, to a surviving father following her death. It is only when neither parent remains alive that this responsibility is taken over by siblings or, if there are no surviving siblings, by a friend or nonrelative.

Indeed, it is rare for there to be no family involvement, and it is only in those cases in which both parents have passed away and there are no surviving siblings that this occurs—in our study, in only 3 instances. Even when the siblings are not geographically in close proximity, they generally still assume and carry through on this responsibility from afar.

This convey of caregiving (from mother to father to sibling) is governed by gender and generational patterns. Although fathers are not in the role of primary caregiver to the adult with retardation while their wives are alive, fathers play an important supportive role that sets the stage for their new responsibilities after the death of their wife. Fathers have long shared their living space with their son or daughter. The low rate of placement of adults who have a surviving father may suggest that it is easier for fathers to move into the role of primary caregiver than to adjust to the empty nest resulting from placement. Placement may also be a reminder of the father's own mortality and the reality that the adult child will eventually be parentless. Regardless of what causes this pattern, it is clear that fathers are flexible in taking on new caregiving roles.

In those families in which there are no surviving parents, siblings also exhibit great flexibility in taking over responsibility. In five families, a sibling has invited the brother or sister with retardation to live with him or her, while in the other families with no surviving parents, the siblings have taken on the roles of guardian and advocate, and include the brother or sister in outings and family gatherings. In some cases, the siblings said they felt obligated to take on this responsibility, while others reported that they did so willingly. In every family with nonsibling siblings, there is some sibling involvement, and for families with multiple siblings, there generally is regular contact with more than one of them.

A second implication for practice concerns life-style changes that follow the death of a parent. We found that life for those adults who are living with at least one parent is fairly stable. However, for those who have experienced the loss of their last surviving parent, which generally leads to a move outside of the parental home and inevitably to a change in caregiver, and for those who have lost one parent and subsequently moved to a residential placement, the world these adults have known all of their lives is turned upside down. For most, there is a change in residence, day or work program, and social life.

Social activities also undergo profound changes associated with parental death. Interestingly, the most frequent contact with relatives occurs in those families in which the father has died and the adult is still living with the mother, even more frequent than in families in which there are two surviving parents. It may be that widowed mothers act as kinkeepers and encourage family involvement by creating occasions for their son or daughter to be with relatives. It also may be that widowed mothers are seen by family members as particularly vulnerable and they rally around her, with consequent increased contact with her son or daughter.

Participation in group recreational activities increases following residential placement. As parents age, arranging for their son or daughter to attend nonfamily social activities may become increasingly difficult and less a priority. Providing transportation to these social activities, particularly those that take place in the evening or during inclement weather, may be difficult for older parents. It may also be that adults who live with family are content to spend time at home and are less interested in participating in group recreational activities than those who live in residential placements (Krausz, Seltzer, & Goodman, 1992). At times, participation in group recreational activities may reflect plans made by the residential setting staff and may not be indicative of the preferences of an
CHAPTER 2

individual. Thus, a lower rate of participation in group recreational activities by adults who continue to live with family should not necessarily be interpreted as social isolation.

The number of services received by these adults is affected by the loss of the parent as well as placement in a nonfamily setting. For those who continue to live with family, it is only those adults who have a change in primary caregiver who experience an increase in the number of services following parental death. The largest increase comes when the adult moves in with a sibling. It may be that these siblings perceive that their brother or sister with retardation needs more services than he or she received when the parents were alive. It may also be that competing commitments do not allow these siblings to provide the same level of care to their brother or sister that their parents did; consequently, these siblings may be relying on the service system to make up the difference.

All in all, we see evidence of a ripple effect of lifestyle changes occurring after parental death, particularly when there is also a placement. Little in the adult's life remains the same. There is an increased risk of change in where he or she lives, where he or she works or spends the daytime hours, the pattern of contact with friends and family, the context in which social activities take place, and the services that he or she receives. It is difficult to separate out the effect of parental death from the effect of placement here. However, it is noteworthy that the least amount of disruption in lifestyle following placement is found in families in which both parents are still alive but no longer living with their child or daughter. The comparative stability of the lives of these adults following placement as contrasted with the lives of adults who have lost a parent suggests the desirability of advance planning on the part of families and the benefits of placement prior to parental death.

The difficulty of the transition to nonparental care is also evident in the well-being of adults after the death of a parent. We found that health declined in all four groups over time, but was not related to either placement or parental death. Although the adults we studied are in their mid-thirties or older, there is evidence of declining health even at this stage of life. This pattern of decline is the backdrop for all other changes in personal well-being that may be associated with parental death.

In contrast to the pattern of declining health evident for all groups regardless of parental death or change in residential arrangements, there is a more varied pattern of change over time in ADL/IADL skills. For adults who have not experienced parental death, there is evidence of skill acquisition from Wave 1 to Wave 2. Although the increase in skills is marginal when the adult continues to live with parents, it is quite substantial following placement into a residential setting.

The pattern is sharply different when the adult has lost one or both parents. For adults who have a surviving mother, we found a very modest increase in ADL/IADL skills over time regardless of residential status. For adults who do not have a surviving mother, however, there is a decline in skills over time, again regardless of residential status. When an adult has experienced the death of either parent, he or she tends not to gain new skills after placement, as is generally the case when both parents were alive and available to smooth the transition and continue to provide support.

There is no doubt that these adults experience grief at the loss of their parents and find the transition to nonparental care to be a rocky road. Many respondents expressed great admiration for the way in which the adult with retardation in their family had handled all of these changes and losses. It is not without assistance that this pattern of individual and family adaptation occurs. Supportive extended family members and a variety of professionals, including clergy, social workers, service providers, and psychologists, have all been identified as assisting these adults in understanding what has happened and adjusting to their new lives. Whereas for adults in the general population the death of a parent is softened by the existence of spouse, children, and a lifestyle independent of their parents, for adults with retardation the centrality of their parents does not diminish until parental death. It is only then that they are put in a position of adapting to their lives as separate from their parents and are exposed to aspects of life from which they were previously shielded.

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