Siblings of Adults With Mental Retardation or Mental Illness: Effects on Lifestyle and Psychological Well-Being*


Siblings of adults with mental retardation were contrasted with siblings of adults with serious mental illness with respect to (1) the pervasiveness of the impact of the brother or sister on the sibling's life, (2) the closeness of their current relationship and frequency of contact with the brother or sister with the disability, and (3) the factors related to the sibling's level of psychological well-being. It was found that siblings of adults with mental retardation were significantly more likely than siblings of adults with mental illness to perceive that the brother or sister had a pervasive influence on their life decisions and to evaluate their sibling experience as mostly positive. In addition, siblings of adults with mental retardation had a closer relationship with the brother or sister with the disability than siblings of adults with serious mental illness. Finally, siblings of adults with mental retardation had better psychological well-being when they had a close relationship with the brother or sister. In contrast, siblings of adults with serious mental illness had more favorable psychological well-being when they perceived a less pervasive impact of the brother or sister on their life. Implications for future research and service delivery are discussed.

There is increasing public recognition that families are the primary source of support for persons with long-term disabilities such as mental retardation and serious mental illness (Francell, Conn, & Gray, 1988; Hatfield & Leffey, 1987; Leffey, 1996; Seltzer & Krauss, 1989). Although the literature on the circumstances of parents who provide lifelong care to a family member with a disability is growing (Cook & Pickett, 1987; Fisher, Benson, & Tessier, 1990; Heller & Factor, 1991, 1993; Leffey, 1987; Seltzer & Krauss, 1994), much less is known about the consequences for adult siblings in these families. With the realization that parental care will ultimately end when the parents die or become incapacitated, it is critical to gain an understanding of the potential role of siblings as the next generation of caregivers.

Research on the adult sibling relationship when neither sibling has a disability has demonstrated the unique position occupied by siblings among the range of family relationships. Adult sibling relationships are longer in duration than any other kinship tie (Cicirelli, 1982), are based on a common family life space (Ross & Dalton, 1981), and are egalitarian (Avioli, 1989). These relationships tend to be characterized by supportiveness, concern, and mutual affection (Cicirelli, 1982), although these patterns are affected by gender (Rosenberg, 1982), social class (Brady & Noberini, 1987), and stage of life (Goetting, 1986).

There are few systematic investigations of the nature of the relationships between adult siblings when one sibling has a disability, or of the implications of sibling relationships for future caregiving options (Horwitz, 1993a, 1993b; Krauss, Seltzer, Gordon, & Friedman, 1996; Reinhard & Horwitz, 1995; Ribeschi, 1991; Seltzer, Begun, Seltzer, & Krauss, 1991). The available research literature and personal testimonies reveal extremely complex and multifaceted sibling relationships and experiences, which vary across different stages of the life course, and which are colored to a large extent by the milieu of the family (Griffiths & Unger, 1994; Horwitz, Tessier, Fisher, & Gamache, 1992; Stoneman & Berman, 1993). It is also evident that the quality of the relationship between a sibling and his or her brother or sister with a disability is influenced substantially by the meanings attributed by the family regarding the nature of the disability, the reactions of parents to the challenges of the disability, and overall patterns of family adaptation (Begun, 1989; Johnson, 1988; Swados, 1991; Zeitlin, 1986).

The present paper examines differences and similarities between siblings of adults with serious mental illness and siblings of adults with mental retardation with respect to both the context and qualities of the current sibling relationship and factors related to the psychological well-being of the non-disabled sibling. In so doing, the analysis aims to shed light on a more basic question, namely the extent to which the type of disability (i.e., serious mental illness vs. mental retardation) differentiates the experience of siblings or, alternatively, whether the primary fact of having a brother or sister with a disability exerts a common influence, regardless of the type of disability. We hypothesize that the type of disability, indeed, matters. This hypothesis is based on results from our previous research on mothers of adults with mental illness or mental retardation (Greenberg, Seltzer, & Greenley, 1993; Seltzer, Greenberg, & Krauss, 1995; Seltzer, Greenberg, Krauss, & Hong, 1997) and from analysis of the contextual differences of the sibling experience based on whether the brother or sister has mental retardation or mental illness.

There are three central contextual differences in the family experiences of adult siblings of persons with serious mental illness as compared with adult siblings of persons with mental retardation: the timing of the diagnosis in the family life course, the predictability of the course of the disability, and the level of societal stigma and support for the disability.

First, the diagnosis of mental retardation generally occurs at a substantially earlier point in the family life course than serious mental illness. Specifically, persons with mental retardation are typically diagnosed at birth or in the early childhood period. Consequently, most siblings of persons with mental retardation have always known their brother or sister to have significant disabili-

---

*An earlier version of this paper was presented at the Invitational Roundtable on Research Advances in Later Life Family Caregiving of Adults with Disabilities, June 27-28, 1996, Chicago, Illinois. Support for the preparation of this paper was provided by the Joseph P. Kennedy, Jr. Foundation, the National Institute on Aging (ROI AG8768), the National Institute on Mental Health (RO3 66564), the Wasman Center at the University of Wisconsin-Madison, the Mental Health Research Center at the University of Wisconsin-Madison, and the Starr Center on Mental Retardation at Heller School, Brandeis University and by the Rehabilitation Research and Training Center at the University of Illinois Chicago, through a grant from the National Institute on Disability and Rehabilitation Research (H133E00069).

**Address correspondence to: Marsha Mailick Seltzer, University of Wisconsin-Madison, Wasman Center, 1500 Highland Avenue, Madison, WI 53705.

Key Words: caregiving, disability, intergenerational relations, mental illness, mental retardation, siblings.

(Family Relations, 1997, 46, 395-405)
ties. Their formative years included the satisfactions and difficulties of living with a visible "difference in the family" (Featherstone, 1980), and many siblings, especially sisters, were thrust into positions of surrogate parenting (Stoneman, Brody, Davis, & Crapps, 1987; Wilson, Blacher, & Baker, 1989). Siblings of persons with mental retardation, therefore, generally have atypical sibling relationships which are less egalitarian than typical sibling relationships, and in which parental expectations for sibling caregiving may have been explicit since early childhood (Begun, 1989).

In contrast, serious mental illness is more commonly diagnosed during late adolescence or early adulthood. Siblings of adults with mental illness generally spent their childhood and adolescence more or less unaware of the looming mental illness and, hence, were more likely to have established normative expectations of the sibling relationship (Judge, 1994). Granted, the eventual diagnosis of mental illness, in retrospect, may help to explain past troubled periods, but the prevailing family environment during the sibling's childhood generally is less focused on the prospect of disability than on the maintenance of normative family relationships.

Second, the course of mental retardation is distinctly different from the course of serious mental illness. Mental retardation is characterized by stability in day-to-day functioning (Eyman & Widaman, 1987), even if it is at a compromised level. The sibling's familiarity with the capabilities and needs of a brother or sister with mental retardation may help to sustain a predictable relationship between them. In contrast, persons with serious mental illness are subject to episodic crises that may undermine the stability of the family and the household (Beech, Kohler, Pickett, & Cook, in press). Even for adult siblings who no longer co-reside with their brother or sister, the lack of surety in what can be expected from the brother or sister with mental illness in everyday life can jeopardize the maintenance of satisfactory sibling relationships. Thus, the course of the disability differentiates the sibling experience of those whose brother or sister has serious mental illness and those whose brother or sister has mental retardation.

Third, the level of societal acceptance of mental retardation is remarkably different from the stigma of serious mental illness. Persons with mental retardation are more compassionately accepted in society than are persons with mental illness. This difference is reflected in many ways, not the least of which is the level of public services and supports available to them. Although persons with mental retardation vary in the extent to which their service needs are adequately met, in general they have access to a differentiated array of publicly-funded supports and services (Braddock, Hemp, Bachelader, & Fujita, 1995), including residential, day, therapeutic, respite, and social services. Persons with serious mental illness have far fewer services to utilize, are at a much greater risk of having no services available, and even to be homeless than those with mental retardation (Rossi, Wright, Fisher, & Willis, 1987). For siblings, the differential societal support and availability of services may have substantial implications for current and future caregiving roles, particularly following the death of their parents. Specifically, siblings of persons with mental retardation can envision assuming responsibility for their brother or sister in partnership with a fairly well-articulated system of services. Siblings of persons with mental illness, however, must realistically assume that they will have to manage more or less alone in the context of a much more fragmented system of services.

Although siblings of adults with mental retardation and siblings of adults with serious mental illness face distinct challenges arising from these differences in the caregiving context, there are also similarities between the two groups. Both groups of siblings face the certain future death of their parents, which may place at least one sibling in the family in a position of assuming responsibility for the brother or sister with the disability (Gordon, Seltzer, & Krauss, 1996; Horwitz, 1993a). Both groups of siblings face the prospect of integrating the needs of the brother or sister with the constraints and demands of their own lifestyles and responsibilities, which may well be considerable (Krauss et al., 1996). Both groups of siblings fear the possibility of transmission of the disability to their own offspring (Harris, 1988; Judge, 1994; Marsh, 1992). Thus, the range of effects on the nondisabled sibling may be substantial in both groups, although the intensity or valence attributed to these effects may differ as a result of the nature of the disability.

Based on these contextual differences and similarities, we posed three research questions. Our first inquiry was into the extent to which the two groups of siblings differ in their perceptions of how pervasively their brother or sister with the disability has affected their adult life. We also examined whether the experience of having a sibling with a disability has been mostly positive or mostly negative. We hypothesized that siblings of adults with mental retardation would report that more areas of their life have been affected by their brother or sister's disability than siblings of adults with serious mental illness. We base this hypothesis on the difference in the stage of the sibling's life course when the brother or sister's disability was diagnosed. With the earlier onset of mental retardation, siblings learn from childhood that major life decisions are made in the context of having a family member with a disability. In contrast, the timing of serious mental illness occurs much later in the sibling's development, typically at a time when many siblings have begun to establish independence from their family. Thus, siblings of adults with serious mental illness may be less likely to be exposed to the effects of disability during their formative years than siblings of adults with mental retardation.

Although we expected that the brother or sister with the disability would have a more pervasive impact on life decisions in siblings of adults with mental retardation, we hypothesized that siblings of adults with serious mental illness would report more negative appraisals of the sibling experience. Research findings and personal accounts written by siblings of adults with mental illness document the burdens they experience, including disruptions in family and social relationships, grief over the loss of the brother or sister they once knew, and feelings of shame or stigma (Johnson, 1988; Marsh, Appleby, Dickens, Owens, & Young, 1993; Marsh, Dickens, Koeske, Yachovich, Wilson, Leichtler, & McQuillis, 1994; Moorman, 1992). In contrast, the stability of mental retardation and its more limited degree of disruption of family life is expected to result in a considerably less negative set of effects on the sibling experience (Stoneman & Brody, 1993).

Our second research question asked, "what are the differences between siblings of adults with mental retardation and siblings of adults with serious mental illness with respect to frequency of contact and closeness of the relationship with the brother or sister with the disability?" Regarding frequency of contact, personal accounts by siblings of persons with mental illness indicate that many cope with feelings of pain, sadness, loss, and stigma that are associated with mental illness by distancing themselves.
from the family, especially in the early stages of the illness (Johnson, 1988; Moorman, 1992). Grace, Camilleri, and Ayres (1993) found that approximately one third of the siblings of adults with mental illness in their sample coped by cutting off contact with their family, and another 20% limited their involvement to crisis situations. Nevertheless, some degree of contact tends to be common, as reported by Horwitz (1993b), who found that the majority of siblings in his sample saw the brother or sister with serious mental illness about once a month, and another quarter reported weekly contact.

In contrast, most studies of contact between adults and their brother or sister with retardation reveal a high level of in-person and telephone contact, often supported by parental involvement with the sibling (Griffiths & Unger, 1994; Seltzer, Begun, Seltzer, & Krauss, 1991). Thus, we hypothesized that those siblings whose brother or sister has a serious mental illness would have less contact with their brother or sister than siblings of adults with mental retardation.

Although Horwitz (1993b) found that the majority of siblings of adults with serious mental illness felt somewhat close to their ill brother or sister, Pruchno, Patrick, and Burant (1996) reported that siblings of adults with developmental disabilities have more positive affective relationships with their brother or sister than siblings of adults with schizophrenia. Siblings of adults with mental illness face a greater challenge in maintaining close relationships because of the difficulties in interpersonal communication that are associated with the symptoms of serious mental illness. Also, we expect that siblings may attempt to place some emotional distance between themselves and their brother or sister with mental illness to minimize the negative effects on their lives, this restriction, in turn, will limit the degree of closeness in the sibling relationship. The available evidence about the level of emotional closeness in adult sibling pairs when one has mental retardation suggests that positive sentiment persists into adulthood (Begun, 1989; Pruchno et al., 1996). Therefore, we hypothesized that siblings of adults with serious mental illness will report less closeness in the current relationship than siblings of adults with mental retardation.

Our third research question asked, "what are the predictors of psychological well-being in siblings of adults with mental retardation and siblings of adults with mental illness?" For this research question, we hypothesized that three aspects of the sibling relationship would be critical to the psychological well-being of the sibling: (1) his or her feelings of emotional closeness to the brother or sister with the disability, (2) the sibling's perception of the pervasiveness of the effects on his or her own life of having a brother or sister with a disability, and (3) the sibling's appraisal of whether having a brother or sister with a disability has been a mostly positive or mostly negative experience.

For the sample of siblings of adults with mental retardation, it is expected that having a close relationship with the brother or sister will be a positive predictor of the sibling's psychological well-being, as such a relationship will contribute to the non-disabled sibling's feeling of being valued and having a purpose in life. In addition, the timing of the diagnosis of mental retardation in the sibling's life course contributes to the likelihood that the closeness of the relationship will be predictive of psychological well-being. That is, as most siblings in our sample were children when the brother or sister was diagnosed, their early psychological development and identity formation were inextricably linked with having a brother or sister with retardation (Gamble & Woulbroun, 1993). It is likely that the non-disabled sibling's psychological well-being remains vulnerable to variation in the quality of the sibling relationship, even into adulthood. We hypothesized, therefore, that siblings of adults with mental retardation who experience greater closeness in the relationship with their brother or sister would report higher levels of psychological well-being.

A different pattern was expected for siblings of adults with serious mental illness. The benefits of having a close relationship may be counterbalanced by the costs incurred in trying to maintain a close relationship with a brother or sister with mental illness. These costs are many and range from feelings of helplessness because there is little one can do to alleviate the suffering of a loved one, to living with high degrees of uncertainty because of the unpredictable nature of mental illness (Wasow, 1995). Thus, we hypothesized that for siblings of adults with serious mental illness, the closeness of the relationship would be unrelated to the sibling's level of psychological well-being.

For both groups of siblings, we further expected that the pervasiveness of the effect of the brother or sister with disabilities on the sibling's life would influence the sibling's level of psychological well-being. However, it was our expectation that the direction of this influence would depend on whether the sibling evaluated the experience of having a brother or sister with a disability as mostly positive or mostly negative. We hypothesized that if the sibling viewed this experience as mostly positive, perceiving more pervasive effects of the brother or sister would magnify the positive effect on the sibling's psychological well-being. However, if the sibling viewed the experience as mostly negative, perceiving more pervasive effects would predict yet poorer well-being in the sibling.

Method

Sample

This analysis is based on two related longitudinal studies of aging families with adult children with disabilities. In both studies, families met two criteria to participate: the mother was age 55 or older when recruited for the study, and the son or daughter with disabilities was living at home with her at the first point of data collection. Data are collected from multiple family members, including siblings who are the primary respondents for this analysis. Data from the siblings of adults with mental retardation were collected at the third point of data collection of an eight-wave longitudinal study, while data from the siblings of adults with serious mental illness were collected at the second point of data collection of that study.

When the siblings were surveyed, most of the adults with the disability lived at home with their parents (87.5% of the adults with mental retardation and 62.3% of the adults with mental illness). Another 5.8% of the siblings of adults with mental retardation and two siblings of an adult with mental illness lived in the parents' household (along with the brother or sister with the disability) at that point of data collection. All of the families of adults with mental illness lived in Wisconsin. Half of the families of adults with mental retardation lived in Wisconsin, and the other half lived in Massachusetts.

All of the adults with mental illness had been diagnosed as having a serious mental illness, including schizophrenia (72%),
bipolar disorders (17%), major depression (9%), or other psychiatric diagnoses (2%). According to agency records, most of the adults with mental retardation had mild (38%) or moderate (41%) retardation, and the remaining 21% had severe or profound retardation. More than one-third (40%) had Down syndrome.

The two samples of siblings were selected using the following procedures. Siblings of adults with mental retardation were identified by their mother, who was asked to indicate which of her other adult children was most involved with the adult child with mental retardation. Of the 431 families in our sample when the sibling study was conducted, 102 did not participate in the sibling study. Of the nonparticipants, 31 of the mothers had no other children, 47 declined to name one of their adult children, and 24 siblings declined to participate. Of the 329 participating siblings, the sibling was the only other child in addition to the brother or sister with mental retardation in 76 of the families. In the other 253 families in which a sibling participated, we selected the sibling whom the mother designated as being the most involved with the brother or sister with mental retardation. The 329 participating siblings represented 82% of the eligible 400 families.

All siblings of adults with serious mental illness were invited to participate in our sibling study. Of the 96 families who were participating in the study when the sibling survey was conducted, 35 families did not participate. Of the nonparticipants, 6 families had no other children. 2 had only other children who had mental illness, in 15 families the mother declined to have her adult children contacted, and in 12 families the sibling declined to participate. Of the 61 participating families, in 9 families the sibling was the only other child in addition to the adult with mental illness. In the other 52 families, the mother identified which sibling was the most involved with the brother or sister with mental illness. The sample for this analysis consisted of 61 siblings of adults with serious mental illness (69% of eligible families).

In Table 1, the characteristics of the two groups of siblings are contrasted. As shown in the table, the two groups of siblings share many characteristics. Both groups are members of a family with disabilities. There is no significant difference between the groups in their education level (about 80% of both groups have some education beyond high school), employment status (over 85% of the siblings in both groups are employed), and household income (which approaches $40,000 per year in both groups). Both groups were predominantly White (98% for siblings of adults with mental retardation and 88.5% for siblings of adults with mental illness), although the small sample of siblings who were persons of color precluded statistical analysis of differences by race.

Data Collection Procedures and Measures
A self-administered questionnaire was mailed to all participating siblings. Although the questionnaire designed for siblings of adults with mental retardation differed somewhat from the version used for siblings of adults with mental illness, both questionnaires included identical questions on demographic information, recollections of the sibling relationship and family dynamics during the sibling’s childhood and adolescence, assessments of the current relationship with the brother or sister with the disability, and projections about future plans for caring for the brother or sister after the parents are no longer the primary caregivers. In addition, a group of siblings completed several standardized measures of well-being.

Among the background variables used for this analysis were age (in years), gender of the sibling (1 = female, 0 = male), marital status (1 = married, 0 = not married), parental status (1 = has children, 0 = does not have children), employment status (1 = employed full or part time, 0 = not employed), level of education (1 = high school graduate, 2 = vocational school or some years of college, 3 = college graduate, 4 = graduate school), and household income (in dollars). The distance between the sibling’s home and the home of the brother or sister with the disability was either one hour or less (coded 1) or more than one hour (coded 2). Frequency of contact between the siblings by telephone or in person was coded as 1 = several times a year or less, 2 = several times per month, or 3 = weekly or more often. The number of behavior problems of the adult with disabilities was a count of up to 8 maladaptive behaviors manifested by the adult (Bruninks, Hill, Weatherman, & Woodcock, 1986). The behavior problems were assessed by the mothers and included behavior that is harmful to self, withdrawn or indifferent, destructive to others, destructive to property, disruptive, unusual or repetitive, socially offensive, and uncooperative. Adults with mental retardation averaged 1.72 behavior problems, and the average for adults with serious mental illness was 2.87.

The closeness of the current sibling relationship was measured by the Positive Affect Index (Bengtson & Black, 1973). In this 10-item scale, the first 5 items assess the level of understanding, trust, fairness, respect, and affection that the sibling feels toward the brother or sister with the disability, while the next 5 items assess the sibling’s perception of the extent to which the brother or sister with the disability feels that the sibling is understanding, trusting, fair, respectful, and affectionate toward him or her. Each item is rated on a 6-point scale, with higher scores indicating better relationship quality. In our sample of siblings of adults with mental retardation, scores range from 20 to 60 (alpha = .92). In our sample of siblings of adults with serious mental illness, scores range from 17 to 60 (alpha = .92).
Table 2
Means, Standard Deviations, and Intercorrelations of Variables Included in the Multivariate Analysis*

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>39.330</td>
<td>14.794</td>
</tr>
<tr>
<td>2. Gender</td>
<td>−0.03</td>
<td>0.05</td>
<td>0.03</td>
<td>0.09</td>
<td>0.11</td>
<td>0.08</td>
<td>0.10</td>
<td>0.66</td>
<td>0.47</td>
<td></td>
</tr>
<tr>
<td>3. Marital status</td>
<td>0.48</td>
<td>0.07</td>
<td>0.06</td>
<td>0.04</td>
<td>0.08</td>
<td>0.00</td>
<td>0.27</td>
<td>0.78</td>
<td>0.41</td>
<td></td>
</tr>
<tr>
<td>4. Behavior problems</td>
<td>0.08</td>
<td>0.11</td>
<td>−0.18</td>
<td>−0.16</td>
<td>−0.07</td>
<td>0.01</td>
<td>0.01</td>
<td>0.17</td>
<td>1.72</td>
<td>1.24</td>
</tr>
<tr>
<td>5. Closeness of relationship</td>
<td>−0.08</td>
<td>0.20</td>
<td>−0.12</td>
<td>−0.22</td>
<td>0.07</td>
<td>−0.42</td>
<td>0.20</td>
<td>47.18</td>
<td>8.47</td>
<td></td>
</tr>
<tr>
<td>6. Number of эффект on life</td>
<td>−26</td>
<td>0.00</td>
<td>−26</td>
<td>0.00</td>
<td>−0.04</td>
<td>−0.03</td>
<td>4.41</td>
<td>2.57</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Experience mostly positive/negative</td>
<td>−12</td>
<td>−17</td>
<td>−0.24</td>
<td>0.08</td>
<td>−0.38</td>
<td>0.23</td>
<td>142.82</td>
<td>20.68</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Psychological- social well-being</td>
<td>30</td>
<td>0.16</td>
<td>0.19</td>
<td>−0.24</td>
<td>0.08</td>
<td>−0.38</td>
<td>0.23</td>
<td>142.82</td>
<td>20.68</td>
<td>142.82</td>
</tr>
<tr>
<td>Mean</td>
<td>38,178</td>
<td>0.54</td>
<td>0.59</td>
<td>2.87</td>
<td>3.61</td>
<td>2.64</td>
<td>0.47</td>
<td>139.40</td>
<td></td>
<td>22.49</td>
</tr>
<tr>
<td>Standard deviation</td>
<td>16,194</td>
<td>0.50</td>
<td>0.50</td>
<td>1.93</td>
<td>9.31</td>
<td>2.44</td>
<td>0.50</td>
<td>22.49</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Coefficients in the upper diagonal are based on data from siblings of adults with mental retardation, while the lower diagonal presents coefficients based on data from siblings of adults with mental illness. Coefficients greater than or equal to ±0.10 for the MR samples are significant at the .05 level. Coefficients greater than or equal to ±0.18 for the MI sample are significant at the .10 level.

Siblings were asked to rate the extent to which the brother or sister with the disability had an effect on 11 domains of their life on a 4-point scale (not at all affected, not very affected, somewhat affected, strongly affected). For this analysis, the scale for each life domain was recoded as 0 = not at all or not very affected and 1 = somewhat or strongly affected. The 11 domains were: career choice, where to live, whether to have children, religious beliefs, feelings about self, choice of romantic relationships, relationship with spouse (if married), relationship with children (if a parent), plans for own future, political views, and feelings about people with disabilities. In addition to the ratings, a count of the number of areas of life that were either somewhat or strongly affected by the brother or sister with disabilities was computed. Qualitative data were also collected about how the brother or sister with the disability affected these aspects of life. Siblings rated their overall assessment of the sibling experience as either mostly positive (coded 1) or mostly negative (coded 0).

Ryff's (1989) measure of psychological well-being consists of 6 dimensions: environmental mastery, self-acceptance, purpose in life, autonomy, positive relations with others, and personal growth. Each dimension includes 5 items rated on a 6-point scale, with higher scores indicating more positive well-being. The total score consisted of the sum of all 30 items (Ryff & Keyes, 1995). For the sample of siblings of adults with mental retardation, the scores ranged from 78 to 180 (alpha = .91), and for the sample of siblings of adults with serious mental illness, the scores ranged from 82 to 179 (alpha = .94). There was no statistically significant difference in psychological well-being between siblings of adults with mental retardation and siblings of adults with serious mental illness (means = 142.95 vs. 139.40, respectively).

Plan for Data Analysis

Our first research question utilized descriptive data to examine differences between the two groups of siblings in the effects of and experiences of having a brother or sister with a disability. Contingency tables with chi square tests of statistical significance were analyzed to test for an association between group membership and each of 11 domains of life affected and whether the experience was mostly positive or mostly negative. In addition to these quantitative analyses, qualitative comments about how the brother’s or sister’s disability had affected their lives were analyzed. All of the responses were independently read by the first two authors. Next, they selected quotes representative of the comments written by the siblings in each of the 11 domains in which their lives had been affected. In this manuscript, we only report qualitative data for those domains for which the two groups of siblings differed significantly.

Our second research question investigated differences between the groups in patterns of contact and closeness with their brother or sister with disabilities. Contingency tables with chi square tests were analyzed to test for the relation between group membership and the three categorical measures of contact (proximity, frequency of telephone contact, and frequency of in-person contact). T-tests were used to examine differences in closeness between the two groups. Note that the siblings who co-resided with the brother or sister with the disability were omitted from analyses of proximity and frequency of contact but were retained for analyses of closeness.

For our third research question on the predictors of psychological well-being in siblings, multiple regression analysis was used. For this multivariate analysis, it was necessary to be parsimonious in the selection of predictors because of the small size of the sample of siblings of adults with serious mental illness. Therefore, preliminary exploratory analyses were conducted to select variables for the multivariate model. Only predictors that were correlated significantly with psychological well-being on the bivariate level were included. Separate regression analyses were conducted for siblings of adults with mental retardation and siblings of adults with mental illness. A correlation matrix of the variables used in the regression analysis is presented in Table 2. The upper diagonal presents correlations for siblings of adults with mental retardation, while the lower diagonal presents the correlations for siblings of adults with mental illness.

The structure of the regression analysis was as follows. First, four background variables were entered as control variables (the income, gender, and marital status of the sibling, and the number of behavior problems of the brother or sister), followed by three indicators of the sibling experience—closeness of the sibling relationship, the number of areas of the sibling’s life perceived to be strongly or somewhat affected by the brother or sister with the disability, and the assessment of whether the sibling experience was mostly positive or mostly negative. Finally, we examine one interaction effect, namely the interaction of the number of effects variable and the mostly positive/mostly negative variable.

In conducting the multivariate analyses for siblings of adults with mental retardation, the alpha level was set at p < .05. However, for the sample of siblings of adults with serious mental illness, results significant at the p < .10 level are reported because of the substantially smaller sample size.

1997, Vol. 46, No. 4

399
Findings

Effects on Life

The first research question examined differences in the sibling’s perception of the extent to which the brother or sister with a disability affected critical decisions and domains in their life, either positively or negatively. Consistent with our hypothesis, siblings of adults with mental retardation perceived that their life had been more strongly affected by having a brother or sister with a disability than did siblings of adults with serious mental illness (see Table 3). For five of the eleven domains, a significantly higher proportion of siblings of adults with mental retardation felt strongly or somewhat affected by the brother or sister than siblings of adults with mental illness. These affected areas were: career choice, whether to have children, choice of romantic relationships, plans for their future, and feelings about people with disabilities. There was no domain in which siblings of adults with serious mental illness were more likely than siblings of adults with mental retardation to feel that they were strongly affected by having a brother or sister with disabilities.

One explanation for this more pervasive pattern of perceived influence on the lives of siblings of adults with mental retardation is the age of the sibling when the brother or sister was first diagnosed as having a disability. Most siblings of adults with mental retardation have only known their brother or sister as having a significant disability. However, for nearly three-fourths of the siblings of the adults with serious mental illness (71.2%), the brother or sister was diagnosed after the sibling reached adulthood. Thus, most siblings of adults with mental illness were more firmly established in their life domains prior to the onset of their brother or sister’s disability. To determine the validity of this explanation, we re-examined the pattern of effects, but only in those siblings of adults with mental illness who were age 18 or younger when their brother or sister was diagnosed. Consistent with this stage-of-life interpretation, the responses of these siblings were very similar to those of siblings of adults with mental retardation (data not shown). None of the life domains showed a significant difference between siblings of adults with mental retardation and siblings of adults with serious mental illness whose brother or sister was diagnosed prior to the 19th birthday of the sibling. Thus, the difference between the two groups of siblings in the number of life domains perceived to have been affected by their brother or sister with the disability is likely a function of the level of the sibling’s exposure to the disability during his or her formative years.

Our qualitative data are instructive here to aid in the understanding of the nature of the effect that the brother or sister with the disability had on the life of the sibling. As shown in Table 4, in general, there was a considerably more negative valence to the explanations given by siblings of adults with serious mental illness as to how the brother or sister has affected these domains of life than in the explanations given by siblings of adults with mental retardation.

Lastly, siblings were asked to reflect on the overall experience of having a brother or sister with a disability and to evaluate whether it has been mostly positive or mostly negative. Consistent with our hypothesis, the vast majority of siblings of adults with mental retardation reported that the disability has had mostly negative consequences for their lives.
with mental retardation felt that the experience of having a brother or sister with a disability had been mostly positive (87.4%), whereas just over half of the siblings of adults with serious mental illness felt that it was mostly a negative experience (52.6%).

To summarize, siblings of adults with mental retardation were significantly more likely than siblings of adults with serious mental illness to perceive that the brother or sister had a pervasive effect on their life and that the sibling relationship was mostly positive. In contrast, siblings of adults with mental illness felt that the brother or sister had comparably less of an impact on their life and that the sibling experience was mostly negative.

**Current Patterns of Contact Between Siblings**

Our second research question asked whether there are differences between the two groups of siblings in their current patterns of contact with the brother or sister with the disability. It was hypothesized that siblings of adults with serious mental illness would have less contact with their brother or sister with the disability than siblings of adults with mental retardation.

Data regarding the patterns of contact are shown in Table 5. There were no significant differences between the groups in the distance they lived from their brother or sister or in the amount of telephone contact. Most siblings in both groups live within one hour’s drive and maintained regular telephone contact with the brother or sister with the disability. However, as hypothesized, siblings of adults with mental retardation had more frequent face-to-face contact than siblings of adults with mental illness. Whereas approximately 40% of the siblings of adults with mental retardation had weekly contact, only 25% of siblings of adults with mental illness had such frequent contact. Siblings of adults with mental illness were also more likely to have infrequent contact (several times a year or less often) than siblings of adults with mental retardation.

We also examined differences between the two groups of siblings in their appraisal of the closeness of the relationship with the brother or sister with the disability. It was hypothesized that siblings of adults with mental retardation would have a closer relationship with the brother or sister with the disability than siblings of adults with serious mental illness. Consistent with our hypothesis the data in Table 6 show that the current relationship with the brother or sister with the disability is considerably closer when the brother or sister has mental retardation than mental illness. Siblings of adults with mental retardation rated their feelings toward the brother or sister as significantly more likely to be characterized by sentiments of understanding, trust, fairness, respect, and affection than siblings of adults with serious mental illness. Further, siblings of adults with mental retardation were more likely to perceive that the brother or sister reciprocated these sentiments, as they rated the level of understanding, trust, fairness, respect, and affection from the brother or sister as significantly higher than the ratings given by siblings of adults with mental illness. Thus, on both the “giving” and “getting” dimensions of emotional closeness in the sibling relationship, siblings of adults with mental retardation perceived a closer relationship with the brother or sister with the disability than siblings of adults with serious mental illness.

**Psychological Well-Being**

The third research question asked, what are the predictors of the sibling’s level of psychological well-being and how do these predictors differ in the two groups? As noted earlier, the measure of psychological well-being was a composite of the five scales developed by Ryff (1989) and reflected feelings of environmental mastery, self-acceptance, purpose in life, autonomy, positive relations with others, and personal growth. Table 7 presents the findings of two regression analyses, one for siblings of adults with mental retardation and one for siblings of adults with serious mental illness.

<table>
<thead>
<tr>
<th>Table 6</th>
<th>Closeness in the Sibling Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Siblings of Adults with Mental Retardation (G)</td>
</tr>
<tr>
<td>Sibling’s Feelings Toward the Brother or Sister with MR or MI</td>
<td></td>
</tr>
<tr>
<td>Understanding</td>
<td>4.57</td>
</tr>
<tr>
<td>Trust</td>
<td>4.71</td>
</tr>
<tr>
<td>Fairness</td>
<td>4.66</td>
</tr>
<tr>
<td>Respect</td>
<td>4.93</td>
</tr>
<tr>
<td>Affection</td>
<td>4.81</td>
</tr>
<tr>
<td>The Sibling’s Perception of the Brother or Sister’s Feelings</td>
<td></td>
</tr>
<tr>
<td>Toward the Sibling</td>
<td></td>
</tr>
<tr>
<td>Understanding</td>
<td>3.91</td>
</tr>
<tr>
<td>Trust</td>
<td>5.16</td>
</tr>
<tr>
<td>Fairness</td>
<td>4.70</td>
</tr>
<tr>
<td>Respect</td>
<td>4.87</td>
</tr>
<tr>
<td>Affection</td>
<td>4.85</td>
</tr>
<tr>
<td>Total Closeness Score</td>
<td>47.12</td>
</tr>
<tr>
<td>*p &lt; .001.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 7</th>
<th>Multiple Regression Analysis of Predictors of Siblings’ Psychological Well-Being</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Siblings of Adults with Mental Retardation</td>
</tr>
<tr>
<td>Control Variables</td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td>27***</td>
</tr>
<tr>
<td>Gender</td>
<td>.07</td>
</tr>
<tr>
<td>Marital status</td>
<td>15*</td>
</tr>
<tr>
<td>Behavior problems</td>
<td>.08</td>
</tr>
<tr>
<td>Indicators of the Sibling Experience</td>
<td></td>
</tr>
<tr>
<td>Closeness of the relationship</td>
<td>20***</td>
</tr>
<tr>
<td>Number of effects</td>
<td>-.05</td>
</tr>
<tr>
<td>Mostly positive/negative</td>
<td>.09</td>
</tr>
<tr>
<td>Interaction</td>
<td></td>
</tr>
<tr>
<td>Number of effects x positive/negative</td>
<td>-.16*</td>
</tr>
<tr>
<td>R²</td>
<td>.22</td>
</tr>
</tbody>
</table>

*The coefficients reported are standardized betas.
+ p < .10, *p < .05, **p < .01, ***p < .001
As shown in column 1 of Table 7, income was a predictor of the psychological well-being of siblings of adults with mental retardation; the higher the sibling's income, the more favorable his or her well-being. Gender was not a significant predictor of well-being. The sibling's marital status was predictive of psychological well-being, with married siblings having more favorable well-being. Finally, variation in the number of behavior problems of the brother or sister with mental retardation was not predictive of the sibling's level of psychological well-being.

The closeness of the relationship with the brother or sister was a predictor of psychological well-being. As hypothesized, having a closer relationship with the brother or sister with mental retardation was associated with better psychological well-being in the sibling. Neither the sibling's perception of the extent to which the brother or sister had affected his or her life nor the assessment of whether the sibling experience was mostly positive or mostly negative were related linearly to the psychological well-being of siblings of adults with mental retardation. Rather, as hypothesized, the effect of the interaction between the number of effects variable and the assessment of whether the sibling experience was mostly positive or negative was a significant predictor of psychological well-being for siblings of adults with mental retardation (see Figure 1). Consistent with the hypothesis, the psychological well-being of siblings who perceived that their brother or sister with mental retardation had a greater effect on their life was dependent on whether they felt that the experience was mostly positive or mostly negative, those who thought that it was mostly positive had considerably more favorable psychological well-being than those who thought it was mostly negative. However, the psychological well-being of siblings who perceived that their brother or sister had fewer effects on their life did not depend on whether they felt the experience was mostly positive or mostly negative.

Column 2 of Table 7 shows the same regression analyses conducted with siblings of adults with serious mental illness. Consistent with the prior analysis, when the sibling had a higher income, he or she had better levels of psychological well-being. Also, gender of the sibling was unrelated to psychological well-being. In contrast to the prior analysis, marital status was not predictive of the sibling's level of psychological well-being. In addition, number of behavior problems was a significant predictor, with siblings having poorer well-being when the brother or sister with serious mental illness had more behavior problems.

As we hypothesized, the closeness of the relationship with the brother or sister with mental illness was not related to the sibling's level of psychological well-being. However, contrary to our hypothesis, regardless of whether the sibling perceived the experience as mostly positive or mostly negative, the number of effects was a significant negative predictor of well-being. Feeling as if the brother or sister exerted a broader pattern of effects on the sibling’s life predicted lower levels of psychological well-being in siblings of adults with serious mental illness.

Discussion

Siblings of adults with mental retardation and siblings of adults with mental illness shared several characteristics. They were similar in age, gender, parental status, level of education, employment status, and household income. In addition, they had a similar frequency of phone contact with and geographic proximity to their brother or sister with the disability. Also, it is important to note that the two groups of siblings were similar in their level of psychological well-being.

That is where the similarity ends. Siblings of adults with mental retardation report having more face-to-face contact and a closer relationship with the brother or sister with the disability than siblings of adults with serious mental illness. These siblings also report more pervasive effects of the brother or sister on their life, and an overwhelming assessment of their sibling experience as mostly positive. In contrast, siblings of adults with serious mental illness were less likely to perceive a broad pattern of effects on their life. The majority of this group felt that the experience was mostly negative.

Our analysis showed that a likely explanation for this more pervasive pattern of perceived influence on the lives of siblings of adults with mental retardation was that most siblings of adults with mental illness were over the age of 18 when the brother or sister was first diagnosed as having a disability, whereas most siblings of adults with mental retardation have only known their brother or sister as having a significant disability. Thus, siblings of adults with serious mental illness tended to have been firmly established in their life domains prior to the onset of their brother or sister’s disability and were less likely to have been exposed to the effects of the disability during their formative years.

Another aspect of difference between the two groups was the centrality of the role of sibling to the sibling’s level of psychological well-being. When the brother or sister had mental retardation, the sibling had better well-being when he or she perceived that the sibling relationship was emotionally close. When the brother or sister had serious mental illness, the sibling had better well-being when the brother or sister had fewer effects on the sibling’s life. Thus, intimacy in the case of siblings of adults with mental retardation and psychological distance in the case of siblings of adults with mental illness predicted better psychological well-being. The only exception to this pattern was in the case of those few siblings of adults with mental retardation who felt that the experience was mostly negative; they were more similar to the siblings of adults with mental illness in that more pervasive effects predicted poorer psychological well-being.

Yet another notable difference between siblings of adults with mental retardation and siblings of adults with serious mental illness was the extent to which the number of behavior problems of the brother or sister with the disability was predictive of the sibling’s level of psychological well-being. For siblings of adults with serious mental illness, the brother or sister’s number of be-
behavior problems predicted poorer sibling well-being, but no such relationship was found for siblings of adults with mental retardation. We interpret this difference in terms of the sibling's attribution of control or responsibility by their brother or sister for his or her behavior problems. One of the challenges faced by siblings of adults with disabilities is determining how much control their brother or sister has over his or her behavior. Since persons with serious mental illness often have symptom-free periods which are followed by upturns in problematic behaviors, their siblings may have difficulty determining whether the behavior problems are intentional and manipulative or due to the illness. This ambiguity may add to the sibling's feelings of stress and resentment and, therefore, may result in poorer well-being. In contrast, siblings of adults with mental retardation tend to be more understanding of and sympathetic with their brother or sister's behavioral difficulties because they attribute them to the disability and not as being a matter of self-control. Future research is needed to investigate this issue directly.

Even though siblings of adults with serious mental illness perceive their sibling experience to be more negative than their counterparts whose brother or sister has mental retardation, our findings suggest a pattern of regular contact and often positive interactions between such siblings and their brother or sister. Specifically, nearly half viewed the sibling experience as mostly positive and more than half had at least monthly face-to-face contact with the brother or sister with mental illness. These findings are consistent with studies conducted by Horwitz (1993a, 1993b) and Pruchno et al. (1996). They imply that future research should avoid an over-emphasis on the negative effects of serious mental illness on family relationships, and instead should aim to investigate the factors that explain the resiliency of such siblings and the positive as well as negative features of such relationships. There is a parallel here with a shift in research on siblings of persons with mental retardation that occurred in the 1980s, when a primarily negative and pathological view of the impact of having a sibling with this disability was replaced by research employing a more balanced investigation of the positive and negative effects (Stoneman & Berman, 1993).

A final distinction between the two samples is the extent to which co-residence between the parents and the adult with disabilities is a typical living arrangement. It is much more common for adults with mental retardation to live at home than adults with mental illness. For families of adults with serious mental illness, co-residence may imply either greater commitment to caring for the adult child or, alternatively, the absence of other options. In addition, co-residence between parent and an adult child with mental illness may increase a sibling's feelings of obligation and hence may increase their involvement in order to satisfy parental expectations. It was not possible to investigate directly the effect of variations in co-residence on the findings presented in this paper because of the small sample of siblings of adults with mental illness. This is an important issue for future research.

Our research has a number of limitations. First, our analyses are based on cross-sectional data, and although we conceptualized the sibling's level of psychological well-being as the dependent variable, it is impossible to determine from this analysis the extent to which there are bi-directional relationships between aspects of the sibling experience and the or her psychological well-being. Second, all families volunteered to participate in the research. Thus, the generalizability of the findings to the larger population of families of adults with disabilities is unknown.

Third, these data were obtained from siblings who were more involved in the lives of their brother or sister with the disability than the other non-disabled siblings in their family. The findings, therefore, do not generalize to all siblings, but they do pertain to the sibling most likely to play a more prominent role in the life of the brother or sister with the disability. A related point is that all siblings had at least one living parent at the time of their participation in the research. The extent to which the findings apply to siblings after both parents have died is unknown. Fourth, our findings regarding siblings of adults with mental illness should be interpreted cautiously, given the small sample and the consequent limitation in statistical power. We were unable to investigate differences by race because of the very small number of African Americans (n = 7). Finally, the siblings of adults with serious mental illness had been coping with the illness for many years at the time of our research, as their brother or sister had their first psychiatric episode more than a decade ago. We suspect that the sibling experience varies significantly depending on how long they have been coping with mental illness in a brother or sister.

Although these factors are limitations of the present study, our research overcomes three weaknesses of previous investigations of siblings of adults with disabilities. First, with the exception of the Pruchno et al. (1996) study, prior research has been limited to one-group designs, restricting the analysis to examining variation within the group of siblings whose brother or sister has either mental retardation or mental illness. The comparative design used in this study allows us to shed more light on how the type of disability uniquely shapes the experiences of siblings. Second, many of the previous studies on siblings (see Horwitz 1993a; 1993b; and Horwitz et al., 1992, for exceptions) have been based on samples recruited from membership organizations, such as the Alliance for the Mentally Ill or The Arc, which provide support and education to families of persons with disabilities. In our study, we used multiple strategies to recruit participants, including approaching members of family support groups, families of service recipients, and older caregivers of adults with disabilities known to the aging and disabilities service networks, as well as via media announcements. Thus, a strength of our study is that it may more fully capture the diversity in the experiences of siblings of adults with disabilities than represented in previous studies based on the experiences of members of family advocacy and support groups. Third, most prior research has taken a negative perspective on the well-being of siblings with a disability (see Stoneman & Berman, 1993, for an analysis of this issue). In our study, we focused on positive indicators of well-being and of the sibling relationship.

**Practice Implications**

The results of these analyses point to three critical implications for service providers who work with families of adults with lifelong disabilities. First, family support and care for adults with disabilities draws upon the energies of all family members, including siblings. Even though the parents are the primary providers of day-to-day supervision and support, adult siblings are part of the fabric of the lives of persons with either mental retardation or serious mental illness. We found that most of the siblings lived within an hour's drive of the home of their brother or sister with disabilities, and that over half maintain at least monthly contact with them. However, all too often service providers have overlooked the needs of siblings for support and informa-
tion about the disability (Krauss et al., 1996; Judge, 1994). There are two steps service providers can take to rectify this situation. First, they should include siblings when they take a "social inventory" of individuals who provide regular support to an adult with disabilities. In addition, they can expand current outreach efforts to siblings. To inform such outreach, service providers should recognize that the concerns of many siblings are not only with the present situation but also with planning for the future when their parent may no longer be able to continue as the primary caregiver.

Second, our analyses revealed important differences between siblings of adults with mental retardation and siblings of adults with serious mental illness. Perhaps most striking was that the majority of siblings of adults with mental retardation said that their experiences had been mostly positive, whereas more than half of the siblings of adults with mental illness said their experiences were mostly negative. Further, these evaluations magnified the influence of the range of effects of having a sibling with a disability, such that siblings of adults with mental retardation who perceived that their experiences were mostly negative and who perceived more pervasive effects on their adult lives had lower levels of psychological well-being than those who had more positive views of the sibling experience or who perceived less pervasive effects.

These findings suggest that service providers need to explore the meaning of disability to siblings in order to gauge the potential roles that they may be willing to assume in the future. Clearly, siblings who feel harmed by their experiences will be poor candidates for increased responsibility when their parents cease caregiving Oversight. Siblings who have a more positive view, in contrast, may be quite willing and able to assume active, ongoing caregiving roles (Krauss et al., 1996). The important message is that individual variability with respect to the consequences of having a brother or sister with a disability is to be expected. Our data suggest that, in general, siblings of adults with mental retardation feel more positively about the sibling relationship than siblings of adults with severe mental illness. However, we also found that this is not uniform, as there were a subset of siblings of adults with mental retardation for whom the experience was more similar to the experiences of siblings of persons with mental illness. Ultimately, each sibling's appraisal of his or her family history and current responsibilities will present a unique set of options for the future. Service providers should not assume that all siblings are comparable in their capacities and interests as the next generation of caregivers.

Third, when the quality of the current relationship between the sibling and the brother or sister with the disability is perceived by the sibling to be primarily negative, the possibility of supportive interventions should be considered, such as counseling, structured opportunities to engage in positive interactions and shared activities, and assistance in planning for the future. The literature on normative sibling relationships suggests that there are marked changes over time in the level of intimacy, connectedness, and assistance exchanged between siblings (Cicirelli, 1982). There is no reason to assume a static quality to sibling relationships in which one has a disability. The capacity for change and growth may well be as strong in such siblings as in others unaffected by disability.

The primary conclusion we reach from our data is that structurally similar family roles—in this case, being a sibling of an adult with a lifelong disability—have markedly different effects depending on the specific features of the caregiving context. In this era of generic services, there is the temptation to search for commonalities rather than to identify the uniqueness of persons with different disabilities and their families. Although we, too, have searched for the similarities, it is the differences between sibling groups that stand out in our data. It is clearly not the diagnosis per se, but rather the unique challenges that accompany the different diagnoses that make the experience of siblings of adults with mental retardation fundamentally less stressful and more positive than is experienced by families of adults with serious mental illness.

References


