

## Life Course Studies of Siblings of Individuals With Developmental Disabilities

Marsha Mailick Seltzer, Jan S. Greenberg, Gael I. Orsmond, and Julie Lounds

The sibling relationship constitutes the longest lasting family tie, beginning with the birth of the younger sibling and ending with the death of one member of the sibling pair. Siblings share a common family heritage, both genetically and experientially, and perhaps for this reason, the sibling relationship is normatively characterized as egalitarian, reciprocal, and mutual. How is the sibling relationship distinct when one member of the sibling pair has a developmental disability? Aspects of the sibling tie might be atypical in this context, in several respects. For example, the duration of the relationship might be shorter, as some individuals with developmental disabilities have a more limited life-span. In addition, there may be less genetic and experiential similarity between members of the sib pair and less egalitarianism and reciprocal exchange due to unequal abilities and patterns of life course outcomes. However, there may also be greater continuity in contact across the life course when the sibling has a developmental disability.

Most past researchers of siblings of individuals with developmental disabilities have focused on the sibling pair during childhood (Stoneman, 1998; Stoneman & Berman, 1993). However, individuals with developmental disabilities tend to live well into adulthood and now commonly reach old age. Therefore, there is a need to extend our investigation of the sibling relationship when one has a developmental disability across the life course to better elucidate whether and how this relationship changes when the siblings grow up. Among the general population, the sibling relationship has significant life course variation, as the intense involvement that characterizes sibling interactions during childhood give way to more disengaged relationships during the young adult years, followed by a reintensification of the sibling bond during midlife and older age (Cicirelli, 1982; Goetting, 1986). How these life course patterns are manifested when one sibling has a developmental disability is the focus of this review.

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A growing body of research on adult sibling relationships when one individual has a developmental disability suggests that, in general, these siblings tend to maintain high levels of involvement across the life course, although there is variability in the degree of contact and closeness. In early studies, researchers using qualitative methods suggested the importance of gender in the extent and nature of siblings' contact with their brother or sister with a disability, with sisters playing more of a supportive role than brothers (Zetlin, 1986).

We have conducted a series of analyses of sibling roles and involvement during the adult years, based on our longitudinal study of families of adults with mental retardation. There was a living sibling in 93% of the 461 families who participated in this study.

The most involved sibling in the family had a fairly high level of contact with the brother or sister who had the disability, with about 30% reporting weekly or more frequent phone contacts, 41% reporting in-person visits at least weekly, and 58% living within a 30-minute drive of each other's home (Krauss, Seltzer, Gordon, & Friedman, 1996). Nearly half of the adults with disabilities (44%) had an overnight visit with the nondisabled sibling in the previous year. The most frequently shared activities were going to a restaurant (63%), shopping together (56%), and going to the movies (44%).

Confirming the importance of gender in the sibling relationship, G. Seltzer, Begun, Seltzer, and Krauss (1991) found that the most involved sibling in the family was more likely to be a sister than a brother and that siblings tend to provide higher levels of affective than instrumental support, at least while their parents were still the primary caregivers. In another analysis of the data from this study, Orsmond and Seltzer (2000) reported that brothers without disabilities tended to have the most distant relationships when their sibling with the disability was a sister and

the closest relationships when the sibling was a brother. In contrast, for sisters, the gender of the sibling with the disability did not affect their patterns of affective or instrumental involvement.

One dimension on which siblings were found to vary was the extent to which they expected a future caregiving role, after the time when the parents are no longer able to provide care (Krauss et al., 1996). We found that in some families (19%), there was a sibling who expected to have the brother or sister with mental retardation live with him or her, whereas in other families siblings expected to live in separate households (33%) or had not yet formulated plans for the future (48%). Sisters were more likely to expect to co-reside with their sibling who had a disability than did brothers. In addition, those who expected to co-reside currently had more frequent shared activities with the brother or sister than those who expected to live apart. Severity of disability was also a factor, with siblings whose brother or sister had less severe functional impairments and less severe behavior problems more likely to plan to co-reside. Finally, there was a greater expectation that the siblings would co-reside when the mother was already in poor health. Interestingly, even among those who planned to live apart, at least half had weekly contact with the brother or sister, have had discussions with their parents during the preceding year about future plans, and expected to be the legal guardian of the sibling with the disability after the parents were no longer able to fill this role.

The expectation to co-reside might not predict actual patterns of co-residence after the period of parental caregiving ends. In a follow-up investigation of a subsample of these families following placement out of the parental home, only about 10% of the individuals with mental retardation had moved in with their siblings (Freedman, Krauss, & Seltzer, 1997), which is a smaller percentage than had been predicted when siblings were asked about their future plans. Interestingly, in families in which the individual with mental retardation moved to a nonfamily living arrangement (e.g., group home, supported apartment), nondisabled siblings reported significant increases in their frequency of contact with their brother or sister with the disability over a 3-year period and felt significantly less worried or pessimistic about their brother or sister's future care than in a comparison group of siblings whose brother or sister still lived with the parents (M. Seltzer, Krauss, Hong, & Orsmond, 2001).

This study confirmed that adults with mental

retardation maintain strong sibling ties across the life course. Siblings constitute about one quarter of the individuals who comprised the social support networks of the adults in the sample (Krauss, Seltzer, & Goodman, 1992). In addition, there was evidence of a ripple effect of sibling involvement, as mothers of adults who had high levels of sibling involvement tended to have better psychological well-being than mothers of less involved siblings (M. Seltzer et al., 1991). Thus, the sibling relationship is best appreciated in the context of family relationships across as well as within generations.

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### Comparative Studies of Adults With Developmental Disabilities Versus Mental Illness

As noted above, the research literature on the relationships between siblings when one sibling has developmental disabilities reveals that these sibling ties are generally characterized by supportiveness, concern, and involvement. However, because prior research has been limited to one-group designs (e.g., restricted to siblings whose brother or sister has mental retardation), the question arises as to whether the primary fact of having a brother or sister with a disability exerts a common influence on siblings, regardless of the type of disability, or whether the type of the specific disability uniquely shapes the sibling experience. To address this issue, we investigated whether the experience of siblings of adults with mental retardation was similar to or different from the experience of siblings of adults with mental illness with respect to qualities of the current sibling relationship, the psychological well-being of the sibling who did not have disabilities, and current and future caregiving involvement.

We compared these two groups of siblings because they face many similar challenges in coping with the care of a brother or sister with a disability, but yet confront unique sets of experiences due to differences in the timing and course of these two disabilities. With respect to similarities, because few persons with mental retardation or mental illness marry, siblings are in a natural position to become the next generation of caregivers when a parent dies or becomes disabled. In addition, both groups of siblings face the challenge of integrating the needs of their brother or sister with their own responsibilities to their family and career. Finally, feelings of loss and grief regarding the sibling's disability are common to both groups and may become particularly salient

when the family celebrates typical developmental milestones that are beyond the reach of the brother or sister with disability (Judge, 1994; Marsh, 1992).

Yet, there are two major contextual differences in the sibling experience arising from differences in the timing and course of mental retardation versus mental illness that may significantly influence the experience of siblings. First, the diagnosis of mental retardation generally occurs at a substantially earlier point in the family life course than does serious mental illness. Consequently, siblings of persons with mental retardation have always known their brother or sister as a person who has significant disabilities. In contrast, serious mental illness is typically diagnosed during late adolescence or early adulthood. Thus, nondisabled siblings generally recall a time when the brother or sister did not have the disability. As a result of this difference, siblings of adults with mental retardation may expect from an early age to have future caregiving responsibilities, whereas for siblings of persons with mental illness, caregiving is an unexpected role and one that often requires the redefinition of the sibling relationship.

Second, the course of mental retardation is distinctly different from the course of mental illness. Whereas mental retardation is characterized by relative stability in the day-to-day functioning of the individual with the disability (Eyman & Widaman, 1987), the symptoms of mental illness are more episodic and have a less predictable course. Even for adult siblings who live apart from their brother or sister with mental illness, the cyclical nature of the symptoms greatly increases the challenges of maintaining a satisfactory sibling relationship.

These contextual similarities and differences faced by siblings of adults with mental retardation and siblings of adults with mental illness suggest that researchers comparing these two sibling groups should help identify the unique experience of siblings with each of these disabilities. In one of the first such studies, we compared 329 siblings of adults with mental retardation to 61 siblings of adults with mental illness (M. Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997). These sibling samples were drawn from two related longitudinal studies of aging families of adult children with disabilities (Greenberg, Seltzer, & Greenley, 1993; M. Seltzer & Krauss, 1989). The two groups of siblings shared many characteristics. Both averaged about 40 years of age and were more likely to be a sister of the family member with disabilities than a brother. They were similar in their parental status (with most siblings having children), their level of education, employment status, and income.

Although the two groups of siblings shared many similar characteristics, there was a distinct pattern of differences in other aspects. Siblings of adults with mental retardation reported having more face-to-face contact and a closer relationship with the brother or sister with the disability than did siblings of adults with serious mental illness. Siblings of adults with mental retardation also reported more pervasive effects on multiple life domains of having a brother or sister with a disability than did siblings of adults with mental illness. For instance, siblings of adults with mental retardation were more likely to report that their sibling's disability had affected their career choice and their choice of romantic relationships than did siblings of adults with mental illness. Most importantly, the majority of siblings of adults with mental retardation (87%) assessed these effects as "mostly positive" whereas just over half of the siblings of adults with mental illness (53%) assessed these effects as "mostly negative."

Another aspect of difference between the two groups was the centrality of the sibling role to the psychological well-being of the nondisabled sibling. Siblings of individuals with mental retardation had better well-being when the sibling relationship was characterized by emotional closeness. Siblings of individuals with serious mental illness had better well-being when the sibling was able to distance him/herself from the brother or sister with mental illness. 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.

In a related study, Greenberg, Seltzer, Orsmond, and Krauss (1999) examined the factors associated with current and future caregiving involvement of siblings of adults with mental retardation and siblings of adults with mental illness. The two groups of siblings did not differ in the amount of instrumental support they currently provided to their sibling with disabilities. However, siblings of adults with mental retardation currently provided significantly more emotional support and were almost twice as likely to expect to assume primary caregiving responsibility in the future than did siblings of adults with mental illness. The two groups of siblings were also quite similar in terms of factors predicting current and future caregiving involvement. For both groups, having young children at home was predictive of providing less current instrumental and emotional support to the brother or sister with disabilities. In addition, siblings of adults

with mental retardation and siblings of adults with mental illness who reported having an emotionally close relationship during adolescence with their sibling with disabilities were more involved currently in providing instrumental support and expected to continue to provide this support in the future. Also, for both groups, sisters provided more emotional support than did brothers, and sisters of adults with mental retardation were more likely than brothers to expect a future caregiving role. Therefore, although siblings of adults with mental retardation provided high levels of emotional support and were more likely to expect to assume a caregiving role in the future, the factors predicting their level of current and future involvement were quite similar across these two sibling groups.

Pruchno, Patrick, and Burant (2001) surveyed maternal caregivers of adults with mental retardation ( $n = 487$ ) or schizophrenia ( $n = 351$ ) and confirmed several of the findings reported in our earlier work. Mothers of adults with mental retardation indicated their other children had more positive relationships with their sibling with disabilities compared to mothers of adults with schizophrenia. Also, mothers of adults with mental retardation were more likely to report that one of their other children would assume a future caregiving role than did mothers of adults with schizophrenia. Finally, for both groups, the quality of the sibling relationship was predictive of current as well as future involvement.

The primary conclusion we reach from this body of comparative research is that different disabilities have unique effects on the sibling experience. In this era of generic services, there is the temptation to search for commonalities rather than to identify the unique experiences of persons with different disabilities and their families. Although we uncovered many similarities in the predictors of current and future involvement, it is the differences between siblings groups that stand out in our comparative studies. Siblings of adults with mental retardation felt closer to their brother or sister, provided more emotional support to him or her, and were overwhelmingly more likely to expect to take on a future caregiving role. Although they perceived their lives as being more pervasively affected by having a sibling with mental retardation, they evaluated these effects more favorably. Whereas psychological distance was used by siblings of adults with mental illness to maintain their psychological well-being, intimacy in the sibling relationship was the key to the well-being of siblings of adults with

mental retardation. We recognize that it is probably not the diagnosis per se, but rather the characteristics associated with a diagnosis, such as differences in timing and the course of the disability, that make the experience of siblings of adults with mental retardation so different from the experience of siblings of adults with serious mental illness.

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### Issues for Future Life Course Sibling Research

Although great strides have been made in our understanding of the relationships between siblings when one member of the sibling pair has a disability, important conceptual and methodological considerations have yet to be satisfactorily addressed. Our comparative research between siblings of adults with mental retardation versus those of adults with mental illness suggests that in future studies about siblings, researchers should be even more specific about the etiology and level of disability observed in participants, examining sibling relationships among individuals with specific subtypes of developmental disabilities (such as autism or Down syndrome). With studies whose authors define samples with greater specificity, we can begin to disentangle which relationship characteristics are common among all siblings of people with developmental disabilities and which are specific to certain conditions or diagnoses.

Autism is a specific developmental disability that warrants greater research attention at the present time, given the rapidly rising prevalence of this disorder and given the limited understanding of the impact of autism on the family, including siblings, across the life course. Few disorders in children pose a greater threat to the psychosocial well-being of families than autism because the behavioral characteristics of this disorder tax even the strongest family systems (M. Seltzer, Krauss, Orsmond, & Vestal, 2000). When siblings of a child with autism are compared with siblings of a child with no disability or with other developmental disabilities, they tend to show greater risk for negative psychological and behavioral outcomes (Fisman, Wolf, Ellison, & Freeman, 2000; Hastings, 2003; Rivers & Stoneman, 2003).

Although there has been growth in studying the effects of autism in siblings during childhood, there have been virtually no published studies that focus on adolescents and adults whose brother or sister has autism. This is particularly problematic because after the child with autism reaches adolescence, the impacts on the family appear to intensify

(Bristol & Schopler, 1983), and adjustment problems for siblings tend to increase (Fisman et al., 2000; Wolf, Fisman, Ellison, & Freeman, 1998). Thus, when siblings of individuals with autism reach adulthood, they may be at greater risk for psychopathology than adult siblings of individuals with other types of developmental disabilities. Given the rising prevalence of this disorder and the elevated mental health risk of their siblings, there is a need at the present time to prioritize studies on adult siblings of individuals with autism.

There are several methodological limitations in studies of siblings of persons with developmental disabilities that warrant attention in future research. First, to date, such studies tend to be based on nonrepresentative samples, which may lead to conclusions that may be not generalizable. Researchers using population-based samples will begin to address whether their findings are representative of siblings in the general population.

Second, in most studies of sibling relationships, investigators use self-reports. It is surprising that there are few standard, widely accepted instruments measuring sibling relationships in general, much less sibling relationships when a member of the dyad has a developmental disability that is applicable to the adult years. Self-report measures of sibling relationships should be designed to address issues particularly relevant when one member of the sibling pair has a developmental disability. In addition, most of our knowledge about sibling relationships has been collected from the nondisabled sibling. Self-report measures that can be administered directly to the person with the developmental disability are also needed. This will allow future researchers to explore how the sibling with the developmental disability views the relationship, and how his or her perception affects the relationship with the nondisabled sibling.

Third, methodologies other than self-reports to measure sibling relationships should also be developed. Observational measures of sibling interactions, for example, could explore the objective characteristics and qualities of sibling relationships, thereby expanding our understanding of the sibling relationship beyond the nondisabled sibling's subjective assessment. Future research also should be focused on new ways to measure sibling relationships, both in terms of methodologies used to obtain information and the specific measures administered to participants.

In addition to methodological issues for future

research, there are a number of specific research questions relating to sibling relationships that have yet to be explored. One such question concerns the effects of having a sibling with a developmental disability on certain normative life course events or transitions, such as getting married, having children, or providing care to parents. These transitions may be more (or less) challenging for siblings of individuals with developmental disabilities. Another question relates to how researchers define *optimal development*. Although past research has often been focused on psychopathology in siblings, it is now more common to recognize the importance of measuring indicators of positive psychological well-being. Future researchers should explore the ways in which "happy" or "successful" families are defined. In most cases, it is important to look beyond an absence of psychopathology and instead focus on positive factors, such as prosocial behaviors, empathy, and psychological well-being in our efforts to understand the life course impacts of having a sibling with a developmental disability.

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#### Authors:

**Marsha Mailick Seltzer, PhD** (E-mail: MSeltzer@Waisman.Wisc.Edu), Vaughan Bascom Professor and Director, Waisman Center; **Jan S. Greenberg, PhD**, Professor, School of Social Work and Waisman Center; **Julie Lounds, PhD**, Assistant Scientist, Waisman Center, University of Wisconsin, 1500 Highland Ave., Madison, WI 53705. **Gael I. Orsmond, PhD**, Assistant Professor, Department of Occupational Therapy and Rehabilitation Sciences, Boston University, 635 Commonwealth Ave., Boston, MA 02215.