

Siblings as Caregivers for the Seriously Mentally Ill

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SINCE THE 1960S POLICY TOWARD THE SERIOUSLY mentally ill, through its emphasis on community care, has stressed both the benefits of living in the community and the detriments of hospital life for this population. Its impact has been dramatic: from a peak of 550,000 in 1955, patient populations in state and county mental hospitals dropped to about 100,000 in 1988 (Mechanic 1989). The initial proponents of community-oriented treatment assumed that patients—freed from institutional confinement—would find support, comfort, and assistance in their communities that would easily replace the panoply of services provided by mental hospitals (Grob 1991). However, they did not specify who in the community would supply these services. Indeed, we still do not know which social supports and living arrangements are available to the mentally ill in the community (Goldman 1982). Thus, it is vital to identify individuals who are available and willing to provide this support.

Communities are not abstract entities, but comprise people who have specific relations with each other (e.g., parents, spouses, brothers, sisters, friends, neighbors). Social support and assistance are provided on the basis of concrete ties between individuals through a hierarchic process (Bulmer 1987; Finch 1989). Married adults turn for support first to their spouses, who have personal, social, and legal obligations to provide

many forms of aid. The second line of support is between parents and children. Social norms prescribe that parents provide material and subjective aid to adult children who are in need; reciprocally, children act as the main source of aid to aged parents (Rossi and Rossi 1990).

Support obligations outside of the spousal and parent-child bonds are ambiguous (Bulmer 1987; Finch 1989; Rossi and Rossi 1990). More distant relations—cousins, nephews, nieces, uncles, or aunts—usually are not legally, morally, or personally bound to provide support. Similarly, friendship involves companionship and emotional support, but not necessarily exchanges of tangible forms of assistance. “Community members,” neighbors, or acquaintances also do not usually offer ties strong enough to generate the long-term services and support required by chronically ill populations like the seriously mentally ill.

The issue of how far along the chain of social relations the duty to provide help exists is especially important in the care of unmarried chronically ill persons, including the seriously mentally ill. The vast majority, about 90 percent, of persons with serious and persistent mental illnesses are unmarried and thus lack the possibility of obtaining help from spouses or children (Kramer 1983; Grusky et al. 1985; Horwitz et al. 1992). In the absence of spouses, many seriously mentally ill people rely on their parents (Lefley 1987). Parents are often a major source of assistance, providing both material services—financial aid, housing, or meals—and help in crises and emotional support (Horwitz and Reinhard 1992). However, as the mentally ill enter midlife, parental caregivers will die or become too disabled to provide care; recipients of parental support will generally outlive their caregivers. The large cohort of baby boomers with aging parental caregivers will bring this crisis into sharp focus in the near future. When parental caregivers are not available to provide support and assistance, which relations might come forward to take their place?

For many unmarried chronically mentally ill adults who lack parents and spouses, siblings provide the next line of possible support, especially because the friendships of the mentally ill are typically few, fragile, and tend to be with other mentally ill people, who are limited in their own ability to provide support (Hammer 1981; Estroff 1981). Sibling obligations exist on the boundary between intimate relations, characterized by the duty to provide help, and distant ties that do not include this obligation (Adams 1968; Avioli 1989). Sibling roles encompass some obligation, but the commitment to aid brothers and sisters is highly variable.

However, there is virtually no scholarly research into the perception by brothers and sisters of their responsibilities in caring for chronically ill populations (Landeem et al. 1992).

The issue of whether only spousal and parent-child relations contain strong enough role obligations for long-term care is salient for seriously mentally ill people. If so, disabled persons who lack spouses, parents, or children will not be able to obtain much support in the community. Another model might show social support being provided in a sequential manner: the disabled would receive support from more distant members of their social networks, like their brothers and sisters, when closer relations are not available to provide help. When people with closer ties, like parents, are present, siblings might play a limited role in social support, but when parents die sibling social support could increase. It is important that we discover how willing siblings are to participate in support processes for populations like the seriously mentally ill, whose ability to obtain long-term support from intimate relations is limited.

The Sibling Role

Research into adult sibling relations in the general population varies in its conclusions about the strength of ties between siblings. Some studies find that adult siblings exchange many services and have frequent contact (e.g., Sussman and Burchinal 1962; Johnson 1982; Wellman and Wortley 1990); others show limited support and contact (Adams 1968; Avioli 1989). Sibling support varies over the life course: after intense relations in childhood and adolescence, sibs tend to withdraw into families of procreation in adulthood, but come closer together as their children leave home and their spouses die (Goetting 1986; Avioli 1989). Sibling support is especially important for unmarried adults, for older people, and in short-term crises (Johnson 1983; Bedford 1989; Connidis 1989). It is clear that some brothers and sisters maintain close and supportive ties, whereas the connection between others is loose. What factors might affect the provision of social support?

Obligation to provide support underlies much social support from intimates like spouses, parents, and children, whose roles entail strong normative obligations to help in times of need. However, the literature on adult siblings in modern societies indicates that sibling obligations

are less explicit and not as demanding (Adams 1968). Neither social nor legal norms prescribe long-term caretaking duties for siblings. In addition, because autonomy is a social value for adult siblings, norms of self-sufficiency limit the amounts of aid that one sibling would provide and another would receive comfortably (Avioli 1989). Further, married sibs are obligated to weigh the needs of their families of procreation more heavily than those of their families of orientation. The weakness of obligatory norms to help siblings and the primacy of claims for support by others could limit the willingness of sisters and brothers to act as the chief sources of social support to seriously mentally ill siblings. However, despite the lack of obligatory norms to provide support, when primary caretakers (spouses and parents) are not available, siblings might assume more responsibility for caregiving.

Reciprocity is a second source of caregiving: people provide support to those who have supported them in the past and/or might support them in the future. Although support that stems from social obligation should be relatively unconditional, reciprocity limits support to relations in which a potential caregiver foresees some return from the recipient. In the general population, reciprocity probably is the primary source of sibling exchange and support (Avioli 1989). Brothers and sisters are a source of support, chores, assistance, visits, presents, goods, and services to the extent that they have received or expect to receive comparable services in return. However, chronically ill people like the seriously mentally ill may not have the capacity to engage in reciprocal exchanges, possibly limiting the extent to which reciprocity underlies sibling caregiving for disabled groups. It is an open question whether reciprocity can motivate sibling care for severely mentally ill people to the degree that it does in the general population.

Personal affection is a third possible motivator of social support. One person provides care to another out of feelings of love and affection, apart from any obligation or expectation of reciprocal help. Because siblings are usually age peers and share common backgrounds and experiences, deep ties of affection often develop between them (Bank and Kahn 1982). Such relations underlie much support between siblings in the population. Yet the ties that bind siblings coexist with rivalry, competition, and comparison, sometimes giving rise to ambiguous or hostile relations (Handel 1985). When sisters and brothers have poor personal relations they face little pressure to provide assistance (Finch 1989). When one sibling is mentally ill, hostile relations might outweigh posi-

tive feelings. Intense antagonism may develop, especially during adolescence and young adulthood when the mental illness usually arises. In addition, the encompassing demands on parents of the seriously mentally ill sibling can engender feelings of neglect among their brothers and sisters. The nature of mental illness might exacerbate the negative aspects of normally ambiguous relations between siblings.

Each of these factors depends on a number of other variables, including geographic proximity, stage in the life cycle, social class and ethnicity, the supply of other potential caregivers, and the need for care of the ill sibling. As a first effort to gain some insight into the multiple factors affecting sibling caregiving for the seriously mentally ill, I conducted an exploratory study as part of the Milbank Households and Policy Services Review. This research focused on three questions:

1. How much support do siblings provide to seriously mentally ill brothers and sisters and how much are they willing to provide if necessary?
2. Does sibling participation in support processes increase after the death of parental caregivers?
3. What factors are associated with why some siblings provide social support and others do not?

Finding answers to these questions will be important for the long-term welfare of persons who suffer from mental illness in an era of deinstitutionalized care. Promoting sibling relations might be one way to strengthen links between people who suffer from mental illness and their intimate support systems and, consequently, to reduce the secondary disabilities that might otherwise arise (cf. Gruenberg 1974).

An Exploratory Study of Sibling Caregiving to the Mentally Ill

To obtain information about the nature of sibling social support, I sampled siblings of participants at one treatment program for the seriously mentally ill. I interviewed 108 siblings with seriously mentally ill brothers and sisters who were members of the Club, a community treatment program in New Brunswick, New Jersey. Persons with a history of severe psychiatric disorder lasting two or more years and significant impairment

in social and/or vocational functioning who reside in the catchment area of the local community mental health center are eligible to participate in the program (Rosenfield 1992). The two exclusionary factors are a history of violent behavior and a primary diagnosis of substance abuse. About 80 percent of the participants have diagnoses of schizophrenia and 15 percent are being treated for bipolar disorder.

Sixty-two percent of Club members provided informed consent to interview a sibling. Although there were no statistically significant differences between this group and the entire Club population in diagnosis, age, sex, education, or ethnicity, it is likely that refusers have more strained sibling relations than consenters. These data, then, are likely to overrepresent siblings whose relations are more positive.

Siblings of the 116 consenting Club members were approached for telephone interviews. Of these, sisters and brothers of 85 Club members were contacted and interviewed, a completion rate of 73 percent of siblings of consenting patients. When Club members provided the names of more than one sibling we attempted to interview each listed brother or sister. We interviewed a total of 108 siblings of 85 Club members. All of the findings reported here control for whether the respondent was the only sibling interviewed ($n = 65$) or had another brother or sister who was also a respondent sibling ($n = 43$).

The siblings in the study population were predominantly white (88 percent), female (56.5 percent), and in midlife (average age 40 years). Twenty-four percent did not go to college, 31 percent attended some college, and 45 percent were college graduates. Eighteen percent had household incomes of less than \$20,000; 38 percent, between \$20,000 and \$50,000; and 29 percent, over \$50,000. Although this sample is not representative of siblings with seriously mentally ill brothers and sisters, it provides the best available data yet collected on this group.

Social Support from Siblings

One aim of this study was to examine the extent of social support siblings provide to the seriously mentally ill. Social support has a number of dimensions (Fisher, Benson and Tessler 1990; Rossi and Rossi 1990). *Associational support* refers to the frequency of contact between providers and recipients of support. Associational support is measured by the amount of face-to-face and telephone contact reported by siblings. *Affectional support* refers to the extent of closeness and intimacy

between siblings. Finally, *functional support* indicates how much help siblings provide. We examined the amount of help siblings provided in seven areas. We also asked how much help brothers and sisters were willing to give if necessary and recorded their responses to a variety of hypothetical situations requiring social support.

About two-thirds of the siblings who participated in this study lived within an hour's drive from their ill sister or brother. In general, they reported regular contact and good relations with their ill brothers and sisters. On average, they saw each other about once a month and also called each other about once a month. Only one respondent reported no contact over the past year and about a quarter of the siblings had some form of contact every week. It is noteworthy that only 3 percent of respondents wanted less contact with ill sibs, whereas 49 percent desired more contact and 47 percent were happy with their current amount of contact. Most respondents also felt close to their ill sibs. About two-thirds said they were "very close" or "fairly close" and only one-third said they were "not close" or "a little close." Siblings overwhelmingly reported affectionate relationships: 91 percent agreed with the statement that they liked their brother or sister and 94 percent disagreed with a statement that they did not like them.

The amount of help siblings provided varied considerably depending upon the type of help. In increasing order, respondents had provided at least a little help over the past year with household tasks (17 percent), shopping (33 percent), support in crises (43 percent), lending money (45 percent), transportation (48 percent), giving gifts (87 percent), and emotional support (93 percent). The actual amount of sibling support depended not only on their willingness to help, but also on the availability of other caretakers and on limiting factors, such as physical distance. Brothers and sisters who did not currently contribute much support said they might be willing to provide more if necessary. Subjects in this sample reported considerable willingness to offer assistance if no one else was available to provide help. From 52 to 95 percent said they would aid brothers or sisters "sometimes" or "frequently" in the seven categories of support. In addition, when presented with ten hypothetical situations (e.g., "If [sibling] needed a place to stay overnight, I would let him stay in my house"), a majority said they would provide support in most situations.

Without a comparison group, it is difficult to evaluate the absolute amount of social support from siblings. In general, these siblings

reported regular contact with their ill brother or sister. They also indicated a great deal of affection for their ill siblings. Although the help they currently provided was usually limited to nondemanding support, such as gift giving or emotional support, they claimed to be willing to participate in more substantial activities if necessary. Possibly these responses indicated socially desirable attitudes that would not necessarily translate into actual help. Nevertheless, they provided grounds for optimism that siblings would be willing to play a larger supportive role if called upon in the future. Within the limits of the particular nature of this sample, these siblings seemed to be a valuable, potentially supportive resource.

Sibling and Parental Support

A critical issue in the study of sibling support is whether brothers and sisters will increase their levels of social support when parents are not available as primary caretakers. Siblings whose parents are currently alive might not be major participants in support processes as long as their parents are alive, but might provide more help after their parents die. A longitudinal sample that examines levels of sibling support before and after the death of parents provides the optimal research design to study this question. Instead, because we collected cross-sectional data, we compared levels of support from siblings who have both, one, or no living parents.

Half of this sample had two living parents; 28 percent, one living parent; and 22 percent, no living parents. To examine the impact of parental availability we conducted multiple regressions that used two dummy variables. They compared the amount of support that siblings with no parents or one living parent, respectively, provided compared with the reference category of siblings whose parents were both alive. The regressions controlled for the physical distance between respondent and ill siblings, the perceived severity of the illness, the alternative marital, parental, and work roles of the sibling, and whether the sibling was the only brother or sister participating in this study. They also controlled for the demographic indicators of sex, age, and education.

The regressions indicated that all types of support—associational, affectional, and functional—increased as parental availability declined. Siblings without living parents had more face-to-face and telephone contact, reported that their relations were more intimate, and provided

more help than siblings with two living parents. Having no living parents was second only to physical distance in predicting face-to-face contact and was the best predictor of telephone contact and intimacy between siblings. Although siblings with one living parent (in 90 percent of cases, a mother) did not report more contact or intimacy, they provided more help than those with both parents living. In such cases assistance to the sibling may have been at the request of an elderly mother. In addition, siblings who were older reported more contact and intimacy (although not more help exchange), suggesting that sibling support increased over the life course.

Although these results are cross-sectional, they suggest that brothers and sisters often step forward as caregivers upon the death of their parents. Although a majority of siblings in fact provided only forms of support that were not time consuming or encompassing, such as exchanging gifts and emotional support, they generally expressed willingness to offer more substantial help, such as housing and financial support if called upon in crises. Reports that they provided this support increased when parents were not available. These results, however, must be tempered by the fact that the consent process probably excluded siblings with the most strained relations. Nevertheless, the findings that sibling support was highest when parents were no longer available and as siblings aged suggest that brothers and sisters can be an increasingly important resource for seriously mentally ill people over the life course.

Motivations for Sibling Caregiving

What factors account for why some siblings participated in caregiving whereas others did not? If sibling care is better understood, it might be possible to develop and implement policies that could enhance their involvement. The study considered how several possible motivations for caregiving—social obligation, reciprocity, personal affection, and policy incentives—influenced sibling involvement in caretaking.

The interview contained a five-item index of attitudes toward family obligation. Statements that required response included these: "People should always support their families if they are in need." "People should live close to their family and see a lot of them." Although siblings who expressed higher levels of obligation to their families neither had more contact with nor provided more help to their mentally ill brothers and sisters, they reported more intimacy and were more willing to help their

ill siblings in hypothetical situations if necessary. The extent of family obligation did not depend on having living parents. Levels of obligation actually increased across the three parental groups and were somewhat higher when both parents were not alive ($r = .204$). This finding tends to support our earlier suggestion that siblings can become an increasingly important resource for the seriously mentally ill over their life course.

The interview also contained a scale of reciprocity that indicated the extent of help ill siblings provided respondent siblings in seven areas. In ascending order, respondent siblings received at least a little help from their ill siblings: economically (6 percent), caring for others (10 percent), chores (20 percent), companionship (63 percent), gifts (76 percent), family activities (78 percent), and affection (84 percent). Contrary to the expectation that reciprocity would play a limited role in sibling caregiving to the seriously mentally ill, regression analyses indicated that reciprocity is a good predictor of all forms of social support. Whenever the ill sibling engaged in activities such as exchanging gifts, providing companionship, or giving small services, their brothers and sisters maintained more contact, experienced greater intimacy, provided more help, and expressed more willingness to help if needed. It is evident from the types of exchanges between siblings that reciprocity was mostly symbolic. Exchanges centered around subjective support, participation in family activities, and gift exchanges that required little objective effort or resources, but had powerful symbolic value. Nevertheless, these sorts of exchanges seemed to reinforce strong sibling bonds.

Whereas both reciprocity and obligation were associated with supportive processes in the multiple regressions, reports of the quality of sibling relations were not predictive of any type of support. This could result from the nature of the consent process, which limited the inclusion of siblings with strained relations. Most of these respondents reported positive feelings toward their ill brothers and sisters, so personal affection did not distinguish siblings who helped from those who did not. Further, respondents who reported that the illness created disruption in their own and/or the lives of their families did not provide less support than those who were less affected. Evidently, social norms of family obligation and reciprocity were able to overcome siblings' personal feelings toward their ill brothers and sisters. Even siblings who reported that the illness had disturbed their lives in the past, as children, were willing to help their ill siblings as adults.

Policy Incentives. Although the hope of instrumental rewards is not a normatively appropriate basis for support between family members, it is possible that governmental incentives could enhance support efforts. To test this possibility we assessed sibling willingness to provide several forms of help in hypothetical situations. The results indicated that siblings were responsive to help provision. For example, 87 percent reported they would allow ill brothers and sisters to stay in their houses overnight and 53 percent said they would permit them to stay for a month. No less than 26 percent would allow siblings to live with them on a regular basis. However, when siblings were asked if they would allow their ill brothers or sisters to live with them if the state paid them a subsidy, only 15 percent responded positively. The possibility of state subsidies, oddly enough, was a *disincentive* to providing care in this sample.

The negative responses to public subsidies could have several sources. First, siblings might have felt that their efforts should stem from informal norms of family obligation or reciprocity rather than from the possibility of material rewards from the state. If so, informal norms, rather than formal policy incentives, would have to underlie efforts to enhance sibling involvement in caregiving. Second, siblings might have feared that acceptance of a state subsidy would entail more long-term obligations for care than they were voluntarily willing to assume. In either case, these findings suggest that financial incentives to sibling caregivers are not likely to promote sibling caregiving. Third, these findings could stem from the nature of the sample, which included few members of groups of lower socioeconomic status. It is possible that state financial subsidies would enhance support efforts among more economically disadvantaged individuals. In this sample, however, sibling help stemmed from a sense of duty to family members and reciprocity rather than from material inducements.

Sibling Placement. We also examined whether the structural relationship between the respondent and ill sibling affected support processes. However, factors such as birth order, whether the respondent was younger or older than the ill sibling, whether siblings were of the same or different sex, and the age difference between siblings had no effect on support. The only structural characteristic of the sibling group that predicted support was whether or not the respondent was the only participant in this study. Respondents who were the only sibling interviewed

for this study reported more intimacy, help provision, and willingness to help than respondents who had another sibling also participating in the study. Although this research was not designed to test the impact of multiple sibling involvement in social support, the finding suggests that when multiple siblings actively provide support, they create a division of labor that allows each participating sibling to give less support.

Demographic Factors. We also studied the impact of a number of respondent and ill sibling characteristics including income, ethnicity, gender, age, and marital, parental, and work status on support processes. Surprisingly, these factors had little overall impact in this sample. For example, sisters neither provided nor received more social support than brothers and siblings of varying educational levels did not differ appreciably in support levels (with the sole exception of less educated siblings reporting more intimate relations). Even more surprisingly, sibling role commitments did not influence their help efforts: those who were married, parents, or employed did not provide less help or report less willingness to help than those who were not. Perhaps the relatively limited type of aid siblings gave allowed them to incorporate assistance to brothers and sisters into their family and work obligations. Only age was associated with support: as siblings grew older they had more contact and reported more intimacy (although they did not engage in more help exchange) with ill brothers and sisters.

One possible explanation for the lack of demographic differentiation among these siblings might be the relative homogeneity of this mostly white sample in their middle years. Another explanation is that the nature of the sibling bond is similar across brothers and sisters of differing social characteristics. A broader sample of siblings would be necessary to generalize from these findings.

Policy Implications

The siblings in this study are probably not representative of all siblings of seriously mentally ill people. Nevertheless, these findings provide insight about the role siblings might play in the caregiving process. Most of the brothers and sisters surveyed here had regular contact and positive relations with their mentally ill siblings. Although their current help centered on providing emotional support and giving gifts, most siblings manifested a high willingness to participate in more substantial caregiving activities such as becoming involved in crisis situations that required

finding a place to live, offering some money, or giving emotional support. That the amount of actual help from siblings increased as parents became less available to provide support could indicate that reports of willingness to help reflected more than socially desirable responses. Instead, as parental caregivers of the seriously mentally ill aged and died, siblings appeared to take on some of the caregiving activities previously assumed by parents.

These findings also indicate that mental health professionals should be able to encourage sibling caregiving. First, they must recognize the potential importance of siblings in the caregiving process even in cases where siblings are not currently playing a major supportive role. The major role of reciprocity suggests that seemingly small things such as arranging for a visit, giving a present, or inquiring about a brother's or sister's well-being generates a reciprocal process of support. This implies that treatment professionals should encourage their mentally ill clients to engage in exchanges with their brothers and sisters. Because ill siblings often participate in organized forms of treatment, initiating contact through the ill sibling should be more efficient than trying to reach dispersed and unorganized well siblings. Whichever sibling initiates support processes, norms of reciprocity can then lead to supportive activities in return from brothers and sisters.

These data also suggest that state incentives to enhance sibling care might not be effective for the types of siblings represented in this sample. In response to hypothetical questions, siblings actually reported more willingness to help when no state aid was involved than when the government offered monetary incentives. Although more economically disadvantaged populations might react differently to receiving compensation for caregiving, monetary incentives did not seem to enhance participation in caregiving in this largely middle-class population.

Conclusion

Studies of family obligation in presumably individualistic societies have repeatedly found that family ties persist across generations and distance (Finch 1989; Rossi and Rossi 1990). The strength of family bonds is also evident in sibling caregiving for the seriously mentally ill. Although siblings do not often undertake the arduous and time-consuming tasks of parental caregivers, they are willing to participate in significant ways in

the caregiving process. For seriously mentally ill individuals, support from brothers and sisters might help them avoid the social isolation that is one of the most serious secondary disabilities of mental illness.

Although siblings can be a potentially significant caregiving source, it is also important to recognize the limitations of sibling caregiving. A significant minority of people have no siblings. In the general population in the United States in 1980, about 21 percent of whites, 16 percent of blacks, and 13 percent of Mexican Americans were only children (Sweet and Bumpass 1987, 275). Thus, siblings are not possible caregivers for about a fifth of the population. Geographic distance is another limiting factor for many forms of caregiving. In a highly mobile society, many siblings will not live close enough to provide forms of assistance that require proximity. In addition, although most siblings say they will participate in caregiving, few are ready to take on intensive caregiving duties, such as long-term housing or major financial support, that parents often provide. Thus, sibling caregiving must be seen as a supplement to, rather than a replacement for, governmental provision of basic resources such as housing and financial assistance for the seriously mentally ill.

Despite the limitations of sibling care, professionals should actively try to stimulate their support. Ties of reciprocity and family obligation bind brothers and sisters of the seriously mentally ill as they do other siblings. Therapists should encourage their clients to reach out to their brothers and sisters and strengthen the bonds between siblings that persist despite the often tumultuous and strained history that mental illness might have caused in earlier years. In addition, strong sibling bonds should not lead to overdependency, a possible negative consequence of fostering parent-child support for the seriously mentally ill. Not only the seriously mentally ill, but also other chronically disabled unmarried populations, such as the developmentally disabled or persons with severe physical disabilities, should benefit from an activated sibling support process. Professionals should not ignore the important, but neglected, resource of siblings of chronically ill populations.

This study provides only an exploratory look at sibling caregiving. Perhaps its most important contribution is to indicate the critical issues that future studies of sibling care should explore:

- longitudinal studies that examine how levels of sibling social support change after the death of parents

- studies that explore the division of caregiving labor within the entire sibling group
- explicit comparisons of the characteristics of sibling caregiving with support from parents, spouses, and more distant members of the social network
- examinations of how siblings interact in their caregiving activities with other members of the social network and with mental health professionals
- studies of how sibling caregiving diverges across different ethnic and socioeconomic groups

As community care continues to be the dominant policy for the seriously mentally ill, it will become ever more critical for both policy makers and mental health professionals to involve relations of mentally ill people, such as their siblings, in supportive activities. Policy makers, mental health professionals, and researchers should all be aware of this potentially important resource.

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Acknowledgments: The research reported here was supported by a grant from the Households and Health Services Policy Review of the Milbank Memorial Fund. I am grateful to Gerald Grob, Ellen Idler, David Mechanic, and Sarah Rosenfield for their comments on an earlier draft of this manuscript. I am also grateful to Sandra Howell-White, Sherree Neese-Todd, and Tina Weishaus for their assistance in conducting the research.

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