Wisconsin Families and Mental Health Services

Aging Families of Adults with Schizophrenia: Planning for the Future
A Report on Parental Planning and the Future Involvement of Siblings

- Authors -

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# Aging Families of Adults with Schizophrenia: Planning for the Future

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Purpose of this report

During the past 5 years, we have conducted three sets of interviews with over 200 mothers who have an adult child with schizophrenia or schizoaffective disorder. Three important goals of our study were to identify the types of services and programs adults with schizophrenia will need in the future, to learn about the type of plans parents have in place to meet these needs, and to identify the obstacles they face in planning for the future.

When thinking about the future, many parents hope that one of their other adult children will be able to help their son or daughter when they are no longer able to provide care. Thus, we wanted to hear directly from siblings about their expectations for being involved in their brother or sister’s life and the obstacles that may prevent them from assuming a more active role in the future.

At our last visit in 2003-2004, we asked mothers to describe plans they have made for the future, as well as to identify which of their other adult children would be primarily responsible for helping the adult with schizophrenia if the need arose. This identified sibling was then asked to complete a self-administered questionnaire, which focused on past experiences and anticipated future responsibilities. At the same time, we also interviewed adults with schizophrenia about their sibling relationships and asked them about ways they would turn to their siblings for help in the future.

The response we received to the sibling study was very positive. We are truly grateful to siblings for sharing their unique perspectives. We hope you enjoy reading this report.
Study participants

Mothers:

- 236 participated; 7 mothers had two children with schizophrenia
- average age was 72 years old
- 55% were married
- 71% reported being in good or excellent health
- approximately 53% belonged to NAMI-Wisconsin

Sons and Daughters with Schizophrenia:

- 161 participated
- average age was 43 years old
- 75% were male
- 32% worked at a job for pay for about 23 hours per week
- 34% lived with their parents

Siblings:

- 146 participated
- average age was 44 years old
- 56% were female
- 75% were married
- 66% were employed full-time; 17% reported part-time employment
- 66% lived within an hour’s drive of their sibling with schizophrenia
- 59% saw their sibling with schizophrenia at least once a month
What are the future needs of adults with schizophrenia?

We asked mothers about the type and amount of help their adult children with schizophrenia will need in the future and who was likely to provide this assistance.

As shown in Figure 1, there was considerable variation in how much help mothers thought their adult children would need in the future with daily living activities such as cooking, cleaning, and transportation. For instance, whereas 29% felt their son or daughter would need “a lot” of help with household chores, an almost equal percentage (30%) felt their adult child could manage these tasks on his or her own.

Finding a place to live and money management appear to be the two primary areas in which adults with schizophrenia will need the most help in the future. Over 50% of the mothers thought their adult child will need “a lot” of help managing money and a similar percentage felt their adult child would also need help finding a place to live.

Approximately 40% thought their child would be able to manage daily living tasks with a “little or some” assistance. However, only 3% felt their son or daughter would be completely independent in performing daily living tasks.

Thus, our findings suggest that there is wide variation in how much assistance adults with schizophrenia will need in the future to live independently in the community. Few will be able to manage completely on their own. Many will be able to manage with occasional assistance. But a majority (approximately 60%) will need substantial assistance if they are to maintain a high quality of life. In general, mothers felt that mental health service providers would be the primary source of this assistance, with siblings assuming a secondary caregiving role.
In what ways have families planned for the future?

By our third interview, over 90% of the mothers reported that they made some plans for the future care of their son or daughter with schizophrenia. The types of plans are reported in Figure 2.

![Figure 2: Types of Future Plans](image)

Nearly two-thirds of the families had financial plans in place by either establishing a general trust, a special needs trust, or a will. However, few parents had gone beyond developing a will or trust. For example, less than 25% had a residential plan.

The majority of mothers (70%) reported that they had spoken to their adult children about the future care of their brother or sister with schizophrenia. However, fewer (26%) had spoken to a mental health service provider about their son’s or daughter’s future care. Only 40% of the siblings whom we surveyed reported discussing with their parents the financial plans in place for their brother’s or sister’s future care.
What obstacles do parents face in planning for the future?

A major obstacle to future planning involved the high degree of uncertainty parents face concerning the future needs of their sons or daughters with schizophrenia. Almost 80% of the mothers had difficulty planning for the future because they were unsure of what type of help their son or daughter would need. One source of this uncertainty revolved around whether their son or daughter with schizophrenia would continue to take medications as prescribed.

In the words of one mother:

“I worry that he won’t be able to take care of himself and will become homeless because he stops taking his medications.”

Another source of uncertainty arose from the precarious nature of the mental health system, as illustrated by this parent’s experience:

“We got him into a community program, and that was really good for him. They had classes and activities and took him on outings. He got to do lots of things that he otherwise would not have been able to do. Then the agency cut the funding. And it left all of these people with nothing to do.”

Another problem that parents faced was the reluctance of the son or daughter to talk about the future. About 60% of the mothers reported trying to talk to their son or daughter about the future, and of these, approximately 40% shared that their son or daughter reacted negatively to the conversation. In the words of one mother:

“We've talked about me not being here forever. She gets upset and doesn't want to talk about the future.”

For about a quarter of the parents (26%), an obstacle to future planning was the pain brought on in thinking about the future. A somewhat smaller percentage (20%) shared that they did not know what steps to take to plan for their child’s future care.
The thoughts of adults with schizophrenia on their siblings’ future involvement

Adults with schizophrenia were asked which sibling they would turn to if they needed help with specific activities and their parents were unable to provide them with assistance (see Figure 3).

Figure 3: Adults with Schizophrenia would ask a Sibling for the Following Help

The great majority of adults with schizophrenia felt that they would turn to a brother or sister in time of need. Between 70% and 80% felt that they would turn to a sibling for an emergency loan, to talk about personal problems, help with an illness, getting places, or going to dinner or a movie. However, 20% of the adults reported that they didn’t feel that they would turn to a sibling for assistance.

As shown in Figure 3 above, for the most part, adults with schizophrenia reported that they were as likely to turn to a brother as a sister if they needed help. There were a few notable exceptions. They were more likely to turn to a brother than a sister if they needed to borrow money (46% vs. 36%, respectively), but were more likely to turn to a sister than a brother if they needed help during an illness (45% vs. 35%, respectively).
What expectations do siblings have about their future involvement?

The majority of siblings indicated that they intend to help their brother or sister with schizophrenia in the future. As shown in Figure 4, siblings expected to help their brother or sister with a range of activities of daily living.

Figure 4: Type of Help Siblings Expect to Provide in the Future

Over 80% of the siblings expected to provide care for their brother or sister during a physical illness, and 70% expected to help their brother or sister manage his/her money. Almost all siblings expected to remain socially involved by including their sibling in family gatherings, social activities, and by visiting regularly.

Many siblings spoke of living near their brother or sister with schizophrenia in order to be able to help if the need arose:

“I know that he’ll be okay but I will try to live near him to help him when my mother dies.”

“I know that I’ll be responsible for her as we age, and I will need to live near her.”

“My husband and I talk about retiring to Arizona and then stop and think, ‘what about him?’.”
Although they expected to be involved, some siblings expressed apprehension about the future:

“I worry about how much more help my brother will need as he gets older and when mom dies.”

“I dread the day my mother can no longer be helping my sister. There will be money and logistic issues, and worse will be the emotional drain.”

Siblings reported many different motivations for wanting to help their brother or sister with schizophrenia, but a common theme was teaching their own children the importance of family. In the words of siblings:

“I hope that I am teaching my children that families are families. We help, love, and don’t desert one another.”

“It shows my children how to keep loving your family regardless of an illness.”

“Allows me to teach my children the importance of family and that no matter what happens to one another, you take care of each other.”

Among married siblings, spouses’ feelings weighed heavily in their decision about their degree of future involvement. For some, discussions around their involvement in the future were a source of stress.

“We talk about him living with us, and it creates friction.”

“My spouse is leery of my sibling spending the night at our home and thinks my family imposes too much of a burden on me with respect to my sibling.”

Others reported that their spouse was more supportive.

“We plan to have my brother live with us. Yes it will be a change, but my spouse and I believe it will be positive. We know there will be trying times but there will also be good times. And good is what counts.”

“My wife is very supportive and understanding of my situation and my sister’s condition.”
How have the lives of siblings been affected?

On the positive side……

Siblings spoke of many positive transformations that occurred in their lives in the process of coping with the challenge of their sibling’s illness. These transformations included developing a greater sense of compassion and patience, strengthening of marital and family bonds, and a deepening spirituality.

“My own sense of compassion for others was because of my sister and family’s influence. I am a teacher because of this.”

“I didn’t know before my brother’s illness if I would be strong enough to deal with someone close to me becoming mentally ill. We made it through and I have much greater confidence in my ability to deal with crisis.”

“I’ve had a few counseling sessions to help me learn to let go. I would love to fix my brother and I have a strong desire to make him better. But he has made me a stronger person, someone who can help others and learn along the way.”

“It has taught me patience. I seem to be able to understand my own son more.”

“I have learned patience and good listening skills.”

“It has given me a larger perspective on life. This has helped me more personally than professionally.”

“The complexity of my brother’s illness has at times caused divisions in our family but it also has brought us together in unity and a deeper understanding of ourselves.”

“His condition has brought us closer together spiritually. It has magnified what is truly important in life, our relationship with one another.”

“My spouse stayed with me and never distanced herself from this crisis. We are stronger today because of this.”

“My two children have learned to be caring and understanding of others. I’m so proud of them.”
On the negative side……

Siblings wrote about the difficulties they confronted in coping with their brother or sister’s illness. Siblings who were young children when their brother or sister became ill appeared particularly vulnerable.

“When growing up, the neighbors would get very angry with my brother. I felt the neighbors’ anger was directed not only at my brother but also at me at times. Being so young, I thought people didn’t like me because something must be wrong with me.”

“When I was younger, I thought my brother’s illness was a reflection on me. I feel better about myself now. But it was a long struggle.”

Others spoke of how their sibling’s illness had affected their relationships with their spouses, parents and other siblings.

“There were times when my brother’s phone calls were excessive and it created conflict in my marriage.”

“It is difficult to visit my parents as they focus a lot on my brother when he calls. It takes away from my visit with them.”

“Family get-togethers are strained. I try to avoid these events but then feel that I’m missing out on time with my parents, siblings, and nieces/nephews.”

“I get along with my other siblings great but resent that they have never included my brother in any family activity. They don’t even think of him unless I initiate it.”

“We (siblings) disagree on what our involvement should be. Who will do what and when. We also disagree about his treatment, living arrangements, and what the future holds.”

“There is a great deal of tension between my mother and brother, which affects the other siblings.”
Other siblings spoke of experiencing a sense of helplessness:

“Sometimes I feel helpless and don’t know how to interact with him. I want to do more for him, but don’t know how.”

“My efforts in engaging my brother in vocational and social activities has been largely thwarted, resulting in a form of learned helplessness for me.”

Siblings had different strategies for coping with these challenges. One of the more common strategies was to distance themselves from their brother or sister’s illness:

“I’ve tried hard to understand my brother and get along with him. But he went through some especially difficult times, and I had to step away from the situation to protect my children.”

“I stay physically distant, and guard our children from my brother’s aggressive behavior.”

“My sister chose to live at a distance. My other brother chose to have little or no contact with him. This can be very stressful for everyone.”

“My sister has decided to distance herself from the effects of mental illness on our family.”
What programs and services would facilitate sibling involvement?

Although many siblings expect to be involved in assisting their brother or sister with schizophrenia, they may need additional information and support to carry out these responsibilities. We asked siblings about the types of information they needed (see Figure 5).

Figure 5: Information Needed By Siblings

![Bar chart showing information needed by siblings]

- Siblings reported the greatest need for information on the long-term course of schizophrenia and the availability of community resources.

- About half of the siblings reported the need for more information on the causes of mental illness, treatments available for their brother or sister, strategies to help them cope with their brother’s or sister’s symptoms, and the medications their brother or sister uses and its side effects.

- Our findings indicate that siblings typically received most of their information about their brother’s or sister’s mental health condition and treatment from their parents and have relatively little contact with their sibling’s mental health providers. Less than 25% of the siblings reported that they have had contact with their brother’s or sister’s psychiatrist or social worker over the past year.
Finally, we asked siblings to identify programs and services that might facilitate their future involvement in the care of their brother or sister (see Figure 6).

Figure 6: Programs, Policies, and Services

More than 60% felt that the availability of tax credits would ease the burden of helping care for their sibling with schizophrenia. Over half of the siblings expressed an interest in workshops targeting siblings. Although only about 20% of siblings have participated in a support group in the past, approximately 40% felt that participation in a support group now or in the future would help facilitate their involvement.
Conclusion

We have learned a great deal about parental planning and the future involvement of siblings in the life of individuals with schizophrenia. We found that many parents have made financial plans for their son or daughter’s future care either through a trust fund or will. A major gap that we have identified in our research is the need to help parents develop plans for the future that go beyond financial planning. We have found that few parents are aware of what else can be done beyond establishing a will or trust. We are working with NAMI - Wisconsin to develop a workshop to be held in November of 2005 in Madison that will help parents develop more comprehensive plans for their adult children with schizophrenia. Information about the workshop will be available in September through NAMI-Wisconsin (1-800-236-2988).

We also found that the great majority of siblings expect to be involved in the life of their brother or sister with schizophrenia when their parents are no longer able to remain actively involved. Two major obstacles faced by siblings are the competing personal and family demands and the geographic distance from their sibling’s home. With the passage of time, competing family demands will likely diminish as the sibling’s children become adults and establish independent lives. Overcoming problems of geographic distance maybe a more formidable challenge.

In addition, there is great variation in how siblings are affected by having a brother or sister with schizophrenia. Whereas the lives of some siblings seem to be transformed in positive ways, other siblings are negatively affected and appear to distance themselves from their brother or sister’s illness. We are in the process of trying to understand why some siblings are able to grow through the experience of coping with their sibling’s illness whereas for other siblings the experience takes a considerable toll on their well-being.

These preliminary findings demonstrate the commitment of families to caring for a relative with schizophrenia. The universal concern for aging parents with an adult child with schizophrenia is, “what will happen to my child when I die?” This is the first large-scale study of aging families of persons with schizophrenia that has been able to follow families over several years, and therefore designed to begin to give us an answer to this universal question that parents ask in their later years. Families have experienced many changes during the past five years. These include declining parental health and the move of the adult child with schizophrenia from the parental home into an apartment or group home. Regrettably, we have also seen a decline in the physical health of many adults with schizophrenia over a relatively short period of time.
In our next report, we will describe the changes experienced by the adults with schizophrenia over the past five years, and how they have coped with these major life transitions. Ultimately, we hope that the study findings will be used by mental health professionals and policy makers to put programs and services in place that will help adults with long-term mental health problems cope after their parents are no longer able to be their primary caregiver.

Thank you for your interest and continued support of this research. For more information about this study please visit our website:  

http://www.waisman.wisc.edu/family/index.htm