

Aging Parents of Mentally Retarded Children: The Impact of Lifelong Caregiving

Summary of Year-One Findings and Project Update

Summer, 1989

Project Staff

Marsha Mailick Seltzer, Ph.D.
Co-Director

Marty Wyngaarden Krauss, Ph.D.
Co-Director

Barbara Larson, B.S.
Project Manager—Wisconsin

Helene Chaika Fausold, Ed.M.
Project Manager—Massachusetts

To Our Project Participants

Our project is now being conducted in two states—Wisconsin and Massachusetts—and involves 450 families. It is the largest study of its kind in the country and we are so pleased that you are involved in it.

Our research began as a one-year project but we have expanded it to five years. This decision was made for several reasons. We have learned a great deal from the first set of interviews in Wisconsin and Massachusetts. We now have a basic understanding of the services provided to families with an adult retarded child, the other sources of support for caregiving families, and the concerns of families as they look to the future.

However, a great deal more can be learned by meeting with the same families over the course of several years. This "longitudinal" approach will allow us to see how things change for caregiving families in their middle and elder years, and to learn what might be causing these changes. By expanding our study, we will be able to gain a more complete understanding of the strengths and needs of caregiving families at this stage of life. We are very pleased that our study is now longitudinal and hope that you will continue to work with us.

In this first report of our work, we want to tell you a little about what we've learned so far and describe our future plans in more detail. We hope you will read the whole newsletter because *you* are the reason we have started this study and we want you to be as informed as possible.

What is the History of this Project?

This study began in 1988 when Dr. Marsha Seltzer was a professor at Boston University and Dr. Marty Krauss was (and still is) at the Heller School, Brandeis University. With the support of grants from the Andrus Foundation of the American Association of Retired Persons and the March of Dimes Birth Defects Foundation, we recruited and interviewed 225 mothers in Massachusetts who were at least 55 years of age and who had a mentally retarded son or daughter living at home with them. The interviews went extremely well, with the mothers giving very generously of their time and insights. Many of the fathers of these adults with retardation also participated in the study by completing questionnaires.

Our study faced a major challenge, however, when Dr. Seltzer moved to Madison, Wisconsin in the summer of 1988 to assume her new position at the University of Wisconsin. Because the project was going so well, and because there has been so much interest in our research, we decided to expand the one-state study to include two states: Massachusetts and Wisconsin. We received grants from the Retirement Research Foundation and the March of Dimes Birth Defects Foundation for the Wisconsin component of our research. We recruited another sample of 225 mothers in Wisconsin who were similar to those in Massachusetts, that is, at least 55 years old and caring for a son or daughter with retardation in their home. The response in Wisconsin was as enthusiastic as we experienced in Massachusetts. In fact, many more mothers volunteered to be in the project in Wisconsin than we could possibly interview in person.

What is the Purpose of the Study?

We have three basic reasons for conducting this study. First, most studies about families with a retarded member are focused on families with very young children. This is important because everyone wants families to get off to a good start. However, it is also important that we understand more about families who have been providing care for decades. As policy makers, program providers, and researchers become increasingly aware of the large number of families like yours, we felt that a specially focused study was necessary.

Second, we are very interested in learning from your experiences as a parent of a retarded child. Other parents whose children with retardation are younger than yours may not know what to expect as the family gets older. You can help other families by sharing your perspectives about what parenting a child with mental retardation means for you, for your family, and for your community.

Third, you are at a very interesting stage in your own lives. You have special characteristics that set you apart from many other parents your age. Researchers are interested in studying what it means to provide care to a child with a disability during one's middle age and elder years. By virtue of your caregiving responsibilities and age, you are able to provide important information to people who want to have a deeper understanding of what these two issues mean to you.

For these reasons, we expect that our study will have a strong impact on many different groups of people, including policy makers, program providers, researchers, and other parents of retarded children who will benefit from your accumulated wisdom and experience.

Two Case Examples

We present these case examples to illustrate the range of families that participated in the study. The names used in these case studies are fictional, and all identifying information has been altered to protect the confidentiality of these families.

The Peterson Family

Mrs. Peterson is 73 years old. She is widowed and lives with Matthew, her 48-year-old profoundly retarded son. She also has a 39-year-old married daughter who lives nearby with her husband and young children. Matthew attends a day program on weekdays. However, other than the time spent at the day program, he only goes out of the house accompanied by his mother.

Matthew's health status is poor and has become worse during the past few years. He can dress himself but needs assistance from his mother with a variety of daily living skills, including bathing and remembering to use the bathroom. He does not perform any household chores. Mrs. Peterson provides all needed support to Matthew. In light of the intensity of the care that Mrs. Peterson provides to Matthew, they receive very little formal and informal support. Other than social security, Mrs. Peterson receives no services for herself. Matthew participates in the day program, but his mother feels that not all of his needs are met there. Specifically, Mrs. Peterson told us that her son needs physical therapy, occupational therapy, a visiting nurse, and some sort of recreational program. Regarding informal support, Mrs. Peterson turns only to her married daughter and to her son-in-law for help. She said she has no friends she can really count on when help is needed.

Mrs. Peterson is in poor health. She has a heart condition and arthritis. Her main concern is trying to find a "special home" for Matthew because she feels that she cannot take care of him much longer. While she hopes that her daughter will provide this special home, this plan has not yet been fully worked out.

The Sullivan Family

Mrs. Sullivan is 58 years old and lives with her husband and two children in a suburban community. The Sullivans also have three grown children not living at home. One of the Sullivan children, Sharon, has mental retardation. Sharon is the eldest of the five children.

Sharon is mildly retarded. She is 35 years old and has always lived at home with her parents. Last year she completed a vocational training program, but she does not currently attend any program or engage in any kind of work. She goes out with friends or other family members for social activities about twice a week, and also goes out on her own several more times each week. Sharon is very independent and requires no assistance with personal care or with many house-keeping tasks. Her mother told us that Sharon makes a real contribution to the family by cleaning the house and doing errands for other family members.

Mrs. Sullivan is in good health. She holds a part-time job and has a large circle of friends and extended family. She turns for support to her husband, to her own sisters, and to several close friends. With the exception of one sister, all nine people who comprise Mrs. Sullivan's support network live within an hour's drive of her home; most live within a few miles.

Mr. and Mrs. Sullivan strongly believe that their other four children should not have to accept the full responsibility for Sharon. Mrs. Sullivan states that she wants each of her children to be able to "live their own lives." While she and her husband respect Sharon's determination to be independent, they also fear that this may prevent her from accepting needed help.

Although Sharon has a social worker, she currently refuses to participate in any formal services. However, her mother feels that she would benefit greatly from vocational guidance and from participating in a structured recreational program. Both Mr. and Mrs. Sullivan are concerned that Sharon lacks an adequate support network and worry that her refusal to accept services will become a much greater problem when they are no longer here to provide for her. Mr. Sullivan expects that Sharon will have to live out her life in some type of special setting. However, his wife is very uncomfortable with this possibility. While the Sullivans have accepted Sharon's limitations, it has been much more difficult for them to come to a decision about her future.

How Did We Find the Families Who are in the Study?

We used several strategies for finding the families who are participating in the study. First, we worked with professional staff from agencies responsible for serving persons with mental retardation in both Massachusetts and Wisconsin. They were very cooperative and agreed to help us by distributing information to families that met our criteria. We also contacted Associations for Retarded Citizens in both states. The people who work for the ARC were equally helpful and many families became known to us through the ARC's efforts.

The response in both Massachusetts and Wisconsin was overwhelming! Over 1,000 families volunteered to participate in the study. It is impossible to visit and interview everyone who contacted us, as we do not have enough money for such a large study. You, of course, continue to be a member of our in-person study. However, we will be surveying by mail other mothers who met our criteria but who could not be included in our in-person interviews. It has been truly gratifying to see how willing families are to participate in this research project and we thank all of you for contacting us.

Who are the Participants?

The Mothers

- 66% are married and living with their spouse; 28% are widows.
- Most had lived at their current residence for about two decades.
- 98% are Caucasian; 51% are Catholic.
- The mothers range in age from 55-85 years, with an average age of 66.
- 81% graduated from high school; 40% continued on with additional education.
- The majority are no longer or were never employed.
- Over 75% said they were in excellent or good health
- Average family income was about \$24,000/yr.

The Fathers

- Husbands were on average two years older than their wives and had been married about 41 years.
- Most were Caucasian and Catholic.
- 87% graduated from high school; 60% continued on with additional education.
- The vast majority described themselves as being in excellent or good health.
- About half of the fathers were still employed.

The Sons and Daughters

- Slightly more sons than daughters with retardation are part of the study.
- Age range is 15-66 years, with an average of 34 years.
- The vast majority are mildly or moderately retarded. More than one third had Down syndrome; others had cerebral palsy, autism, or epilepsy.
- Most were in excellent health. Very few had been hospitalized during the six months prior to our interview; most had seen a physician at least once in the preceding six months.
- Over 80% had always lived at home. For those who had lived elsewhere, they were age 15 when they first lived in the other setting. They lived in another setting a little more than five years on average before returning to their parents' home.
- Most attended a day program for about 31 hours per week at the time of the interview.
- Most had a "service coordinator" or social worker who was responsible for ensuring that their service needs were met.
- Most commonly received services were transportation, vocational, social work, financial, and recreational /social activities.
- Most commonly needed services were social or recreational, speech therapy, physical therapy, and psychological services.

How Much Assistance do Mothers and Fathers Provide to Their Son or Daughter?

Mothers were asked about the assistance they provided to their mentally retarded sons or daughters. On average, mothers assisted in many activities of daily living and their involvement was greater than other family members or non-relatives. The most common areas in which assistance was provided were: grocery shopping, preparing meals, and doing laundry.

Fathers also provided some assistance for their retarded son or daughter. The only task which fathers provided more help with than mothers was in performing minor home repairs. Fathers helped almost equally to mothers if their child needed some assistance with mobility, such as walking up and down stairs, or moving in or out of chairs.

How Much Support Were Mothers Receiving?

We asked about services mothers received to help them care for their retarded son or daughter or for their own personal needs. Mothers in our study received very few publicly-supported services to assist them in taking care of their retarded child or for themselves. The most common types of services received were respite care and financial assistance, generally social security benefits.

Most mothers said they didn't need any more services than they were getting. For those who did say they needed a service but weren't receiving it, the most commonly expressed need was for respite care.

We also asked mothers about their informal support networks—family, friends, and other people who are important to them in their daily lives. The mothers' friends and family members tend to live nearby (most within an

hour's drive of the mothers' home) and have frequent contact with them. On average, mothers have known the people in their support networks for over 30 years. Most of the mothers were very satisfied with the level of support they receive from friends and family members.

When Will You be Contacted for Another Visit?

As we described earlier, the study will include three more interviews during the next four years. In the second interview, we hope to get an update from you about how things have been going for you and your family since the last time we visited you. We also will want to hear more about *your views* on the experience of raising a son or daughter with retardation to adulthood at home. Lastly, we would like to meet your son or daughter and collect some information directly from him or her. We have assembled another packet of information for you that we will bring with us to the next interview.

We will be in contact with you either in the fall or winter of 1989 (for the Massachusetts families) or the spring of 1990 (for the Wisconsin families) regarding the scheduling of the second visit. Of course, your ongoing participation in the study is completely voluntary, but we *very much* hope you will continue to take part in this project.

This packet also includes a brief form that you can use to let us know if your address or phone number has changed since your last interview. If it has, please complete the form and send it back to us in the envelope provided. Also, we include two newspaper articles about our project—one from Massachusetts and one from Wisconsin—so you can see the kind of publicity we have generated.

This research is being conducted under the auspices of the Waisman Center at the University of Wisconsin-Madison, the Heller School at Brandeis University, and the Eunice Kennedy Shriver Center in Waltham, Massachusetts. Support for this research has been provided by grants from the Andrus Foundation, the March of Dimes Birth Defects Foundation, and the Retirement Research Foundation.
