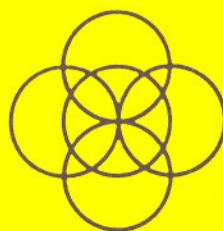


**A BOOK OF QUOTES  
FROM FATHERS:  
SHARED EXPERIENCES OF FATHERS  
OF ADULTS WITH MENTAL  
RETARDATION**

"Aging Families of Adults  
with Mental Retardation: The Impact  
of Lifelong Caregiving"



Principal Investigators

Marty Wyngaarden Krauss, Ph.D.  
Heller School  
Brandeis University

Marsha Mailick Seltzer, Ph.D.  
Waisman Center  
University of Wisconsin-Madison

# STUDIES ON AGING AND DEVELOPMENTAL DISABILITIES

Marsha Mailick Seltzer, Ph.D.  
University of Wisconsin  
Waisman Center  
1500 Highland Avenue  
Madison, WI 53705

(608) 263-5760

Marty Wyngaarden Krauss, Ph.D.  
Heller Graduate School  
Brandeis University  
P.O. Box 9110  
Waltham, MA 02254-9110

(617) 736-3831

Dear Family Members,

Over the past year and a half, we interviewed over 150 fathers who have an adult son or daughter with mental retardation. Although fathers participated in our study before by completing written questionnaires, this was the first time that we conducted interviews with them. The views and insights of fathers has greatly increased our knowledge and understanding of individuals with mental retardation and their families.

In this booklet, we have assembled some of the wisdom, experiences, and concerns that fathers shared with us. While many of the comments reflect common themes expressed by families, there is also a wonderful diversity, representing individuals' unique views and experiences.

We are extremely grateful to all the family members -- fathers, mothers, and their children -- who have participated in our study, and have guided us toward a better understanding of what mental retardation can mean to families.

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## OBSERVATIONS OF FATHERS ON LIVING, LOVING, & LEARNING . . .

. . . "She's a joy to have around. We often go out for breakfast together. We enjoy her and like helping her."

. . . "This is what we have to do; it's our lot in life. We were chosen for this special responsibility and we are accepting our responsibility."

. . . "I enjoy helping her. She's very dear to me. If I can do things for her, I do it."

. . . "I imagine when a child like that is born, things look pretty bleak, but when they get as old as my son, things are different and they are fun."

. . . "We love him and enjoy doing everything we do for him. We couldn't love him any more if he were president."

. . . "Sometimes it's hard, especially when my wife and I want to do things together. Overall, I'm happy. I would rather have her here than worry about her living somewhere else."

. . . "Years ago when she was small, the trend was to institutionalize. If I had to do it again, I'd do the same. We have had to build our lives around her. We still get to do a lot of things, and we have a lot of people who help us out. We just have to put her first. We've had a good, complete life."

. . . "I would like to give more help, but I'm accused of spoiling him. I try to stay out of the way as much as possible. I have the feeling no one can do as good a job as I can. He has to learn to do things more independently. You have to struggle through these times."

. . . "Family life has always been a big thing for us. We're doing things together and we like it. She's a real sweetie, a good person. If she weren't here, we'd be a little more sedate. We stay active. We have a normal life here; I wouldn't want it to change."

. . . "The relationship between us is good. We don't get too concerned that he can't be 'normal.' We accept him."

. . . "We are very fortunate to have this child in our family."

. . . "We've become accustomed to our life. We like our life. It's been this way for so long."

. . . "Early on we worried that we wouldn't be able to do enough for him. He went to the doctor a lot when he was young. The doctors said he would live to be about seven. He's now in his thirties."

. . . "He keeps us young!"

. . . "When she goes to camp and we are all alone, it seems empty."

. . . "It's all part of life. He's far more advanced than others. He is not a burden, but is an important member of our family."

. . . "I've had a very fulfilling life. I'd tell people, 'Don't let life scare you. There's a lot of challenges, but there's nothing more interesting.'"

. . . "He's my son and I love him."

. . . "I wonder how we can make people aware that they will be involved in both personal and property aspects of the guardianship. It was a revelation to us when we became guardians for him."

. . . "This gives me some purpose in life. I'm glad to do it."

. . . "Although he is retarded and physically handicapped, he is accepted as an equal not just within our family but also as relates to other relatives and friends. There would now be a serious void in our lives if he were no longer with us. He has done as much to enrich our lives as we have done to enrich his life! We don't regret for a minute the fact that my wife gave birth to an 'abnormal' human being. He is us!"

## FATHERS' VIEWS ON THE DOWNSIDE . . .

. . . "We rarely see him smiling, enthusiastic. He just misses the whole thing."

. . . "We try to give her therapy such as latch-work. It's hard on her, her concentration isn't there... How much time can you give? Maybe it's because we're getting older."

. . . "I think she's afraid of new challenges or environments."

. . . "Sometimes when you're tired at night, it's hard to gear up; she has to be taken care of too."

. . . "Just the fact that he has retardation is stressful. If he was 'normal,' you'd expect him to have his own family by now."

. . . "There were projects I wanted to attempt when I retired, but have never gotten to them. She takes a lot of time."

. . . "It's been difficult to see her turned down for jobs so many times because of the attitudes of others who don't understand."

. . . "We can't go anyplace without him or find anyone to stay with him."

. . . "I wish we had enough money to provide a trust fund."

. . . "It's not his fault he got a tough break at the time of birth; negligence on the part of the doctor. It's like having a ten year old around all the time. It's tough, my wife and I are up there [in years]."

. . . "My wife hasn't been able to do what her girlfriends have been able to do. The only regret I have is what she has had to sacrifice."

. . . "She controls us 100% of the time."

. . . "The limitations that he's under. I feel sorry for him, the problems that he has to deal with. I feel for him more than I do for myself, like he can't drive, etc..."

. . . "We used to socialize a lot. We can't go together; we must take turns."

. . . "I always dreamed I would take a year and travel across the country. I will never be able to do it."



## FATHERS' VIEWS ON THE NEED FOR SERVICES . . .

. . . "One of the things that has been a help in the past, that has been somewhat difficult to achieve, is respite care. We impose upon friends..."

. . . "Give him 'a friend,' someone who will go places with him."

. . . "Speech therapy was offered in the past, but is no longer offered. I guess because he didn't respond enough. But that's my son, he always does everything very slowly and deliberately. I'd like to see more speech therapy and I wonder if they are sufficiently qualified to really make a difference."

. . . "Respite care would be desirable for the parents. Other than that, he is getting a complete life."

. . . "We need respite, someone to take her out for activities. We've had respite in the past but, over time, the services gradually dwindle."

. . . "People like us who established these programs, now find themselves on waiting lists for services they established. We go back to when there wasn't any training in University Schools of Education. We had a little bit here, our superintendent did what he could. My philosophy was that you try to do something that helps everyone."

. . . "She needs someone that she gets along with to come and take her out to dinner, etc."

. . . "Our biggest need is to have a source of respite care so if we want to take a trip we can leave him. "

. . . "Currently, we want more recreation, small group interaction, and transportation. She also needs training in communication skills. Over the long-term, there is a lack of creativity in planning for future housing needs. More could be done, but we need leadership."

. . . "Our need is a place for her to go like a group home, but there's just none available."

. . . "We'd like more organized physical activities, as well as transportation to and from activities. He is overweight and needs exercise."

. . . "The services she received when she was going to school haven't continued. We wish they would."

. . . "We would like to have her learn to tie her shoes."

. . . "I wish there were more continuity of staff. There's a big turnover in people who are in contact with her every day, and they're probably not trained very well to do the job before they do it. This may have to do with the pay scale. Also, at her work, there may be some employees that don't understand the individuals."

. . . "I don't need services. I'll take care of her. I see other parents looking for someone else to provide. I'll do it myself."

. . . "He is not on SSI. He pays for transportation while the people he works with get free transportation. He needs more of a helping hand. He's a very hard worker, and we want more to help make life easier for him."

. . . "Learning about Medicare, wills, trusts, and estate planning for families of children with retardation is needed."

. . . "She should be doing more socially, but as we get older, we're not taking her out anymore. If we could have someone take her out for us it would be helpful."

. . . "She chooses the things she wants to do. They are within the realm of what she should do."



## FATHERS' THOUGHTS ABOUT THE FUTURE

### FOR SONS AND DAUGHTERS WHO LIVE AT HOME . . .

. . . " My daughter and son-in-law have insisted they will take him in, but my wife and I have felt they shouldn't have to do that, so we put his name on a waiting list."

. . . "We're very happy with him at home, but we do feel we need to prepare for the future. That's why we put his name on the waiting list."

. . . "We don't think the quality of life for him could be maintained in a group home situation. He is so active socially and recreationally."

. . . "We're going to build him a house. We're working on that now. We've had so much experience. We've had our architect friend design a group home. It will have living quarters for a family and four suites for the folks with disabilities, with a little kitchenette . . ."

. . . "We've approached him on group homes in the area and he says, 'I have a group home right here.' He's not ready to go yet. Most of his friends are in group homes but he wants to stay here."

. . . "Last year we talked to a few people. We're thinking of leaving our home to the disabled. We're in the process of working this out. We can stay in the house and will be taken care of along with our daughter."

### FOR SONS AND DAUGHTERS WHO HAVE MOVED . . .

. . . "When she first went into the group home, that was the worst time that I can recall, after getting over the shock of her being born."

. . . "She's getting along fine. She's happy with the situation, likes her supervisors, likes her job, can come home to visit when she wants to. Things are going very well."

. . . "She has a spacious apartment, with two others, overlooking the river."

. . . "She's living independently and her favorite phrase is 'she likes her privacy.' When she lived at home, she spent a lot of time in her room."

. . . "At first we stayed away so he could get adjusted to staying. I feel now we're somewhat satisfied with how much we can see him . . ."

. . . "Where my son is now, we practically have to be available at all times . . . He gets sick easily. We get him, he comes home (when he's sick)."

. . . "We have some free time now. My wife gets to do a little less; she can sit down once in a while."

. . . "We were concerned about what would happen when we were deceased. Now there are new problems, like getting bills paid, and the people she comes in contact with."

. . . "It was awful hard when she first went to live there. She's feeling more positively about the group home, and happier about going back now. She's feeling happier about it so we are, too."

. . . "My wife and I are in senior citizen range and I'm retired. Our health was getting to the point where we were no longer able to provide him the help he needed. People younger in age would be better able to care for him. It was better at this point in time to make this move rather than wait until an emergency arose."

. . . "The place they're at now could stand more in room space. The handicapped appreciate space as much as anyone else."

## OTHER THOUGHTS ABOUT THE FUTURE . . .

. . . "I still have concerns about what will happen to her when we pass away. I feel more positively because I think she's becoming more self-reliant, more independent. She's more independent and doesn't rely on us as much."

. . . "What happens when we die is our only worry."

. . . "Getting decent programs and plans in place to help him lead a decent life is a worry."

. . . "I find that the older I get, the more adjustments and compromises I must make to insure my son's future. It is important to be able to make changes in plans because plans can change from day to day because of monetary considerations, and deterioration in health and physical ability. These changes occur not only to me but also to everyone else so it is imperative to be flexible while keeping the main goal - my son's future - in mind."

. . . "I wish someone could come up with a magic formula for how to ease the anxiety of what happens when we die."



## SUPPORT FROM FAMILY AND FRIENDS . . .

. . . "My wife is my right hand."

. . . "We live in a community where I think we've acquired a lot of friends and a lot of help as a result of having her."

. . . "My wife is wonderful, intelligent. My children had a wonderful mother."

. . . "There isn't anything I want or that I think I need that my friends and family wouldn't give me."

. . . "They go out of their way to do what they can do. I can depend on them."

. . . "If anything goes wrong, my son and daughter are right beside me. I don't need to ask for anything twice."

. . . "They'd come right away if we called for help."

. . . "I don't look for a lot of support but if anything comes up, if I'm sick or hurt, they're right there by my side."

. . . "No one knows what you go through on a day-to-day basis. They're supportive to the extent that they can be. They have their own lives. It's our responsibility, and we have to handle it."

. . . "We've always been there for everyone. They haven't been there for us."

. . . "They are always available. His brother and sister grew up with him. They are the reason we did not institutionalize our son."

. . . "Everybody is willing to help when there's a problem, for example, with transportation. Sometimes we hate to ask, but they're always willing to help."

. . . "My wife has been a pillar of strength."

. . . "My greatest support came from facing our son's diagnosis together with my wife."

. . . "All our other children have been very supportive to us when we needed it. He was included in everything we did."

. . . "I would like a better social network, or some more meaningful things taken care of."

. . . "You always ask more of people than what they give. It's philosophical but true."

. . . "They, I don't think, could do much more. They'll do things for us you wouldn't think kids would have to or would. My son and grandson come up and take me coon hunting and my son-in-law takes me when he should be picking corn."

## **OTHER SOURCES OF SUPPORT . . .**

. . . "Best thing that ever happened is her work program. It gives her something to do, a place to go, responsibility."

. . . "Her day programs have helped us since she was about 15 years old."

. . . "The ARC helped us a lot. We did not know where we were going until we got involved."

. . . "Involvement with Special Olympics has brought us together with the same group of people over a period of time, who understand what's involved, and are similar in their experiences."

. . . "The workshops and social activity programs are enormously helpful."

. . . "When we first became aware of his condition, we joined a parent group. Getting together with other parents helped us better understand and cope with the problems."

. . . "The greatest support has come from one individual in the last 30 years -- the principal of my son's school."

. . . "Having other families in the same circumstances is helpful. We have a very nice network of people whom we have known since she was in kindergarten."

. . . "Her day program makes her feel useful."

## VOICES OF EXPERIENCE

### WORDS OF WISDOM FROM FATHERS TO OTHER PARENTS . . .

. . . "Give all the love and care you can to your children. Give them a chance to express themselves."

. . . "Analyze the situation, do all you can, be realistic, and make life for your family as normal as you can."

. . . "I think we all fall in a special group and by talking to the other families we can help one another - especially young couples. I feel with our experiences we can help. Every situation is different though."

. . . "Work with a psychiatrist or psychologist if necessary, but establish a good relationship with your child."

. . . "Treat your child as you would a 'normal' human being. She had no handicap for me. I taught her to do many things."

. . . "I would not want people to think that this is such a burden that you have to be a saint to do it. I find it's been very fulfilling to take care of my son over the years. I'm as proud of him as of my other children. When you work for someone else, that is one of the greatest things you can do and the most fulfilling. Things work themselves out. Support groups are important to know you're not alone. It's difficult to bring up a handicapped child in a normal society, but very satisfying, too."

. . . "Each situation is very different. Caring and loving a youngster is all you can do. Know what help is available and use it."

. . . "If you can care for the adult with retardation, then do so. When it gets to be a problem, find someone whom you know will bring them up as you would."

. . . "Don't lose patience. Be there for your child."



## WORDS OF WISDOM FROM FATHERS TO PROFESSIONALS . . .

. . . "Don't ignore the person with the disability. Talk directly to him/her. Take a look at what is coming up in the years ahead."

. . . "It's a tough job. Don't give up."

. . . "Work with us. Don't tell us what we need. We must have people who understand the family and the person with retardation."

. . . "We need better education, more help and better understanding of the problems parents are faced with. Unless you live with a child day in and day out, nobody realizes the sacrifices a parent makes..."

. . . "Consider the parents as well as the child. Consider the amount of stress and burden. For example, they want us to train her to do household tasks. We work and are too tired at night."

. . . "Keep up the good work."

. . . "There should be a more holistic view. She needs more than an 8 to 2 schedule each day. She should be able to go to the mall when she wants to go. She needs to be like other women her age. She needs to be working and learning in the real world."

. . . "I'd like them to know how very important she is to us."

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