

UNANTICIPATED LIVES

Aging Families of Adults with Mental Retardation:

The Impact of Lifelong Caregiving

A COMPILATION OF STUDY FINDINGS AND REFLECTIONS

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Aging Families of Adults with Mental Retardation: Impacts of Lifelong Caregiving

Introduction

Since 1988, we have studied 461 families, all of whom provided in-home care to an adult son or daughter with mental retardation when the study began. These parents face an atypical and unstudied dual challenge: the continuing caregiving responsibility for an adult child with a disability and the personal challenge of adjusting to the manifestations and consequences of their own aging.

The overall purpose of the research was to investigate the factors contributing to residential transitions for adults with mental retardation, the consequences of such decisions for families, and changes in the well-being of adults with retardation who continue to live at home as compared to those who have moved to a different residential setting.

The study addressed these issues with the largest existing sample in the U.S. of older mothers and fathers (average age = 66 years in 1988) and their adult sons and daughters with retardation (average age = 35 years in 1988), about one-third of whom have Down syndrome. Data have been collected from multiple family members a total of eight times.

During the study period, about a quarter of the adults moved out of the parent's home. In other families, the primary responsibilities for caregiving shifted from the mother to the father, and sometimes to an adult sibling, often due to declining health of the mother. In the majority of families, however, one or both parents continued to provide in-home care. All members of the study have described both gratifications and worries as part of their experiences as long-term caregivers. Thus, for some, the last ten years have witnessed a continuation of a life long pattern of in-home caregiving. For others, many, many changes have occurred that have altered the lives of the parents and their adult child with mental retardation. We have been privileged to observe these changes and the consequences they have set into motion.

Below, we present some of the findings from our study. First, we describe what we learned about major aspects of the lives of adults with mental retardation, particularly with respect to the services they receive, changes in their lives during the study period, and the range of behavioral issues they have. Next, we describe what we've learned about the mothers, fathers, and siblings of these adults with retardation. The booklet concludes with wonderful quotes from study participants--mothers, fathers, and siblings. We find that the study participants are the most eloquent "reporters" of their lives and we are pleased to share their thoughts and concerns directly.

Major Findings About the Adults with Mental Retardation

1. On average, adults with mental retardation living at home receive between 4 and 5 publicly-supported services. During the course of the study, the amount of service received did not increase significantly, except for those who moved to a residential program. People who lived with their families throughout the study were less likely to receive therapeutic services (such as physical therapy, speech therapy) than those who moved subsequently to a residential program. Further, people living in residential settings received more social work, recreational and social services.

2. About a quarter of the adults with mental retardation moved to a new residence during the study. Of those who moved, 70% moved to a supervised community living setting, such as a group home or supervised apartment. Another 15% moved to an independent or semi-independent living setting, while 10% moved to a congregate setting (such as a nursing home or institution). Only 5% of those who moved went to live with other relatives.

3. There is great diversity in what adults with mental retardation do during the daytime. We found that about 14% of the adults in our study who lived with their parents had no vocational placement. About three-fourths of those who had a day placement worked in one setting during the day. On average, these people worked about 30 hours a week. Interestingly, over the course of the study, many adults changed from working in one setting to working in multiple settings during the day. For example, many adults now work part-time in a sheltered workshop and part-time in a supported work environment.

4. About three-quarters of the adults with mental retardation had behavior problems. About a quarter of the adults had no significant behavior problems. Another 44% had behavior problems but none that was considered "clinically significant." About 30% of the adults in the study had fairly severe behavior problems. We also found that some of those who subsequently moved to a residential setting during the course of the study had more severe behavior problems in comparison to those who remained at home during the study period.

5. The mothers are the mainstay of the social lives of their adult sons and daughters with mental retardation. On average, fully half of the members of the social support network of an adult with mental retardation were also members of his or her mother's support network. Women and those with mild retardation were more likely to have developed an independent set of friends and other social supports than men and those with more severe retardation.

Although these adults do not lack social relationships, they do not have enough social activities to fill their free time. This is a prominent concern expressed by the parents in our study. Over the decades, the parents have taken steps to fill the time not occupied by work or a day program. However, as parents age, this responsibility become ever more difficult. Driving at night, organizing activities, finding age-appropriate recreation are all increasingly burdensome.

Major Findings About Families

1. Lifelong family care is an affirmative choice made by many families. When asked why

they decided to have their adult son or daughter live at home long after the age at which most adults establish their own household, the majority of parents explained that it was their preference to live together. Many commented that it was consistent with their family values for family members to take care of one another. Others noted that their son or daughter made the decision to live at home, preferring this option to a community residence. Still other parents had investigated the alternatives and felt either that the options were inadequate or that no residence was available near their home. Although there are stresses and strains that accompany living together, these families decided not to relinquish the role of active parent.

2. Although mothers have had a very long period of active parenting (35 years on average at the beginning of our study), they have an unexpectedly favorable level of personal and social well-being. They lead full and active lives, and have multiple personal, family, and social roles -- wife (64%), mother of a non-disabled adult (94%), employee (26%), etc. Although they have continued their parenting responsibilities for their adult child with retardation, the mothers in our sample *thrive when they hold multiple roles*. Thus, later-life parenting an adult child with retardation does not appear to disrupt ordinary or valued patterns of social activities.

Further, mothers appear to be more satisfied with their lives than age peers who are caregivers for elderly relatives. Also, they had no higher level of depressive symptoms than other women their age and their social support networks were as active and large. Thus, there is evidence that older mothers who continue to live with their adult child with retardation have adapted well to their ongoing parenting responsibilities, feel positively about their lives, and have coped successfully with the extra demands on their time and energy.

We also found that over the ten years of the study, most mothers maintained positive social and psychological well-being. Mothers whose son or daughter has moved to another residence during the study period, however, reported more stress as a caregiver and lower levels of psychological well-being both at the beginning of the study (prior to their child's relocation) and even following the move.

3. Fathers also provide care to their adult child with retardation, both directly and indirectly through support to their wives. Most fathers (85%) provide some direct, hands-on care, but they help with only about one-third as many necessary tasks as their wives. Fathers provide proportionally more help to adults with severe/profound retardation than mild/moderate, and they help sons more than daughters. The wives of fathers who provide direct care to their adult child have better health and morale than women whose husbands do not give care, suggesting multiple benefits of father caregiving.

4. Siblings of the adults with mental retardation provide an important source of support for both their mothers and their brothers and sisters with retardation. In most families, there is at least one sibling who is currently involved, either emotionally or with respect to "hands-on care" with the brother or sister with retardation. The most involved sibling is more likely to be a sister (64%) than a brother, older than the adult with retardation (66%), and living within an hour's drive of the parental home (83%). Families with involved siblings tend to be more emotionally cohesive than families with either no child other than the adult with retardation or families in which none of the siblings is substantially involved with their disabled brother or sister.

Mothers of involved siblings were in better health, more satisfied with their lives, and were less stressed and burdened by caregiving than mothers who did not have another child involved with the adult with retardation.

Siblings also vary in the expectations for future involvement with their brother or sister with retardation. In about 19% of families, a sibling expects that his/her brother or sister with retardation will live in his/her home after the parents are no longer able to be the primary caregiver. In another third of the families, the sibling does not expect to co-reside, but anticipates continual active involvement. In the remaining 48% of the families, the siblings' plans for their future role vis-à-vis their brother or sister with retardation are not firmly established. Sisters of sisters with mild retardation with higher levels of current involvement are most likely to expect to co-reside.

5. Mothers of adults with mental retardation experience the same range of stressful life events experienced by others their age who do not have parenting responsibilities. For example, during an 18 month period, more than half of the mothers in our sample (53%) experienced at least one major stressful life event (e.g., death of a close friend or family member, retirement, declining health). This is a similar pattern to other older women who do not have a son or daughter with a disability. Mothers who experienced at least one stressful life event had higher levels of depressive symptoms than mothers who had not experienced a negative event. However, the use of "constructive" coping strategies (active planning, focusing on the problem, and seeing the positive aspects) reduced the negative effects of these life events.

6. Respite care is an important source of support for aging parents, supporting the continuation of in-home family care. Over half of the families in our study use respite care services, primarily in their own homes, to provide a needed break from the demands of caregiving. The families most likely to use respite care have a son or daughter with more severe functional limitations and the mothers feel more burdened by their caregiving responsibilities. Health problems in the son or daughter with retardation are a significant barrier to respite use, possibly because of the lack of trained respite providers who can manage complex medical problems.

7. The transition to non-parental care is a prolonged process, involving multiple distinct options, each with different implications for the well-being of the adult with retardation and the family as a whole. We have learned that although virtually all families can articulate their preferences as to where their son or daughter should live after they are no longer the primary caregivers, fewer than half (45%) had made a specific plan. The most commonly made plan is for a move to a non-family residential program (such as a community residence or apartment program), although living with siblings is the choice for some families. Being on a waiting list is the most powerful predictor of an eventual move. In addition, older age of the son or daughter with retardation and poorer maternal health predicted the move to non-parental care. Thus, moves are most likely to occur when the mother can no longer provide the needed care due to aging and health constraints.

8. Residential placement is most likely following parental death. Fully three quarters of adults with mental retardation who have lost both parents moved to a new residential setting, while the others whose parents have died moved to the home of siblings. The increase in the individual's

functional skills that ordinarily accompanies a move to a community residence is less likely to occur when the move is made because of parental death, suggesting the benefits of placement prior to the death of both parents. Parental death results in multiple changes in the life of the adult with retardation -- where he or she lives and works, who the primary caregiver is, the pattern of contact with family and friends, and the services that are received.

Final Thoughts....

In summary, family care is the dominant residential arrangement for persons with mental retardation. It is estimated that nearly 85% of persons with mental retardation in the U.S. live with their families. Our research has revealed the gratifications and frustrations of family-based care among older families who have provided lifelong support to their son or daughter with retardation. Far from being a bleak experience, most parents profess great pride and pleasure in their life's work and in the quality of life they have ensured for their loved one. While it is inevitable that the adults with retardation living with their parents will ultimately move to a new setting or have different caregivers when their parents die or can no longer shoulder the responsibility, the legacy of love and support that the parents have instilled in their family is a truly dominant finding.

Putting Our Findings to Work

We also have worked hard to inform the public and professionals about the strengths and needs of aging families who have an adult member with mental retardation. These efforts include:

- Articles in newspapers: *The New York Times*, *The Boston Globe*, *The Boston Herald*, *The Capital Times* (Madison, WI), etc.
- Radio programs: National Public Radio, Wisconsin Public Radio, etc.
- National public policy forums: President's Committee on Mental Retardation, National Institute of Aging, 1995 White House Conference on Aging, annual reports to national professional associations in the fields of developmental disabilities and aging, etc.
- State-level public policy activities: Massachusetts, Wisconsin, California, New York, Washington (state), North Carolina
- International presentations: Ireland, Finland, Australia, Hong Kong

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**REFLECTIONS FROM MOTHERS
OF ADULTS WITH MENTAL RETARDATION**

In the Beginning. . . .

. . . "The first two years were bleak, with institutional placement the recommendation of professionals. How did we cope? Well, first we formed a parents' group. Then we helped to establish a special kindergarten class and turned it over the school board. The best way to cope is to join with other parents early on, learn together, and then you can help to provide the best possible future for all retarded children."

. . . "At first, I thought I was too perfect to have a retarded child! God wouldn't do this to me! You have a choice--you can accept or reject this child. At first I was devastated and kept thinking, Why me? But, you cannot reject your own child--he's been a delightful baby since birth."

. . . "When I was growing up, I was very good at everything. Everything I did was the best. If it wasn't, it was done over again. When my daughter was born and took sick, I had to face up to the fact that here was something that I could not throw away and start over again. That built a lot of character. I had to pick up the pieces and keep on going."

. . . "I came from a family-oriented family and felt my son deserved the same love and care that was given to me. Our lives revolved around his activities. It hasn't been easy. He's given us much pleasure but also heartaches."

Thoughts About Residential Care. . . .

. . . "Every parent should give themselves a chance to try raising their child at home. I was told to place him in an institution but I thought he would not learn there. I've never been sorry. He's paid me back one million times over for all the care I've given him. He's open and loveable."

. . . "I thought perhaps she might be happier living with people more like her. Quite a few years ago, I asked her if she wanted to live there and she cried. I never mentioned it again."

. . . "Placing our daughter at the group home last year was both the most positive and negative event of the year. I know this is a contradiction in terms, but while it was a very positive event in one sense, in another sense when one gives up their only child to another, it is a very negative experience."

. . . "I still feel very much like a parent even though my daughter has another home now."

On the Need for Services. . . .

... "I wish there was someone available to take her bowling, swimming, or to dances. She needs more social activities outside the home without her mother!"

... "I can't get my daughter into the tub. She could use nursing services but I don't dare ask for anything with all the cuts."

... "Now I understand that they (legislators) want elderly people like us who have had our children home all these years to share part of the responsibility and money for whatever's coming up. But they don't realize that they're not asking any money from the people who have already put their children into an institution and never paid a cent. Why penalize us for having him at home? I sometimes wonder if in the State House any of these people have a retarded or disabled child at home. If they did, they'd know and understand what things mean to a family. It costs more to keep a child in a state institution than it does for us to have him live at home. He could move across the street to my neighbor's and get more than he gets staying at home with me. But who gives him better care than his own family?"

On Learning and Living. . . .

... "It all depends on how you look at the situation. There could be two people living in the same house--one could be happy, the other miserable. I look at this as my lot in life and I did it and I still do it. He's made a greater person out of me."

... "There is nothing negative about raising a retarded child."

... "She provides almost as much care for me as I do for her. She's kind and sees what I need. We both provide company for each other."

... "He's a blessing. He's doing things today I never dreamed he would do, like traveling. I'm so very proud of him. He does many things around the house and has a beautiful disposition."

... "I think she's darn near perfect."

... "When she was born, the only place we could put her was an institution, but I was very disappointed by what I saw. They only thought she'd live six years. It's been a long haul, but full of love that nobody, unless they've been through it, can understand. She's taught me compassion and understanding. She's taught me to treat people properly."

... "You are never the same after having a handicapped child. You are probably more responsible and protective of that child. You are concerned about the family being strong. You look at the basics."

On the Down Side. . . .

. . . "The hardest part is at night, when he's laying there peacefully and you're thinking the 100,000 thoughts of what could have been and all the reasons why this happened. You think that from day one, and I think you ask that all your life. And it goes on 24 hours. It does not end."

. . . "There are a lot of things she needs, but I always have to be the one that arranges, takes, etc. -- and I'm tired of it."

. . . "It is limiting. By now, most children are off on their own. I have a 'forever child'. We can't just run out or be spontaneous. Things have to be planned way ahead and then they don't always work out."

. . . "I feel frustrated that I can't do more for him. His life is sort of drab. I guess he'd like a little more excitement in his life. There's a lot of things that he's interested in and I cannot expose him to them unless I have the money."

. . . "As a couple, we have very little time for ourselves. He's always needed us. My husband suffered more than I because mothers usually take these things more in stride. I was fortunate--we met a lot of fathers with disabled children who just walked out on their wives because they couldn't deal with it. We stuck together."

. . . "There was never a question that she would live any place but home. I have felt that the Lord would let me live long enough to care for her as long as she lives. Now that I am getting older, it isn't that I have lost faith in the Lord, it is that I have lost faith in myself."

On the Future. . . .

. . . "My whole heart and mind is wondering what will become of my daughter."

. . . "My greatest fear is that I'll die before she's in a home. I want to be around to help her adjust and to have her home weekends. I'd just as soon have her home, she's fun. But for her sake, I'd like her in a home and settled."

. . . "My only worry is what he's going to do and where's he's going to be when we're not here. I think maybe we were better off when the retarded children had a shorter lifespan and they didn't survive their parents and we could take care of them their whole lives."

. . . "This is the best place for her and I've always felt that way. I'm haunted, though, by the thoughts of what will happen to her as I get older."

On How People Have Changed. . .

. . . "This experience has made me a better person. It's been a profound experience -- and a great equalizer."

. . . "He taught all of us patience. He was loving and brought us together and made his brother and sister more responsible and more loving."

. . . "It gave direction to my life and gave me something to work for. It also became a positive for others. In helping my own daughter find a niche in the world I also inadvertently helped other families to do the same for their children."

. . . "I am well aware of the price I paid to be a full-time mother to our son. It cost me the opportunity for a career and what might have been a good education. But he was worth it, and I'd make the same choices again."

. . . "It makes you more determined to survive and more stubborn to fight for your kids. From a meek little soul I became a lion, a tiger."

. . . "I think my husband's and my attitudes were changed in regards to raising a handicapped child. When our daughter was born in the late 1950s, there was nothing for her. And, it made us vulnerable. People still don't understand what we have been through in thirty years. We don't see things in the same way as other people. We had nobody and no one. There was just the three of us. And that's hard when you have a little one. A lot of the hurt is gone, but it's still in the back of our minds."

. . . "A lot of people who have these 'normal' children have many, many problems with them-- drugs, alcohol, stealing, and all that stuff. Whereas, I have none of those stressful things. She's a good kid."

. . . "One time a lady told me I didn't know what a hard day's work was. She was a farmer's wife and worked with the handicapped. Then I told her I had a mentally retarded daughter. That shut her up!"

. . . "Having a retarded child is a terrible tragedy, but I wouldn't trade him for any normal child. If one can get beyond the grief and sorrow about what he has lost, and that takes some doing, experiencing life through his eyes and sharing a life with him so filled with joy and innocence has been an extraordinary path to take. I wouldn't have missed it for the world."

On Watching Their Son or Daughter Get Older. . . .

... "He doesn't seem to age the way others do. He's become more mature and every year his understanding gets better. Physically, his knee poses more of a problem."

... "She acts differently. She's more set in her ways. She's very stubborn and she was never like that before."

... "He is slowing down and chooses fewer activities. I don't think he's as happy and his hearing may be declining. He's getting forgetful."

... "He used to stay in his room for hours drawing or watching TV. Now he only spends a couple of hours and he's up and down and up and down the stairs. His face is drawn and his hair is whiter. He's slower moving and eats a lot slower."

... "He hasn't changed. There haven't been any changes. Even my friends have remarked about this."

... "She's reached her change of life now. She's on hormones and her hair is getting gray. She's matured and is not as moody since her changes."

... "I think he worries more about parents getting older and dying. Living with older people and some of his friends' parents have died. He reads obituaries in the paper, and was very interested in Princess Diana's death and funeral."

... "I see him progressing all the time. He's happier, more outgoing, more helpful, I'd say he continues to improve."

On Life After Their Son or Daughter Has Moved to a New Home. . . .

... "I'm going to Hawaii in September. It's the first time I've scheduled a vacation without having to worry about her. It's my first airplane flight and the first real vacation that I've ever had."

... "It's positive because I don't feel the consuming pressure of his presence."

... "We each have our independence and are able to nurture a loving adult relationship."

... "He now has security for the future, something in place and a way of life established for him that is independent of his parents. I like that his horizons have expanded beyond his immediate family, though this took me time to get used to."

... "I've reconciled to the situation. I miss her, but I'm glad she's learning to be on her own. I'm

glad she calls all the time."

... "We had him home over 27 years. I couldn't work and we had financial struggles. There was no quality of life, and we were getting worn out. An evaluation told us he needed services that would only be available in a medical facility. He gets so much more there than we could give him at home."

... "It's gotten much less traumatic. For three years, I would physically feel it in my stomach as I drove away from the residence."

... "To some degree, it has given me more time for myself, but there's been so much aggravation. Something always is happening that is wrong, and something always has to be remedied. Really, we've had such a traumatic time."

... "It's been positive because we've seen him grow in genuine independence. Now we see him as a householder, instead of a dependent. He has his own roots."

... "He's doing the things that normal people do. If something happens to me now, I don't worry. He's got friends and they go places and do things like Summerfest, movies, etc."

... "I feel guilty that she's there and I don't know what to do."

... "She feels more secure, and I have accepted some things I thought were dangerous."

On Changes in Their Son or Daughter Since They Moved. . .

... "He feels he is independent and can get along without his parents. He's proud that he's living on his own."

... "He is more friendly at his day program and now has female friends. He's learning new things like cooking."

... "She learned to be independent and how to cook. She can go to a bank and cash a check. She learned how to use a laundromat and shop for groceries."

... "She has taken off some weight as a result of increased activities. She's involved in a lot more social activities, goes out to eat, and goes to dances with her group home peers."

... "There was a period when he would retire to his room and not circulate. He snapped out it, though. He has a resident who sleeps near him who often sleeps in the day and yells and makes noises at night. For a while, he refused to leave the day program and then wouldn't leave the van

to return to the house. There's been multiple staff changes in the residence."

... "She has a nice, small group of friends who do things together. She has independence now and has the capability to use it."

... "His speech has improved. He has made friends. He is more outgoing than he was."

... "Getting involved with Special Olympics -- especially basketball."

... "There is such a turnover of staff. She just gets to really like someone and then they are gone."

... "Hard to answer. So changeable this year. Sometimes she has trouble with the other girls and sometimes she's blissfully happy."

**REFLECTIONS FROM FATHERS
OF ADULTS WITH MENTAL RETARDATION**

On Living and Learning. . . .

. . . "When our daughter was born and we found out she had MR, we were devastated. I think that was a selfish reaction. We were thinking of our own expectations. She is as happy as most people and in some ways, she is better off. I am more reconciled to the situation. Not every parents has their expectations fulfilled of what their children's lives will be like. We treated her like our other children. She was a very loving and affectionate child. We have no regrets. We accept the situation now."

. . . "She should be doing more, 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. Most of it falls on my wife."

. . . "My son can do a lot. He may be retarded, but he isn't stupid. He often disappears when I need him to do something!"

. . . "At the time of my retirement, I had a bad back and we couldn't go off on day trips. We have to constantly think of what we're going to do with our daughter. She has limited us doing what we'd like to since everything revolves around her. She gets tired because of her weight, so she can't walk around too much."

. . . "No one knows what you go through on a day to day basis. They're supportive to the extent that they can be but that's the extent of it."

Thoughts About Residential Care. . . .

. . . "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'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."

. . . "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."

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

... "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."

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

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..."

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

... "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 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."

... "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."

On Watching Their Son or Daughter Get Older. . .

. . . . "He is not as ready to participate in physical activities. He now holds back and hesitates. It's hard to discern if he has any pain or arthritis. We don't know what he is feeling. He can't communicate that well."

. . . . "He's gaining weight. He's still interested in the same things, but he does worry about his health."

. . . . "She has become more mature. She rests for longer periods of time. She's more predictable and more cooperative with ADLS. Her demeanor in public places has improved, just like everyone else."

. . . . "She's less compliant and getting to be a 'fussy old maid'. She has little rituals that she must do in order to get going."

Advice to Other Parents of a Child with Mental Retardation

. . . . "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."

. . . . "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."

. . . . "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."

Advice to Service Providers

. . . . "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."

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

. . . . "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."

. . . . "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."

REFLECTIONS FROM BROTHERS AND SISTERS OF ADULTS WITH MENTAL RETARDATION

On Childhood. . . .

. . . "Through grade school, I felt he was more like another ordinary brother, but as I went through high school, I went through all sorts of stages--extreme embarrassment, extreme protectiveness, disgust, as well as love and compassion."

. . . . "My mother taught us that others would readily accept my sister if our own attitudes reflected comfort and acceptance. We found this to be true and we developed a 'game' of molding others' behaviors and attitudes. It helped us have a sense of humor about any differentness."

. . . . "I missed parental attention at times while growing up. It is difficult to watch my parents giving up things in life like independence and freedom from children."

. . . . "I regret not being able to go to activities with both my parents. One always had to stay home. My parents weren't able to go to my sports or school activities and I felt disappointed. I know my behavior in elementary school was poor and it was indicated to my parents that I needed more attention. I can see that much time was devoted to my sister, and she needed it. I wanted her in our home, but I acted out to get the needed attention."

. . . . "We were closer in mental abilities when we were younger, but as I grew older, she didn't develop the mental skills I did so we grew a little further apart. The emotions never really changed, just the time spent together."

. . . . "I remember always wanting to please my dad--and he generally returned his admiration for my scholastic accomplishments. In some ways I felt I needed to make up for the things my brother could not do."

On Neighbors and Community Acceptance. . . .

. . . . "We were very comfortable with my brother's presence and I honestly don't think we thought of 'being different'."

. . . . "The first example that pops to mind is we had neighbors up the street who filed a petition to send my brother away, because they felt he shouldn't be at home. Also, being out in public, he'd receive strange stares or laughing. So sometimes it felt like guilt by association. But mainly I felt the need to defend him."

.... "It's more than just the retardation but also the fact that we didn't have a lot materially because of my brother's expenses. I used to tease retarded kids until I found out my brother was retarded. Then, I saw it differently and I defended retarded people. That made me and my family different."

.... "There were those, I think, that saw us as different, that had a hard time accepting that there were 'people like that.' On the other hand, there were many to whom it made no difference, possibly because they were more aware, or not so afraid, of the handicapped."

.... "We were a very close family and did a lot together and were very proud of every accomplishment made by my sister. Sometimes people envied us!"

On Relationships. . . .

.... "I feel an immediate connection to other individuals I meet who grew up with mental retardation in the home. I support Special Olympics where I can. I have patience with learning disabilities. I have respect for mentally delayed or dysfunctional adults."

.... "I sometimes get angry with my sisters and brothers for not making sure our retarded sister is included all the time, that she's ok, or not taking her for a visit at their homes."

.... "I get very frustrated with my father because he is overprotective and does everything for my retarded sibling instead of allowing her to do what she can do for herself."

.... "I think in the beginning I resented my mother's total attention to my brother. I didn't understand at 9 the awesome responsibility. Later I was in my teens and didn't want to share the responsibility. Now, as an adult, I still see her struggling to keep him in a sheltered workshop that's losing funding, taking him to doctors, and preparing to make provisions in case there are no funds. Her whole life has been devoted to him, but now it's including me, we are involved with his future."

.... "We have a large family with many people having many things going on and happening from illnesses to nephews to vacations. She was discussed along with everybody else. We are an 'equal opportunity' family."

.... "I resented my father for not understanding the emotional and physical demands made on my mother because of my sister. He argued that "we" should be responsible for my retarded sister and not an institution but all he had energy for was the financial demands. He didn't have to deal with the daily red tape, the late cabs, the driving to and from activities. He assumed we could always handle it."

.... "My father is very strong willed. He keeps insisting on how I should take care of my brother after my parents die. He has no regard for my way of life, just my brother's life."

On the Future. . . .

. . . . "I know my mom is depending on me to be there when she and my dad are gone. I know it gives her a sense of peace knowing she can trust in my decisions whatever they may be."

. . . . "I grieve for my mother who is unable to let go of my brother, and yet she deeply resents having a 35 year old child to take care of. I am worried about taking care of him in the future."

. . . . "The future holds great uncertainty. My brother has not been plugged into any social service or system. I feel that his living at home has not necessarily been the best decision for him, although I'm not sure how other decisions would have played out. I feel the social stimulation issues are lacking in his life. An adult retarded child may have needs that go beyond what a loving, consistent home can fulfill."

. . . . "Build more group homes quickly!"

. . . . "We never talk about it. Seems like everyone thinks mother will always be there to take care of my sister."

Advice to Parents of a Child with Mental Retardation. . . .

. . . . "I think parents of a retarded child need to somehow balance the needs of all their children. Since everything seems to be so much easier for a normal child, it's easier not to pay as much attention to them. But, things that may seem minor to a parent in comparison to what a retarded child needs to cope with, may not seem minor to the normal child."

. . . . "If there are two parents, have one take the child with retardation on a fun short trip to let the others feel that you are available. Parents need to switch off so everybody gets special time, but most importantly, the other children have a chance to talk and share ideas about activities, family talks, trips, problems, etc. Give them permission to pursue their dreams and don't burden the children."

. . . . "It is unfair to expect other siblings to deal with future placement for the retarded child. This should be resolved and in place prior to any serious illness or death of parents."

. . . . "Get out there and find out what services are available for your child and get ready to fight for them. Make plans for the future when you aren't there for them."

. . . . "You will not do anyone a favor by clinging to your child, by living through them or trying to make up for their disability by assuaging your own guilt feelings in keeping them dependent. Learn to let go and let them fulfill their own life."

Advice to Others With Siblings With Mental Retardation. . . .

... . "Probably my strongest advice would be to accept the problem the brother/sister has and then to try and treat the person as simply a person with a type of problem that can possibly be an experience that will make you a more sensitive individual."

... . "There are much worse things that can happen to a family, so look for your blessings. Work hard on accepting that you are who you are, and your parents are who they are. They made their choices and you make yours."

... . "Make sure a parent and a sibling are made legal guardians to protect and be an advocate for your brother or sister. Discuss with your parents and family members the future plans ahead of time so not one person will have to make major decisions. Make sure your parents have a will."

... . "We all have limitations and unique gifts. Your first obligation is to your own growth and loving yourself. Your service to others automatically happens as a result of taking care of yourself. Listen to your heart. Take plenty of rest and time to know your feelings, accepting even those that don't make logical sense. Ground yourself in the present truth and let the future unfold from there."

Advice to Service Providers. . . .

... . "Be realistic and not idealistic."

... . "Be aware that the adult sibling is terrified of having to assume a responsibility that they may see as unfair."

... . "The family knows the personality and limitations of the retarded member best. Service providers must carefully listen to these descriptions and must realize when they are suggesting ideas that family is fairly certain what will not succeed. That has happened is our family. Plans have been pushed that have turned out badly."

... . "As a teacher, I try to have many family oriented events for the children and their families. I've never been invited to any kind of social or supportive event from my sister's schools or rehab settings except when it's an expensive fund raiser."

... . "Imagine that one of your sisters stopped developing at age 3. They walk, talk, and most of the time consider themselves pretty independent, but you know otherwise. That three year old could someday become your responsibility."

... . "Listen to us, Listen to us, Listen to us!!!"