

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

Prepared by

The research staff of the study on
"Aging Families of Children with Mental Retardation:
The Impact of Lifelong Caregiving"

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STUDIES ON AGING AND DEVELOPMENTAL DISABILITIES

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Dear Family Members,

Over the last five years, we have conducted many interviews with over 460 families who have an adult son or daughter with mental retardation living at home. When we first started our project, we thought that parents might be a bit reluctant to talk openly with "strangers" about their lives. We were so wrong!! We discovered an incredible group of families who have been willing, and at times, eager to describe to us what they have learned as parents of children with lifelong disabilities.

In this booklet, we have assembled many of the important lessons we've learned from you. There's much wisdom, energy, and struggle expressed in these comments. Some of the comments may surprise you, others will ring true to your own lives, and some may help you see both similarities and differences between your family and other families who have walked similar paths.

We are forever grateful to you for your willingness to give so much time to our project, to welcome our interviewers into your homes, and to guide us in helping others to understand what mental retardation can mean to individuals, parents, and families as a whole. We look forward to continuing to learn together.

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. Also, we worked to develop our local sheltered workshop and most recently, we promoted the infant stimulation program for young parents. 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."

. . . "He was our baby and we loved him."

. . . "When I was growing up, I was very good at everything. I was in the top of my class. Everything I did was the best. If it wasn't, it was done over again. I stuck to it. 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."

. . . "Actually, things are going well, considering the situation. A far cry from what we were told at the hospital back when she was 4 years old. We are thankful that things are not worse and I'm sure that both my wife and myself have these thoughts in our minds constantly."

. . . "In the early years, little was known about autism. I was devastated to be blamed by doctors and educators for the autism. It was so frustrating not knowing where there was help."

THOUGHTS ABOUT RESIDENTIAL CARE. . .

. . . WHEN THE SON OR DAUGHTER WAS A CHILD

. . . "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 never considered putting her in an institution of any kind. She's a good kid. She has flareups like everyone else--normal people have these characteristics, too. I've always felt this was her home and she should be here."

. . . "She is my daughter. I think she should be at home. Where else would she be?"

. . . "I love her--she's my child. I knew I could provide the best care. I never want her to feel unwanted. She's special to us."

. . . "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."

. . . WHEN THE SON OR DAUGHTER IS AN ADULT

. . . "I am like a kid in a candy store, as far as enjoying our new freedom, and I say this with a small sense of guilt."

. . . "Placing our daughter at the group home 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."

. . . "One positive event this year was having my daughter adjust to her new living arrangement, being happy and in a safe environment."

ON THE NEED FOR SERVICES. . .

... "My son needs social services and activities that are closer to home. I wish he could get a computer for communicating, but it's too expensive."

... "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 am satisfied with her day program but I do notice that she's happier when she's participating and not just observing. When she just observes, she's sadder when coming home."

... "I would like her to work longer hours -- she's a grown up. She could work all day."

... "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?"

... "I just don't want them to cut any services. It was too hard to get to where we are!"

... "It comes down to 'flight or fight.' I chose to fight. I've struggled for years for adequate services. I benefitted from families facing this struggle before me--you cannot panic! Families that stick together are ahead of the game."

ON LEARNING AND LOVING. . .

. . ."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."

. . ."We accomplished what we asked for. You learn from your child as she learns from you. It makes you aware of problems and gives you insight into yourself and other people. If you run into obstacles, it's different -- when it's successful, you get a lot out of that."

. . ."My daughter has taught me a great deal about life."

. . ."Our son is so appreciative of what is done for him, and tries so hard to be helpful. He truly compensates for the demands of his care....he strengthens the bond between my wife and me. We have much to be thankful for."

. . ."I am perfectly satisfied with my life. I give many thanks to my wife who has been both the greatest backup and leader in my life."

. . ."Anything he did was a thrill. We got more out of this than we expected."

. . ."She's given us a lot of happiness. We've learned a lot from her. It's been good to see her progress -- she's a lot of company for me now that I'm alone."

. . ."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."

. . ."Everything she accomplished is a big step. She can read and can enjoy life."

... "The beauty of it all is the ways in which we all join together to rectify various situations. This includes my retarded son -- he is a champ."

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

... "I remember a neighbor of my mother's saying my mother's attitude had changed a lot after I had my daughter. Before that, she thought things happened to people because of their own efforts, their own doing. She was impatient with other people's frailties. She learned something and I suppose I did, too."

... "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."

... "We were advised by the doctor that he was a vegetable and that he should be placed in an institution. But after investigating, we found support groups and that squared our thinking."

... "You find out the true values in life. It's a good way to get a spiritual education. Having my son has given me an understanding. I wouldn't trade that kid for anything."

... "You learn to be patient and to cool it--none of this hyper stuff!"

... "You learn a lot. You learn how to live with adversity, how to give love and the care he needs. These kids are with you forever. I need him as much as he needs me."

... "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."

... "I feel I am getting more from my son than I am giving. He is a great comfort to me since his father died. I am very thankful that I have him."

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."

. . . "My husband and I have never travelled much. Once in awhile, you'd like to be able to go somewhere. I would like to leave him for 3-4 days at a stretch."

. . . "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."

. . . "It was difficult for his siblings, seeing him called names and teased."

. . . "It takes the wind out of your sails. I wouldn't want other people to go through it."

. . . "I'm sorry raising a child with mental retardation took so much time away from my other children."

. . . "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."

... "I think most parents with handicapped sons and daughters feel that their children are very isolated after they leave school. Parents can't be friends, nor playmates. And that, I think, is the hardest for both the young adult and the parents to bear. And it's more true as the years go by."

... "I find that the older she gets, the harder it gets. And it's just fighting the bureaucracy that makes it so difficult. Instead of thanking us for keeping our children at home, they fight you."

... "I get discouraged when you see from day to day there isn't that much of a change. We're kind of at a point where there won't be any more changes, that our daughter will be like this from now on."

... "You look at the boy and you say, 'God, look at the things he's missing out in life--marriage, girlfriends, dates, sex, everything.' That part is the worst, but then you can't dwell on it. You move on."

... "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."

... "When he was young, it was sad to see him not accepted by other children. He's wanted to do certain things that we've not been able to let him do. When his brother got married, he wondered about that for himself. But he has a bachelor uncle and we told him that he could be like that. There are times when we felt it was unfair."

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."

... "As long as I can care for my two children with mental retardation, I will!"

... "At this point, while I can do for him, I'm satisfied."

... "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."

... "I'm not frightened about aging. When you gather strength to overcome tough circumstances, you get strong yourself."

... "Sometimes I think I'm getting too old to worry about all the things I have to do for my son..."

... "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."

... "I am already coping with the challenges of aging and I do find that (because) I have already passed many hurdles, that I will probably get the strength to cope with many more. However, right now, I realize that I will soon have to think about finding a permanent home for my daughter. It is the hardest thing I will ever have to do."

... "I think when you have a person like my son, you don't spend time thinking about yourself. You are so busy, it keeps you young longer."

ON HOW PEOPLE HAVE CHANGED. . .

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

. . . "I've met many people because of my son. My life is channelled that way instead of being wasted on golf or bridge."

. . . "It makes you more compassionate and helps you to understand others' problems. It makes you a kinder person. He taught me a lot."

. . . "My son, husband, and I are better people because of her. She's a dear, good person. We just don't regret any of the sacrifices or the tolerance we've had to have with her."

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

. . . "Others fall apart over the least little thing -- they seem so weak compared to me. This has made me stronger. I don't fall apart too easily."

. . . "I'm a much better person because a retarded boy was born to me. I was brought up in a selfish world -- having my son brought me down to earth. I'm not a selfish person now and I'm happier."

. . . "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."

. . . "There have been benefits to the whole family. She has kept me busy and increased my tolerance for differences in the world. I've learned to accept things we can't change. I'm grateful for the help we've received. She's broadened my life."

. . . "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."

REFLECTIONS ON A LIFE . . .

. . . "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."

. . . "In the beginning, it was very hard to take. As soon as it starts, you would like it to be ended. But then, you just learn to take it. I'm blessed the way it is now. She's a great help. It's become positive. I know in the beginning that I was thinking that this was the worst thing that could happen to anybody. But now I would love to tell other ones, that it happened to, that it isn't the worst thing."

. . . "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. It made us very cold towards accepting things from people, like if they did something for us, they'd expect something in return. People still don't understand or comprehend fully what we have been through in thirty years. We don't see things in the same way as other people and that is hard for people to accept. We had nobody and no one. Both sides of our family stepped back. 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. We were very active arguing for our rights back in the sixties. I don't think parents have to fight as hard as we did. If they do, then there's something definitely wrong. They shouldn't have to. Because all the groundwork was laid--the schools, the workshops, the respite care. So there really shouldn't be too much for these parents coming up now to deal with if they know what's out there."

. . . "My husband and I have always worked as a team and that's important. In fact, we've found that when parents put their child in an institution, it's often one parent who can't accept the child. But right from the start, we've gotten great support. When I speak to other parents, they'll say they'll never give up their retarded son or daughter as long as they live. And I guess that's true. You just don't ever think of ever parting with them. I suppose if you had a lot of problems, you'd be more apt to look for outside help."

... "I don't think for being as advanced a country as we are, people understand yet the difference between mentally ill and mentally retarded. The conditions are totally different. The things I've become involved with, the people that I've met that have the same type of child that I have--these have been great rewards. And it's been a great education for my other kids, too. I've seen them become involved in things that they never would have. I've got grandchildren involved, so it's been a great learning experience."

... "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."

... "You learn a lot from a handicapped child. All my friends, for many, many years, had children with mental retardation. We understood one another. It didn't make any difference what color or creed they were. It hasn't been negative. I just found that I couldn't be friendly with the ordinary person who didn't have a handicapped child because they didn't understand. And maybe I was jealous of all those who had children graduating--so I had to go a different route."

... "We lovingly call him our Ph.D. in living. A child is meant to be a joy. Nothing has been taken away from you except the anticipation of a normal child. It's fun to see him developing, slow as it might be."

... "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!"

... "It's a wonderful experience. It takes time to realize it but now I can look back and see why it all happened."

... "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."

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