

**SIBLINGS SPEAK OUT:
REFLECTIONS FROM BROTHERS AND SISTERS
OF ADULTS WITH MENTAL RETARDATION**

Prepared by

The research staff of the studies on

**"Siblings of Adults with Mental Retardation:
The Ties That Bind"**

and

**"Aging Families of Children with Mental Retardation:
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STUDIES ON AGING AND DEVELOPMENTAL DISABILITIES

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Dear Family Members,

Until now, there has been almost no research on the extent to which adult brothers and sisters of persons with mental retardation feel their childhood was "different" from their peers, the extent to which their adult lives have been affected by the challenges of having a brother or sister with mental retardation, and the extent to which they maintain active involvement with or are more emotionally or physically distant from their brother or sister with mental retardation. Supported by a grant from the Joseph P. Kennedy, Jr. Foundation, we were eager to explore these important issues, as part of our longitudinal study on older families who have provided lifelong care to a family members with mental retardation.

We are extremely pleased that over 350 adult brothers and sisters were willing to answer many questions and to write about their experiences in their own words. We are delighted to share with you some of what we were told.

In this booklet, we have assembled some of the wisdom, reflections, and ongoing concerns that adult siblings expressed. Siblings also had advice for parents, other siblings, and service providers. The quotations in this booklet reflected the range of thoughts and concerns that surfaced in this study. While there are many common themes among these comments, the uniqueness of each person's experiences is also wonderfully evident.

We are grateful for the generosity of so many busy people who gave so freely of their time to help us learn more about the concerns of adult siblings of persons with retardation. We look forward to continuing to learn together!

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.

. . .As children we played together, were sick together, shared the same bedroom together. We laughed and cried about things, worried about each other, and shared. He looked after me and I looked after him. Our relationship seemed as normal as any other sibling relationship - or so it seemed to me at the time.

. . .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.

. . .I was never told about my brother's "condition", and felt an air of "secrecy" regarding it.

. . .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.

. . .Swinging side by side on a brilliant, crisp autumn day, warmed by the sun, feeling complete and totally at peace. Going to an awards dinner, dancing and celebrating with folks who seemed totally unself-conscious and full of love. Waking up to my sister's bringing me O.J. in bed and saying to me as I wiped the sleep from my drooping face, "you look so beautiful."

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.

... We were seen as different already. My brother's retardation made us seem even more different. Many people liked my brother as he was growing up. Most residents who were active with young people and special education knew my brother and would speak to him on the street. We were also a minority family so it's not clear to me what differences people viewed as solely due to his retardation or our family being black.

... I didn't think as a family we were different. I guess there was a pride involved because she is my sister. I always wanted her to be part of the unit.

... 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!

... Until I was 18, I never had many friends at my house. Of course, I was afraid of ridicule.

... It has never, in my lifetime, affected my friendships. My friends have always been accepting of my sister and kind to her.

On Relationships. . .

. . .My wife and my retarded brother get along very well. We do a lot together with him. He goes camping and on vacations with us.

. . .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.

. . .If I had a date who didn't even look at my brother or speak to him or would make some ignorant remark, that would be the last date with him.

. . .I chose my husband based on his willingness to accept my sister.

. . .I fear that when my mother can't take care of my retarded brother, my relationship with my spouse will be strongly affected.

. . .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.

. . .During visits at our house, she does all we do and we make sure she has her special pleasures and treats. My parents are quite protective of "burdening" us with her, but seem to enjoy the break.

. . .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 knew she was retarded and was an active participant in her "care" as I was the oldest, but began to feel negative feelings as I grew older because of the denial and/or lack of communication about this with my 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.

.. Since my mother has stayed home for 30 plus years taking care of my brother--along with all the things involved with him--I feel she is in depression and I am no longer able to communicate with her.

.. I don't know how my sister couldn't have affected my relationships with my mother, father, and siblings. Would my relationship with them be different if my sister would not have been retarded? Yes, I don't know if it would have been better or worse.

.. I have always felt that I had to take a backseat to her. I never felt I had my mother's attention enough as I grew up, and sometimes even now. Also, I have purposely not confided in my mother when I needed advice or a shoulder to cry on about my problems, as I felt she had enough to handle with my sibling.

.. 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.

.. It was partly that it created a unique bond among us, a universal focus and concern for my brother. We are concerned about each other, but if something is wrong with my brother, everyone is concerned. Not all my siblings have the patience and tolerance that is required to be with my brother for long periods of time.

.. My brother is very important to me and therefore served as "tester" of sorts. If my dates were very uncomfortable around my brother, it was a good barometer to their character. Proven, I think, by the fact that my husband and my brother loved each other at first sight.

.. Because of having a brother who is retarded and having to deal with so many emotional and social and personal issues while growing up, I feel I have more determination, understanding and stamina--which helps in marriage.

On Childbearing and Children. . .

. . .It (the fear of mental retardation) wasn't even considered when we talked about having children, although while I was pregnant, I do have to admit it was a nagging fear.

. . .I am very grateful my children are healthy and without handicaps. I sometimes wonder if I could have been as good of a mother as my mom if one of my children were mentally retarded.

. . .After having a retarded sibling growing up, I hoped my children would not have special needs as I had experienced less attention, being normal.

. . .My sister is very loving and caring. Having a child of my own with mental retardation never worried me.

. . .My son has a learning difficulty which makes language difficult for him. I often feel I'm more patient with him because I was almost always patient with my sister.

. . .Although I never considered not having children, I think I was more aware of the possibility of mental retardation - especially at the time my last child was born and I was over 35 years old.

. . .I feel sad for my friend who has so much fear for her deaf/blind son's future. I tell her to live it a day at a time like I observed my parents do.

. . .I have three adult friends who gave birth to children with Down Syndrome. I felt that I was able to offer them support in their experiences and hope for their children. I readily accepted their children and felt comfortable with them because they reminded me of my sister.

. . .When my child was born, after a very difficult delivery, he didn't seem to progress as fast as other children. I think I was more upset because of having a sister with retardation. When we found out he had a hearing problem, we had surgery done and relaxed, even though they kept telling us he was "behind" and needed speech therapy. I guess what I'm saying is that I had no ambitions for my children--I want them to reach their potential but I am less concerned about what they become--I am more concerned with who they become.

. . .I wanted children and worried myself sick through each pregnancy if the child would be normal. Thank God, they both were. Doctors kept telling me I only had to worry if the retarded brother was on my husband's side, but that didn't convince me.

. . .Until a few years ago, I didn't want children and I think a part of the reason was I kept thinking about what if I had a mentally retarded child, would I be able to deal with it?

. . .I considered my having children a gamble. I won. They are both normal.

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 just know there will be unexpected adjustments if and when he moves in. I also think of him, his feelings. His life could not possibly be exactly the same as with my parents since we do things differently. I wonder if he'll be able to adjust too.

. . .It would be nice to have some financial assistance to make our house accommodations enough so he could have some living independence in a family setting.

. . .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.

. . .I think it would be nice if my sister could live in an apartment near one of her siblings. Close enough so that each of her siblings will be responsible for visiting her and making sure her needs are met each day.

. . .My dad was very concerned about her care after my parents die and it is a great relief for him to know I'll care for her. He's closer to me now that he knows I'll be there for her.

. . .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.

. . .Financially, I have little room. I'm also afraid of what will be available for him work-wise, to keep him occupied during the day. However, I would have him, because there is no one else available. Next to my mother, I am all he has.

. . .As I get older, the inevitable responsibility of the stewardship of my brother looms larger, affecting in minor ways my career choices.

. . .My brother and sisters agreed a long time ago that our brother would always live with one of us. We really feel that he would not be happy in a setting outside of a family situation. We know it will take significant commitment, but we love him - so where's the sacrifice?

. . .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. . .

. . .The parent should not treat the retarded child 'special.' He should be treated like any child, without excuses for bad behavior and the child should be allowed to attempt to do all the things a "normal" child would do.

. . .Do not feel guilty because of the handicapped child. That child is an important part of the family and should be treated as an equal member.

. . .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.

. . .Don't focus all your attention on the child with special needs. Other children feel neglected even though they know the special needs child needs more love. The 'normal' children need attention, too.

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.

Try and take the middle road of responsibility. The high road of total responsibility shuts out the other children. The low road of no responsibility is a less than an admirable example. Try to get as many services as you can for your child so they learn as much as they can. Don't shelter them!

. . .Siblings don't view the child with retardation as a mother or father would. We are a sister or brother to that child. It's a lot to assume that we would want to share our daily life forever with this child or any of our 'normal' siblings either.

. . .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.

. . . Let the normal child be a kid. Don't expect adult behavior from her/him. Make a big fuss over the normal kid because she/he is conscious of all the attention being necessarily given to the retarded child.

. . . Try and give equal time and energy to each child (a very difficult thing in a regular family). Make your concerns about your retarded child known to your other children. It will help them understand some of your actions and attitudes. Talk to parents with similar situations.

. . . Parents need to equally divide attention among all children and plan special activities with each child. Openly discuss plans for future. Don't expect children to take responsibility of the retarded child.

. . . Listen to your other children and read between the lines. Personally, I tend to keep a lot of my emotions in as well as my feelings. I know my mother has a lot on her mind and sometimes tends to ignore or overlook how I am feeling, so I've learned to just suppress my thoughts. If she really listened though, she would pick up on when something is going good or bad with me.

. . . Don't hesitate to discuss the issues you yourself are facing, with your other children. Children are more insightful than we realize, and should be included in generating solutions to problems. Also, there will be times when your other children will be embarrassed by the sibling with retardation, and this should be dealt with in an open manner.

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.

. . .Start planning as early as possible. Become involved in seeing that services and facilities are provided. Make them as independent as possible. Our tendency is to shelter and over-protect them. Stay involved with them on a personal level--there is a lot to be gained.

. . .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.

. . .Make sure you maintain open communication with your family about your needs and your sibling's needs. Remember that your parents have a big responsibility caring for your sibling--relieve them sometimes and give them some time off. It's OK to think about alternatives to living at home and talking about it with parents. It's a good idea to tell your parents that you would support them in whatever decision they make about your sibling.

. . .Be tolerant and understanding of your retarded sibling because they'll never change. Listen to your sibling and be their friend because you can learn a lot from them. Be understanding of your parents because they have a great weight to carry. Give your parents a break by staying home occasionally with your sibling so your parents can enjoy some time by themselves.

. . .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.

. . .Live your own life and set your goals separate from the sibling. Keep in mind that you are your own person, that a retarded child in a family is not a choice we make. This is a situation we are born into. This child can be an enriching part of life and makes us look at life a little differently than most people.

. . .Encourage your parents now to plan for the future and find some kind of independent placement for your sibling that will not impact on your life.

Advice to Service Providers. . .

. . .Be realistic and not idealistic.

. . .I don't feel service providers understand what it's like to be faced with a retarded person 24 hours a day. There are many times they have been insensitive to the burden my mother has.

. . .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 in our family. Plans have been pushed that have turned out badly.

. . .My concern is that there be appropriate services provided and that the service providers be aware of how difficult it can be to care for a severely retarded person at home.

. . .They need to know their resources. A sibling who has grown up and lived with their retarded sibling loves that sibling yet the reality of a life time commitment is awesome.

. . .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 fundraiser.

. . .Many of us function in denial about the difficulties we had growing up. There are internal pockets of embarrassment and shame. Many times we've had to put ourselves second or third or last because of the immense needs of our sibling. We have reserves of grief, resentment, and despair. We need places to discuss our sibling's futures--whether we are actively involved in them or not. There are a lot of ways we may be affected, far more than we know.

. . .Not everyone deals with a retarded sibling the same--everyone incorporates it into their lifestyles in different ways. Listen to each person as an individual and try not to be judgmental.

. . .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 the retarded person's siblings. They know what they're talking about. They grew up with the retarded person. It's much different than reading about it or learning it from a college course. You will never totally understand what it's like to live with a retarded person unless you do it. Service providers should all spend time in a group home or even spend several days with a family and their retarded child. That way they have a first hand experience.

. . . Be aware of guilt feelings and that adult siblings can become too absorbed with their retarded sibling. There was a time in my life when I would have died to save my brother without blinking an eye. That is not right. There are many very deeply rooted emotional ties and intricacies with a retarded sibling that may interfere and be a problem with adult siblings as they get older. They may run into problems and not know how to deal with it. Siblings might use their retarded brother or sister as an excuse not to do things - or not get involved with people.

. . . Today people are having children at a later age. They become the sandwich generation - raising their own children, taking care of elderly parents, perhaps working full or part time. Caring or planning for care of a retarded sibling may get little time allotment. Let them know EVERYTHING that's available in the community (private and public sectors).

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

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