

“What Is It Like To Grow Up With A Mentally Challenged Sibling?”

Sisters and Brothers Share Their Stories

Their stories are sometimes painful, sometimes joyous, always caring and truthful. Each sibling's experience growing up with a mentally challenged brother or sister is unique. But clearly, every one of them has been profoundly affected by the experience. It wasn't easy for them to share these memories. We are grateful to them. We hope these stories reach out to other siblings in the same situation, that they open a dialogue between parents and siblings that might not otherwise take place and offer parents new insights. The notion that the non-disabled siblings in the family can pretty much fend for themselves needs reassessing. Growing up with a mentally disabled brother or sister, it turns out, is as much a life-defining connection for them as it is for parents themselves. These stories show that the experience stretches over a lifetime, often shaping the non-handicapped child's core identity, imprinting itself on attitudes, life goals and the choices we make.

"You Want To Be Like Everybody Else, And

You're Not," explained Mary Kay

*McGuire, whose 5-year old sister was mentally disabled by encephalitis when McGuire was 8-years old. Now the director of a Sibling Support Program in Illinois, she adds in the same interview, * "The achievements of the disabled child get well applauded but they are expectations for the normal child."*

McGuire's observations and a recent spate of books by siblings with developmentally disabled brothers and sisters (some excerpts have been included here), bring to the surface feelings that remind us that there is another side to the story of our challenged brothers and sisters. What of the non-disabled brothers and sister in the family? Of necessity, they often grow up in a shadowland at the periphery of

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"...When I saw him, I wanted to take away his disability - just the way I used to want to heal my siblings."

He wore a plastic name tag upon which he had scrawled "Jerry" in kindergarten penmanship. He was middle-aged, like my brothers, David and Chris, and my sister, Diana...but they can't write their names. I couldn't guess Jerry's condition, but his mental age must have been about 12. Ever since I smiled at him the first time he bagged my groceries at my local supermarket, Jerry has followed me around like an adoring fan...His lack of boundaries made me uncomfortable... I started avoiding him...

There are other grocery stores, but I choose it this one because it employs people with disabilities. I want people like my siblings to have jobs. I don't want them to be ignored the way I am shunning Jerry... ...I wanted to apologize for my aloofness. Jerry was trying his best.

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all the attention and energy centered on helping the household's most challenged child.

Over the past 50 years, much has been written about the "special needs" of the mentally disabled individual in a family. The Herculean effort of parents over a half-century altered negative public attitudes, initiated legislation, and built an amazing network of support systems and organizations such as AHRC, to help their children in need. But in that heroic struggle, the "special needs" of the non-disabled brothers and sisters in the family were sometimes obscured. Their stories linger in the shadows, largely untold, sometimes even unacknowledged by the siblings themselves. AHRC was the first organization to recognize the need to support the family's non-disabled siblings and initiated a special Sibling Committee over 20 years ago. However, only in recent years, as more and more siblings step into the shoes of the first wave of pioneering parents, as advocates and caretakers for their mentally challenged brothers and sisters, has a real awareness in the field emerged to look at the question: "What is the lifelong impact of growing up with a mentally challenged brother or sister?"

This special issue of the SIB Bulletin gives these so-called "shadow siblings" their equal time and a "voice."

** Quoted from "Siblings of Disabled Children Have Their own Special Needs," by Norman T. Berlinger, New York Times, March 6, 2001*

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But when I saw him, I wanted to take away his disability - just the way I used to want to heal my siblings...His grip on the sack tightened. "It's my job, ma'am. I like my job. I like working here."

A tiny voice inside me said. Use the cart to make a boundary for him. I stepped back..."Forgive me, I'm from New York City. I'm not used to people being so helpful."

He laughed. I laughed. He was strangling my bag of groceries, and I didn't care. "I would like some help out." I angled the cart between us and pushed it toward him. Would you like to drive it, Jerry?

The Storyteller: This story is excerpted from , "Too Close for Comfort" an article by Debra Borchert, which appeared in the Lives, a special feature of the New York Times Sunday Magazine, April 11, 2004.

Childhood and the Unattached Young Adult: The shock of learning that a brother or sister is not like you expected them to be raises many questions: Will peers accept or reject my sibling? Do I feel guilty about leaving to do my own activities? Do I resent the family's pressure to stay and help? Who am I and what role do I play in my family?

Learning That a Brother or Sister is "Different":

"My mom and dad were huddled together, eyes red and swollen... I didn't realize how life would be changed for all of us..."

I made the same wish every birthday since I was three -- please let me have a little sister. Finally at 6-years old, I was told my birthday wish was coming true, Mom was having a baby! On November 18, 1954, my first grade teacher announced to my class that she had received news that I "had become a Big Sister." I was dizzy with joy; the day couldn't go fast enough for me. My aunt Beatie came to pick me up after school and told me my

mother would be coming home in a few days so I would be staying with her. I asked asked what the baby looked like; what her name was; how much did she weigh? Did she look like me? Aunt Beatie had no answers. I thought, I'll just have to wait.

When I came home 3 days later excited to meet my new sister, I walked into an apartment that seemed cloaked in mourning. My sister was behind closed

nurse telling me I couldn't see her yet. My mom and dad were huddled together, eyes red and swollen. I did not realize then how life would be changing for all of us. Mom finally spoke to me and said: "Annie, your baby sister, was different, not like other babies," and it was probably "best that you don't see her." I remember being in a fog, so confused. It wasn't only my sister who was different, my whole family was different. No joyous conversation, only funeral whispers among the grownups. A lot of "condolence" calls. No more family outings with the new baby. Instead, we remained at home as if in a fortress keeping the world at bay.

The storyteller: A sister in her 50s with a successful career, whose mentally disabled sister now shares a home with her, her husband and their young daughter.

The Invisible Child:

“My mother always reminded me of my brother’s condition when I complained or got sad.”

I never forgot seeing the sadness in my mother's eyes as we would drive one-hour upstate to Letchworth Village to drop my brother off back at the state facility. I was the youngest of six children and my brother was two years older than me. He was eight years old and I

was six at the time, and scared, felt guilty and was sad. Being the younger brother of a mentally handicapped sibling never let me show my emotions for my mother would always remind me of my brother's condition when I complained or felt sad. Growing up I was somewhat afraid and embarrassed as my friends in the neighborhood would ask questions which I would just

"One good thing about being an older sister of a child with special needs is that I am one of my brother's best friends and he loves me very much. The bad thing about having a brother with special needs is that when he gets mad, he blames me for everything and my parents always believe him."

The Storyteller: Words of a 10-year old girl in: *Views from Our Shoes: Growing Up with a Brother or Sister with Special Need*, Edited by Donald Meyer; Woodbine House Inc., 1997, p. 31

ignore...All my life I would say: "What would it have been like if there was no oxygen lost in his brain during delivery?" How great it would have been to have a normal brother so close in age, and play football, baseball, hockey together. My whole life has been a battle with my emotions. I left home

at 18 because facing the truth has killed me inside, and at the age of 39, I still cry myself to sleep. I never knew how to handle the situation.

The Storyteller: A 39-year old man who works in the Direct Care field with a 41-year old mentally disabled brother living in a supervised setting.

Expectations:

"...I was being discouraged primarily because they were so disappointed."

While my parents "expected" that I would graduate college, they never encouraged me or discussed my career choices. I was on my own.

Even when I was preparing for the CPA exam, my mother tried to prepare me for the possibility of failing the exam. I'm sure she meant well, but at the same time, I felt that my parents did not see me as an intelligent young woman, but rather as someone who should keep her expectations and aspirations low. I assume that I was being discouraged primarily because they were so disappointed with my brother's condition, [and] they never wanted to be disappointed again. Nor did they want me to suffer disappointment as great as theirs.

The Storyteller: A successful professional in her 50s with a sister 6 years her senior and a brother, with Down Syndrome, who is 4 ½ years younger.

Making Life Choices:

"Something slipped away. Something deep in the spirit that gives you the permission to "go for it!"

In my senior year of high school, I received a full scholarship to the University of Chicago, one of the top schools in the country. I was thrilled. Then the editing began. It always does, even after forty years. But that was the moment that would, determine the course of my life. That was the moment when "editing" became a given in my life; second nature.

Once I realized that accepting the scholarship meant going to the Midwest, a sense of guilt seeped into the excitement.

Going away would mean leaving my parents alone in New York with my retarded brother. It would leave my brother unprotected somehow. We had become a unit. I adore my brother. Adored him from the moment they brought him home. But there were times, like choosing a college, when I didn't want to consider his "needs." I didn't want to be an "us." I wanted to take my scholarship. And, although I didn't allow myself to define the feeling at the time, I think I wanted to get away. For a little while not to be "Big Sister." The good child. The responsible child. The caretaker child. The child charged with compensating my parent's "misfortune."

My mother's life hadn't been easy. She herself had grown up with a severely retarded, non-verbal brother. My parents needed me. My brother needed me. But somewhere in that transition from high school to college something slipped away; something deep in the spirit that gives you permission to "go for it!" Trust in my own intuitive sense about what I needed to feel good about myself, grew dulled and confused. After a while it became automatic to filter every important life choice through "how will it effect my brother? My Mother? My father?" It wasn't a conscious thing. It just happened. A "Self" quite different the confident high

school girl with dreams began to inhabit all my choices and what she said was "You'll never get what you want." It wasn't until well into my fifties that I realized how many people's needs I was carrying around in the choices I've made since that high school graduation.

The Storyteller: A divorced businesswoman whose brother, in his 50s, lives in an AHRC group residence in New York City.

Taking on the World:

"I did everything in my power not to cry in front of everyone."

When I was a sophomore in high school we had a half day off. I begged my mother to let me take my brother to the diner for lunch with me and my friend. She finally agreed. Things were fine at first and then my brother was making noises. A few people looked and then went about their business. But this one guy couldn't let go. He insisted on making a big scene on how he couldn't eat with all this noise and how we should be moved. Everyone stopped and stared. The owner knew me and took the guy aside and ended up changing his table to the other room. I did everything in my power not to cry in front of everyone.

The Storyteller: The sister of a mentally disabled brother who is 22 years old, she works in the Direct Care field.

Sibling Relationships: Why don't my other siblings do their share in care-taking? Am I the only one who cares for my disabled brother/sister? I wouldn't be the person I am, if it wasn't for my disabled sibling.

"...having siblings is one of the defining experiences of childhood, with lifelong reverberations. Children become aware of one another before they recognize their own fathers, and they spend as much time together as they do with either parent. Siblings are your first peers, the first mirror that reflects an image your own size. Their impact does not cease when you leave home...No future tie is exempt from their influence; relations with them are the prototype for friendships, romances, and professional connections with coworkers, rivals, and collaborators for the rest of your life..."

Excerpt from The Normal One: Life with a Difficult or Damaged Sibling by Jeanne Safer, PhD., Bantam Dell, A Division of Random House, 2002, p. 39

I, Caretaker:

"I have a strong sense of having been molded from childhood to be a caretaker."

Even today my strongest feeling of "rightness," of comfort and familiarity, comes from care-taking. I am not so good at having a "good time", meeting strangers, or knowing who I am and what makes me happy.

I was, from the start, my handicapped brother's favorite; of the three "normal" siblings, I was "his." He was angry or hurt or both when I got married and didn't "speak" to me for a while. While my own children were growing up and my parents were fairly vigorous, I was a mom-caretaker. When my mother passed away recently, I was struck again, by the extent to which I am "it." Now, again, I am the sibling-caretaker. My sister early on left New York, my brother wrapped himself tightly within his growing family and here I am: the guardian, the person who goes to the meetings, who stays in touch, who's called in emergencies.

I had a glorious few days about ten years ago when I spent some time abroad by myself, and it hit me during a short excursion that no one in the world knew where I was. The feeling of lightness and freedom was indescribable - and I haven't felt it since.

The storyteller: Married and in her 50s, she is a sister actively involved with an organization servicing the mentally disabled for many years. Her handicapped brother, now 48 years old, has been in a residence since he was 13 years old.

It's a two-way street:

"A defining moment in my life came when my sister, Amy, taught me about being courageous..."

When I left for college, Amy, who has Down Syndrome, was just four years old. She was still wearing dresses and playing with baby dolls. When I returned, my brothers' influences had taken over, and Amy was a bonafide athlete, a tomboy. One time, she wanted to participate in the *Jump Rope for Heart*, a jumping-rope-a-thon fundraiser for the American Heart Association, with her classmates in elementary school. We bought her a rope, but watching her attempt to use it correctly initially brought a lump in the throat, sick to your stomach feeling, knowing she probably could not master the task. But Amy did master the jump rope, bringing in more money for the fundraiser than many of her peers. That was my first glimpse of Amy's determination.

A few years later, Amy declared that she wanted to try-out for the girl's basketball team at her middle school. Our protective instincts told us to shield her from humiliation. I mean, she would never make the team. We attempted to talk her out of it to no avail. so, we simply disallowed it. The Thursday of tryouts my mom got a frantic call from the person scheduled to pick Amy up from school. She couldn't find Amy anywhere. Mom panicked. Then remembered to tell the driver to check the gym. Amy emerged from the gym

with a huge smile on her face. Her first words were that basketball team practice was the following Thursday. For an entire week we tried to explain to her that she didn't have practice on Thursday, that although she was a talented athlete, she could not possibly play on that team. The following Thursday mom received another panicked call from the driver. She sighed deeply and sent the driver to check the gym.

Apologetically, he approached the coach and explained about Amy being in the gym. The coach said that the girls were so inspired by Amy's courage and effort at tryouts that they unanimously agreed to make her the manager of the girl's basketball team, but only for home games and practices. They eventually asked her to attend away games as well. Today, Amy is 18 and plays on an inclusive basketball team at the YMCA. When I look at Amy, I see abilities, I see courage, I see determination. I see infinite amounts more of these characteristics than I contain within myself. Sometimes I do dwell on the things that I am able to do that Amy will never experience. Then I remember Amy, who can play basketball better than I ever will.

The Storyteller: A sister now in her 30s, who has two brothers, and a very special sister, who is now 18, and a terrific athlete and basketball player.

*The Sense of Helplessness
and Rage*

**"The hardest part
for me is the reality
that my brother will
never be the person
he once was"**

My brother who is just 23 years old was hit by a car and left for dead on the street. He had massive brain trauma.

The surgeon told us that my brother's skull was cracked. My brother was in the hospital for 3 months. In the beginning everybody came to see him. As days turned into weeks, and weeks into months, no one but myself and immediate family came.

Now that he's home with me, no one even calls anymore. It's just me and him, and our grandmother and my husband who helps me take care of him while I'm at work. The hardest part for me is the reality that my brother will never be the person he once was. I live with such overwhelming hate and bitterness for the person who did this to him that sometimes I scare myself. Sometimes I ask God to please ease my pain. I never thought that I would be in the position of caregiver to my brother. He's always worked, since the age of 15. I am only 3 years older than him. It's a large responsibility, but it's something I know I have to do. I could never send him to a home like the hospital suggested.

The storyteller: A woman in her late 20s whose brother was mentally disabled as the result of a hit and run accident.

"The bold lettering on the door made me jumpy- THE SOUTHBURY TRAINING SCHOOL. Can I actually do this? I wondered.

...The nicely dressed woman behind the desk leaned forward... "You're the brother. Here it is right in her file. this is quite an event...you are the brother."

I hadn't heard those words since I was twenty-one.

"I should have called, " I say. "Maybe it should be another time."

She looked at me deeply, sincerely. "This is important. Her brother has come to see her."

It took just about everything I had not to cry...She didn't ask why I hadn't bothered to come back when I was twenty-one...or thirty-one...or forty-one...or fifty-one...

"Bobby will be right back." For years my mother said it to my sister...He'll be right back..."

I fret about which door my sister will come through. Will she be in a wheelchair? Will she be old?..."

The Storyteller: Excerpt from *Hamlet's Dresser: A Memoir* by Bob Smith who learned in a lifetime of acting and teaching Shakespeare how to re-connect to his sister, Carolyn, when he was 60 years old and she, 52. Scribner Publishing, pp. 277-279.

Dating and Marriage: Will my spouse reject my retarded sibling and treat him/ her disrespectfully? Will my mate stay with me once they know I have future care-taking responsibilities? Can I handle the emotional pressures of a relationship on top of my responsibilities for helping my disabled sibling and my family?

A "Package" Deal:

I was maybe 10 or 11 when some new kids on the block started calling her "retard." I yelled at them and told them their parents were idiots for teaching them that word.

"The word "retard" cut through me like a knife."

It hurt so much and I cried, but not in front of my sister. I knew she could sense my emotions. I wouldn't let anyone see these huge tears that just didn't seem to stop for such a long while - the word "retard" cut through me like a knife.

The only life I ever knew had my sister at my side and I really didn't want one without her. I knew that it would affect any relationships that I may have and it would certainly stop a man from marrying me if he wasn't able to accept my sister as part of my "package." I knew exactly what I would be getting into and I was only 20 years old. I knew I would not be able to have a career - I would be grateful to hold down a job. There is a part of me that

never stops taking care of people and I constantly struggle to take care of myself first.

It will be a lifelong battle.

The storyteller: Before the writer reached 21, her sister passed away .

"...I bricked in all the spaces in my week when I might have seen friends, and so it followed that I lost many of them. I lost my opportunity to indulge in almost all leisure activities as well...But perhaps the greatest forfeit was love. I'd had a few awkward dinner dates in the four years since my long-time live-in romance had come to a mutually tearful and reluctant end, and even those strained opportunities had petered out...I don't know when things stopped working for us; I just know that when he asked me to marry him I could not bring myself to make the commitment."

The Storyteller: Excerpted from the book "Riding The Bus with My Sister" by Rachel Simon, Houghton Mifflin Company, 2002, pp. 7-9

Testing...Testing, 1,2,3

"I would let them know early that my brother had a disability."

In choosing people that I was friends with and/or dating through my life, my brother with Down Syndrome played an important part. I would begin getting to know someone and would start to develop a relationship with them.

I would let them know early on that my brother had a disability and that he was an important part of my life. The true test of any relationship that I had came when they began interacting with him. It seemed to be an automatic response from the person, whether they accepted him or they just "pretended" to accept him. I was able to read them all by their physical responses to him. This ends up being how I was able to judge the character of a lot of people. If they were able to pass this "test," then they were people I would want to make into my friends or boyfriends. I have come out with some very true friendships and a wonderful spouse this way. Life would not be the same without my brother and I would not be who I am without him.

The storyteller: A 35-year old woman whose brother, 37, lives in a residence.

Family with Children: If I have a child will it be disabled; is the disability genetically transmitted? Will our children accept the presence of their disabled aunt/uncle in our lives? Will they mock him/her? Will they help out with, or resent the care-taking? How will my challenged sibling feel towards my own children?

Re-directing Energies:

"God is using him..."

I am one of two older sisters to a 42-year old man who is severely mentally retarded, autistic-like, non verbal and aggressive. Born normal, my brother experienced brain injury from a high fever at the age of six months. Church was not a big part of our life because our brother was not included. The public [school] system became our sanctuary. It was our "church." Before passing away in 1989, my mother was an active volunteer advocate both in New York and Ohio for people affected with disabilities. My older sister is a Special Education teacher. I became a Christian at age 34 and within four years was called to help our Church include families affected by disabilities. I feel that I am the one who is truly blessed. I have two wonderful children, and have been married 17 years to my awesome husband. The disability world was new to him at one time. We all serve Bridge Builders. Because of our inclusion of the deaf community our older daughter wants to be a teacher to deaf children. My life experiences gained by my brother's

presence, has taught me "to have a high tolerance for inappropriate behavior" and to look beyond the exterior image for God has made us all precious in His sight. To be clueless of how God is using him. I have much to learn.

The Storyteller: The older sister of a severely challenged 42-year old brother, she works with "homeless Christians" and devotes weekends to Bridge Builders, a Church group tending to families with disabled children

The Secret:

"...I remember asking our family doctor if it runs in the family?"

I've often wondered why I never married again, never really wanted to have children of my own. Somewhere in the back of my mind when I ask this question, an image of my Uncle Izzy always comes up. Not of my brother, who also has a mental disability, but of my uncle, my mother's brother. Izzy was severely retarded and also mute. He grew up at a time when family's thought nothing could be done to help people like Izzy to be productive and he was allowed to amble around my grandmother's apartment and my grand-

father's shop below it, somewhat unkempt, like a stray dog. His teeth were never cared for and I remember how he would stand in the kitchen mumbling and laughing to himself and be invisible, because everybody around just ignored him and talked among themselves as if he wasn't there at all. As a child, my Uncle Izzy would follow me around. Today, I know it was because he was lonely and wanted a companion. But his grunting and laughter frightened me then. When my brother was born and we found out that he also had mental disabilities, I felt somehow "marked." When I started dating, I remember asking our family doctor if "it runs in the family?" But he brushed my question aside. He told me not to worry about such things and to just "live your life." It made me feel like I had a secret I had to keep hidden, that an enemy was living inside me that nobody but me knew about.

The Storyteller: A divorced woman in her 50s whose brother lived at home until his late 40s but now resides in a residence in Queens.

Sibling Advocacy: “My disabled sibling is taken advantage of by others but he is too passive or so desperate to have friends, he accepts poor treatment and we argue constantly. I want to protect my sibling but I don't always know how or even have the right information.”

Lessons Learned:

"I feel fortunate for the time we had together..."

My first recollection of my brother Steven's disability came at about the age of 5...As I grew older and became more aware of my high functioning brother's "limitations," I was also informed by my mom that he would one day become my ...responsibility and live with me....

Steven was always full of life...he had lifetime friends, whose friendships he initiated in elementary school and re-ignited in the AHRC bowling league as well as at the workshop. ...Steven had a huge sense of feeling responsible and it was this feeling as well as his excellent memory that helped our family right after the shock of suddenly losing our dad...We had to manage Dad's business until we could sell it, I knew nothing about it and was virtually helpless. Fortunately, Steven's approximately 20 years of working for and interest in the day to day particulars of the business paid off...He knew the business bank because Dad would trust him to deposit and withdraw large sums of money, since he ...couldn't get around easily. So it was natural for Steven to offer me guidance and assistance in maintaining the business. SURPRISE! I was shocked, amazed, dumfounded, and then some, that

my so-called "developmentally disabled" brother could help *me*. Steven gave me the names of business contacts from merchandise suppliers to specialty repair shops for the machinery, which, incidentally, he knew how to operate thanks to Dad who had faith in him. Can you imagine my ...pleasure and pride...realizing my brother's business aptitude? I was thrilled that he could finally outshine me and really feel proud of himself...His joy was coupled with my happiness because now he could say that he helped the sister that always had helped him...I saw my brother in a whole new light...

My brother's greatest fight...began when he became ill five years ago. I saw my brother as a determined and valiant warrior battle to survive and live life as fully as possible. The agony of seeing my once healthy, handsome, and loving brother ravaged and then his passing on February 20, 2004, is still indescribably painful. But I feel fortunate for the time we had together, for the bond we shared, for Steven being my brother.

The Storyteller: A sister 3 years younger than her brother Steven, who was planning to move into a residence, when he became ill and passed away at age 57.

"We all talked among ourselves about Brook Farm, but not with David. We had been told that if David had experienced any abuse, he would not talk about it until he could be absolutely sure that he would never go back to the abusive situation. I said a few ridiculous and awkward sentences to him about what he had been through...He didn't say a word.

When David was interviewed for the new program, the psychologist, who had agreed... to explore about possible abuse, said, "So tell me, David, who are the people you like at Brook Farm?"

David mentioned one of his recent house counselors..."Who are the people you don't like

there?" she then asked.

"I'd rather not say," replied my brother. And later, when the psychologist asked David how he broke his finger, he answered, "I'd rather not talk about it."

“They’re going to give him one more chance...And then...”

The Storyteller: Excerpts (p. 182) from *The Ride Together: A Brother and Sister's Memoir of Autism in the Family* (Washington Square Press) written by Judy Karasik and illustrated (pp.106-107) by her brother, Paul Karasik, about life with their brother, David, who is mentally disabled.



Relationships with Aging Parents: "Why can't my aging parents accept the fact that my disabled sibling will need to separate from them when they become too frail and move into a group home? My parents don't understand or accept the complex financial arrangements that must be made to assure that I have enough money to help care for my siblings after they are gone."

Rescuing the Family:

"I became a seeker of solutions, a problem-solver."

My mother and father had their hands full: four children, two of them developmentally disabled, working class wages and a small apartment. As a child, my understanding was that my brothers couldn't talk and often misbehaved, but one day, when they started to talk, we would all be able to go out as a family, like other families did, to parties, to the beach, on vacation, to church, to graduations, to the circus, sightseeing in the stores, to visit relatives. At every birthday for my two brothers, when it came time to make a wish and blow the candles out, my father would always wish that there would be "a change" in my brothers. Year after year, we all joined in this wish. I was very eager for this change to come about. After my brothers reached early adolescence it was very clear to me that my brothers weren't going to change. I felt, "enough already" of lamentations; that we had to figure out how to resolve the problem, not just turn down invitations to join ordinary life because of this cross we had to bear. So I said

I didn't want to hear "we can't because of the boys." I wanted us to acknowledge that my brothers were the way they were, that they were not going to change and that we had to live and work around that. I became then a seeker of solutions, a problem solver.

The storyteller: An attorney in her mid-40s, who has a typically developed brother like herself and two mentally disabled brothers, aged 43 and 40, currently living with their mother, a widow.

Stepping Into My Parent's Shoes:

Only when my mother was dying of cancer did she really communicate her concerns for my brother and his future care. She discussed group homes and guardianship, but had not pursued it herself.

"I never confronted her with the question of why I was left with the burden of making that decision..."

a burden I was angry with both my parents for not performing the duty of responsible parenthood. After she died, I petitioned the court for guardianship and then went about trying to figure out the best situation for my brother. I was beginning to plan to get a larger apartment near his day program and make a home for both of us. A colleague of mine was

My mother's determination to "protect" me from having to take responsibility for Jack made it easy for me to pretend that I didn't have a brother with a disability. She never said, "When we die, you'll have to take care of Jack," or "I need some help with Jack. Could you stay with him this weekend?" She never expected me to change my life for a minute to look after Jack. But she often said to me, "Mary, I don't want Jack to go to a state institution." There was such panic and fear in her eyes that I promised her Jack would never be sent to one.

The Storyteller: Excerpt from *Special Siblings: Growing Up with Someone with a Disability* by Mary McHugh, Paul H. Brookes Publishing Co, 2003, p. 185

diagnosed with cancer. Suddenly I realized that if that happened to me, my support system was too weak to handle the situation. I needed a more stable situation. I investigated group homes and that is where my brother is now. I cried for months trying to figure out the perfect solution, without feeling selfish on one hand and trapped on the other.

The storyteller: A sister in her 40s whose Down syndrome brother was, until recently, non-verbal. She has a sister, six years older, who lives in California and is minimally involved with the brother's care

Recently, a 7-year old walked hesitantly towards me at the end of one of our Sibshops, "Is my brother ever going to get better?" she asked. Within the question, was her wish for her brother with mental disabilities to "get better" and for his problems to "go away" like a cold.

ON THE OUTSIDE LOOKING IN

AHRC's Sibling Coordinator
Shares Her Story

By Amy Goodman

While developing and running AHRC's Sibshops, I have spoken with professionals at schools and with parents who seem to be carrying the weight of the world on their shoulders. I have come to understand that the non-disabled siblings in a family, though often silent about their concerns for their less able siblings, need someone to listen to them; to applaud their achievements, to share their burdens, joys and fears.

The impact of having a sibling with a developmental disability has traditionally been somewhat sidelined by parents and interestingly, by many of the siblings themselves. When siblings were asked to tell a story about the impact of belonging to a family in which a brother or sister has a mental disability, many told their story from their parents' or disabled

sibling's perspective rather than their own. The reflections in this bulletin highlight pivotal moments in life when the sibling's experience leaves its imprint. This bulletin is for the many non-disabled siblings, children under the age of 10 and adults in their 50's and over, who have found their way to my door.

The headings to each section in the bulletin categorize typical stages of sibling experiences from childhood and young adulthood to adulthood and maturity, focusing on the network of relationships between the non-disabled sibling and his or her Special Needs sibling, parents and community service providers.

The non-disabled sibling's world consists of a constellation of systems related to their disabled sibling that exposes them to myriad of community services (i.e., medical, mental health, etc.) not usually experienced by the general population. It has been documented repeatedly that these siblings are more mature, responsible, self-confident, independent and patient and that they develop greater leadership skills, especially in areas where understanding and sensitivity to others is required. Though often well adapted to school and functioning successfully in life, their own sense of "being different" from others tends to create an unspoken sense of isolation. The non-disabled siblings' acknowledgement and self-expression of guilt, anger,

fear and shame should be shared and validated. Their inability to do so sometimes manifests itself in the sibling's pressure to achieve and over-compensate for their disabled sibling. Sibling services provide opportunities for young siblings to meet others with similar life experiences where they can share their feelings comfortably, gain insight and mutual support.

For adult siblings, this bulletin provides an opportunity to share their stories, educate others on the special place their disabled sibling holds in their lives and to promote advocacy. Hopefully, parents reading this newsletter will find a fresh perspective on how to communicate with their children who do not have a disability. We encourage parents to have the non-disabled child talk about their feelings about having a brother or sister with mental disabilities, to include them in decision-making and give them information about their brother or sister's disability. AHRC has an active adult Sibling Committee, which plans social, recreational and educational opportunities for children and adult siblings within the New York City area. The Sibling Committee produced this bulletin.

Note: *The stories in this issue do not cover every sibling or every circumstance. They represent a window into the experiences shared by brothers and sisters who grow up with a mentally disabled sibling and indicate the individuality of responses and the deep bonds that exist with the handicapped sibling.*

SIBLING SERVICES INFORMATION:

At the current time, AHRC Sibling Services offer individual, family and group therapy for children, adolescents and adults.

INDIVIDUAL AND FAMILY COUNSELING is available to help adult brothers and sisters (ages 18 and up) to cope with the stress of caretaking responsibilities and to address other issues related to dealing with siblings with a disability, parents, spouses/partners, relatives and agencies.

SIBSHOPS FOR CHILDREN (AGES 6-12) are three sessions of recreational and therapeutic workshops for children. Sibshops are periodically offered throughout the five boroughs on the weekend. Sibshops are four hours long and transportation may be available.

ADULT SIBLING BOOK DISCUSSION GROUP (AGES 18 AND UP) meets for brunch monthly to discuss a selected book related to Sibling issues and experiences. Adult siblings run this group.

SIBLING ADVOCACY is assistance provided by the Sibling Coordinator to help assure that families get the best possible services for their family members with a disability.

Presentations to professional and parent groups are made by the Sibling Coordinator to discuss sibling needs and share resources which may be helpful for siblings of all ages.

THE SIBLING CENTER for Sisters and Brothers of People with Disabilities, a non-profit organization dedicated to promoting the emotional

health of siblings of people with disabilities. For program details contact **Dr. Ellen Rothenberg, 212-831-5586**

SHOULD YOU REQUIRE ADDITIONAL INFORMATION ABOUT AHRC SIBLING SERVICES, or if you would like to make a referral, please contact: **Amy Goodman, Sibling Coordinator, AHRC at 212.780.2375 or email her at: amy.goodman@ahrcnyc.org.**

INTERNET RESOURCES:

The Arc Sibling Support Project for information and assistance about Sibshops, SibNet and Sibkids Listservs

<http://www.thearc.org/siblingsupport/welcome>

Family Village: A Global Community of Disability-Related Resources

<http://www.familyvillage.wisc.edu/index.htmlx>

KidSource OnLine: National Information Center for Children and Youth with Disabilities (NICHD)

<http://www.kidsource.com/>

Special Education Resources

<http://parentpals.com/gossamer/pages/>

March of Dimes for an explanation on different developmental disabilities

<http://www.marchofdimes.com/pnhec/4439.asp>

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Sibling Committee**

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Our Special thanks to

Shirley Berenstein, Director
of Program Development and
Public Information and to
Donna Gifford for their help in
producing this special edition
of the SIB bulletin.

SIB
Sibling
Information
Bulletin

Published by
the Sibling Committee of
AHRC New York City
200 Park Avenue South
New York NY 10003
212-780-2500

Tell us your story

The sisters and brothers that participated in this issue shared their stories as a way of letting others understand the very special place that their mentally handicapped sibling holds in their heart. But also to explain the unique emotions and responsibilities this special relationship entails over a lifetime.

As one person said: "The relationship with your sibling is often the longest one in your life, longer than with your parents."

Another reason that prompted many to share their stories and perhaps, it is the most urgent and touching reason of all: It was simply to let other brothers and sisters in the same situation know that someone understands, that they are not alone.

AHRC needs your help in building an archive of our stories.

This archive will help professionals who work with siblings like yourself and with families that include a disabled sibling. If enough stories are shared this newsletter will morph into a book one day. Of course, all stories will remain, as they do here, anonymous.

Please include your story in our Sibling Stories Archive. Here is how:

Go to the AHRC website.
<http://www.ahrcnyc.org> click on the **Siblings** button. Go to **Sibling Stories** and just follow the directions.

Or send us your story in writing (no more than 1 or 2 typed or clearly written pages).

Send to: Sibling Stories Archive

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