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(mŭth'ər) *n.* 1. A woman who conceives, gives birth to, or raises and nurtures a child.

From the Editor



In honor of Mother's Day, this issue of the *Newsletter* focuses on mother-daughter relationships when the mother, daughter or both have a disability. Our many contributors share experiences and insights as they consider the question of whether and how disability makes a difference in this most basic, profound relationship. The rich diversity of their answers is truly a celebration of mothers and daughters AND, in several instances, the disability experience. Moms with disabilities are in many ways simply moms, and yet, they can also be unique role models of what it takes to be a strong woman, how to never take "no" for an answer, how to defy stereotypes and how to transform "difference" into a source of pride. Similarly, daughters with disabilities are first and foremost daughters, and yet their disability-related needs and the barriers they encounter can elicit in both mothers and daughters extraordinary strengths, unexpected, empowering roles and an exquisite type of bonding. In addition, when both mother and daughter are disabled, their relationship can be strengthened by their interdependence on one another and their mutual understanding of what it means to be female and disabled.

There has been far too little research and writing on mothers, daughters and disability. We hope this issue of the *Newsletter* will inspire mothers and daughters everywhere to have conversations about their relationships—and to ponder whether disability matters. We can think of no better way to celebrate Mother's Day than through conversation and connection! We invite our readers to share their discussions and discoveries with us.

—Harilyn Rousso, CSW

daugh • ter

(dô'tər) *n.* 1. One's female child.

By Susan Turner



Susan Turner and her mother, 1981

From her sick bed, my mother announced when I arrived from New York, “You look beautiful in that dress,” adding immediately, “I can’t tell you’re crooked.” “Aaaah,” I sigh to myself, at 84 years of age my mother still sees my scoliosis, my disability, my difference at her first glance. And I, at 47 years old, still feel hurt by this.

My mother began on a southern Indiana farm in the early 1900s and was accused of “putting on airs” by family when she aspired to go to college. She put herself through business college in the big city. She worked to put any farm girl habits and styles behind her. Looking right, wearing the right clothes, was part of what helped you to step up to the middle class city life and culture. The right clothes on the right body – tall, long legged, with a regal walk – such as hers. She fell in love with a sharp dressing, fast talking, dapper man who had no upper mobility aspirations except her, his “classy lady.”

She pursued her career and achieved the white-collar circle of friends and the house in the suburbs, with no real help from the still dapper but unambitious husband. She gave birth to two daughters seven years apart. They were to be her finest achievement who would solidify her foothold in the life she was living.

The first born became her beloved alter ego. She dressed her in the best, watched her shine as one of the brightest in her schools, sent her to the four-year college she herself had wanted to attend. She followed and talked about this daughter’s career assiduously. The second daughter, me, had polio at age six and forever changed the landscape of my

mother’s dream. The best of dresses didn’t hide my paraplegia. My being at the top of my class in my “special” school didn’t even make it onto an upward mobility chart so it didn’t count. My illness and subsequent disability left my parents grieving. My father felt sorry for me. My mother felt sorry for herself. Neither were helpful in my finding my place in the world. I felt flawed, unacceptable in her new world.

For my thirteenth birthday, my mother gave me *The Sparkling Years*, a book of etiquette for teenage girls which gave instruction in how to dress properly, how to walk with dignity and how to get in and out of a car gracefully. I practiced for hours different ways to do these moves to make my leg braces and crutches seem less clumsy, less ungraceful somehow. I must be an embarrassment to her, I thought. After my college and graduate school achievements and my professional and community success, conversations with my mother were still superficial. She never spoke to me of anything besides my hair, clothes, my sister and my health. The latter was absolutely fine. I had a disability, I was not ill.

As often happens in midlife, I finally

“You look beautiful in that dress” ...“I can’t tell you’re crooked.”

came to better understand my mother and myself. I came to understand that my mother’s denial/rejection of me as a disabled girl and then as a disabled woman was not about me, but about her. It is she who ultimately felt flawed, I suspect, and needed a perfect looking life and perfect daughters to disguise her. My achievements, my joys and my sorrows were not diminished NOR enhanced by my disability. They were the successes, joys and sorrows of a woman, who also happens to have a disability.

Only four days after my mother’s “crooked” comment (and 14 years after her first diagnosis of breast cancer and a double mastectomy), my mother died. In cleaning out her house, I found a dresser drawer filled with memorabilia – big and small – just about me and my life. A page of my childhood scribbling with lots of XXs and OOs for hugs and kisses in an envelope addressed by the nurse who took care of me when I was first in isolation in the children’s hospital in 1952; school report cards; Sunday school honors;

Mother’s Day cards; my high school awards certificates and accompanying newspaper articles; my Sarah Lawrence College commencement invitation; a letter thanking her for my beautiful wedding; my resume. I found no drawer like this for my sister. ❖

The Complex Connection

By Denise Sherer Jacobson

I find it so hard to capture my relationship with my mother—it was just so complex and it lasted such a relatively short time because she died when I was fifteen. Indeed, my disability had great influence on our relationship, especially in my early childhood when I needed so much physical care and attention. It was care that my mother always gave to me lovingly, whether she was slipping on my socks as she tried to let me get a few more moments of sleep on those early cold winter schooldays, or whether she was guiding the straw into the remaining puddle of a chocolate malted so I could savor those last drops.

I’m sure that physical dependency led to a deep emotional connection between my mother and me, but it also seemed that my mother had more in common with me than with my father or my sister. While my father was content to settle down with the sports page after a ten to twelve hour workday, my mother read thick tomes by prolific authors such as Ayn Rand and James Michener. While my mother nagged my older sister to clean up her room and do her homework instead of watching TV, I sat at the kitchen table with my mother explaining to her how to draw isosceles triangles and the differences in the uses of French accents marks. I think my mother enjoyed my homework more than I did: she would often tell me that she had always been sorry that she dropped out of high school—just because her friends had been more eager to get jobs than graduate. When it came to my academic or creative endeavors, my mother was my number one supporter and fan, and I basked in the glow of her pride in me.

I spent many, many years trying to deny the enormous void I experienced in my life after my mother’s death. Today, having my own child, I regret she didn’t live long enough to see the fruition of her dedication. ❖

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A Mom is Just a Mom

By Carol Ann Roberson

My daughter had invited some friends to play. The minute they came to the door I could see it in their eyes. They had no idea that their friend's mother had a disability. My daughter had not told them anything about the fact that her mother had been disabled as a child and used a motorized wheelchair. It was obvious that I have a disability, it was not hidden or veiled in any way. Now they were at the door and here we were.

I had seen this before. However, I had never questioned why neither of my daughters ever told friends about my disability. I wondered if my own fears were why the question went unasked. Were my daughters ashamed of me? We certainly talked about my disability at home. They seemed happy when I had a day off and picked them up from school. But whenever they brought friends home I sensed the shock of seeing me for the first time.

My daughters Nicole and Giovanna seemed to be pleasant, outgoing, friendly and took part in activities at school and extracurricular activities at the settlement house. They were excited about coming to visit at my job, and about my taking vacation days and visiting museums, theater, and other cultural events. Sure, there had been times when accessibility was not good or when people stared or questioned our presence at a particular activity, but we talked about those times and the girls seemed to adjust well. Sometimes they were angry if people treated me with disrespect or when they stared at a restaurant, but they certainly never denied me or the disability which is a part of me.

I knew that I had to ask the question, and that I needed an answer, if not for them, for myself. That evening as we sat down to dinner I asked my daughter Giovanna. I said her friends seemed not to know and to be quite surprised. Giovanna replied that they don't tell her about the characteristics of their mothers. They don't say that they have blue eyes or, that they are tall, or short, or fat, or skinny, etc. "Why should I tell them anything about you? You're my mom! they don't need to know more than that." Nicole smiled and agreed with her sister. "You are our mom, that's all they need to know." ❖



Giovanna and Carol Ann Roberson

daugh • ter

Teacher of Life

By Giovanna Roberson

When I was young I remember my mother often saying, "Gosh, I can't believe how much like my mother I am," and I remember thinking, "Oh god, please not me." As a young child, it was hard to live up to the standard of a woman who, with many obstacles in her way, did a great deal for countless people. My mother, a post-polio quadriplegic, has achieved so many things. As a five-year-old in an iron lung my mother refused to stop reading, painting, and writing. As a young woman in special education she was determined to go to high school and then college, and did. Towards the end of the civil rights movement my Italian mother decided to marry an African American man, to whom she is still married. Throughout her life, my mother has found a way to achieve all of her goals through hard work and determination. When I was a

youngster, she was my role model. A woman who never took no for an answer, who struggled against the views of the world, and who achieved, thus making it rather hard to follow in her wheelpath.

As a teacher working for the New York City Department of Education, I can see my life coming full circle. Everyday I work to ensure that students work in my classroom to achieve their goals, as well as to encourage them to reach for the stars. There is no basis for failure, no excuse for laziness, and no reason for anything less than the best for each of my students. Whenever students tell me of their life struggles, I listen and then try to show them, through my mother's example how hard it could be. As a teacher of life, my mother everyday models a working, living, breathing example of how much can be accomplished and how far there is yet to go.❖

Back at School

By Anne Marie Gomes

My accident was very difficult for my mother, she took it very hard. When I was released from the hospital, she came from out of town to help me to “settle in.” Part of the settling in was deciding what to do with my life. I decided to go back to college; classes started almost as soon as I got home.

On the first day, I went to class with my sister in tow for moral support. While we were passing through the lobby, the security guard pulled us aside and said that someone was here looking for me – a lady. He didn’t know what she wanted but was certain that she was looking for me, “the girl in the wheelchair dressed in bright blue and yellow.” I deduced it was my mother from the guard’s description and began to panic. Something bad must have happened, I thought. It must be pretty serious for her to come to my school.

After class ended a few hours later, I went home like a bolt of lightning. My mother was there and I asked what was wrong. She said absolutely nothing was wrong. She explained that going back to school was a steppingstone for me in putting my life back together and she simply wanted to see me and give me encouragement on my first day at school – like she had done when I was little. ❖

An Unexpected Benefit: Getting to Know One Another

By Toni Spottswood and Virginia Simon

Toni: I have had MS for many years; although it was progressive, I continued to be independent until about a year ago. I have always had a wonderful relationship with my mom—the type where you take things for granted. We were very close and I knew that she would always be there if I ever needed her, like when I was going through my divorce. Last year, when my MS symptoms became more severe, I told my mom, who was about to go home to Virginia after visiting me, that I was scared to be by myself. I really needed her then and as always, she was there. She stayed with me, and over the past year we have gotten closer. This is because we really got to know each other as people. Today, while I no longer need her to be here, it is very comforting to have her around.

Mom: Toni was always optimistic and trusted that she would be OK. The moment she told me that she had MS I worked through the idea of a possible role reversal—instead of her taking care of me as I got older, I would need to care for her. Yet Toni has been very independent, as though there is no problem; she has made it so easy on me. She was fine until last year. I agree that since then, we’ve gotten closer. I know her so much better now. But I really worry about her. ❖



Toni Spottswood and her mother, Virginia, 2004

Saving Mom

By Edith Medina

When my daughter Natalie was small, I had lots of family problems. I was drinking heavily, going through a divorce and, on top of that I had this daughter with a developmental disability. Natalie needed a lot of care, leaving me little time to spend with my older daughter. I didn’t know what to expect from her—she couldn’t do what other children her age were doing. It hurt me to think that other children were having a “normal” life and she wasn’t. I worried about her all the time; I was afraid that something terrible would happen to her.

Now I realize that having a child like Natalie has saved my life. Because she needs me so much more than my other children, I have had to take better care of myself so I could be there for her. I have been so involved in understanding and meeting her needs that I haven’t had time to get into trouble; many of my own problems have disappeared. It is almost like I have had to think and breathe for Natalie. She cannot talk and tell people what is bothering her. Only I can understand what she is saying; she talks just by looking at me. I have had to be healthy for Natalie. I am all she has. ❖

‘Now I realize that having a child like Natalie has saved my life.’

Driving High

By Harilyn Rousso



Harilyn with her mother, 1990

When my mother announced that she was giving me driving lessons, our family doctor did not approve. Given my disability — cerebral palsy involving some involuntary movement in my arms and

legs — he said he'd be afraid to be on the road with me. "Well, doctor, then take the train," my mother insisted.

I, too, had doubts about my driving, but these had little to do with my physical reality. The image of myself as a driver was incongruous with some internal experience I had of myself of needing to be cared for and directed, of not being able to be in the driver's seat of my own life. There was something comforting and familiar about being driven around, of being picked up and delivered. Some of my fondest childhood memories were adventures in which my mother was behind the wheel, taking me shopping in some exotic store or to an out-of-the-way restaurant. My preference for passenger status held fast even though I was otherwise radically independent.

My mother recognized this incongruity in my independent self and sought to remedy it by insisting that I become a driver. Although it would take her several years of coaxing, she was persistent. She understood the dangerous consequences of surrendering to the impulse to let others take charge. My mother was strong and feisty and in many ways epitomized the independent woman. But when it came to major family decisions, she too often succumbed to being submissive to my Dad, who ruled. This was partly how she came to find herself living far from friends and family, in nowhere, suburbia. In this situation, learning how to drive, largely without the help or blessing of my father, became her salvation.

I remember my mother's stories of how she conquered the gray 1951 Oldsmobile in our driveway. After my father went to work,

and we went to school, she would slowly back the car out, careful to avoid decapitating the red and yellow tulips around the edges of the lawn, and then practice right, left and U-turns in the tree-lined neighborhood streets now devoid of school children. As she described it, parallel parking was the trickiest to master without the help of an experienced pair of eyes to guide her. But she would pick her victims carefully — already bruised cars that wouldn't mind another notch on their fender should she miscalculate as she maneuvered to park behind them.

"Given my disability... he said he'd be afraid to be on the road with me. 'Well, doctor, then take the train,' my mother insisted."

Our neighbors were far from pleased. "I'll call the police if you don't stop driving without a license," the woman living next door yelled. "Mind your own business or I'll report your son for playing hooky," was my mother's immediate response. For her, taking on the police force seemed less daunting than being imprisoned in our less-than-stimulating neighborhood. She secured her license only after repeated tries. Then the world was hers. "Have you heard from Mom?" became my father's most frequently asked question, as he waited for her to show up, hours behind schedule, to cook his dinner and behave like his wife.

After learning to drive, my mother was eager to teach others in need of liberation. I was her most resistant pupil. It was the prospect of renting a car in the British Isles during an upcoming vacation that finally got me to succumb to her wishes. By then I was in my late twenties and no longer living at home. It was grandiosity to think I could drive on the left side of the road when I had not yet mastered the right. But I was still young and eager to please my traveling companion, a non-driving childhood friend who had lived in Scotland and promised to show all, if I would be the driver. My mother seized her moment and showed up on my doorstep two or three times a week for two months to give me driving practice. I remember almost smacking a bus once, and going the wrong

way down a one way street, but none of my misjudgments seemed to faze my mother. She showed fearlessness and perfect confidence that I could do this, I would do this, and I would like it. The promise of a delicious steak dinner at the end of each session and her unshakable will got me through those initial near-disasters.

As skill replaced images of myself lying dead on the highway, I was surprised to discover an amazing sense of mastery and freedom emerging. Why, I could drive myself anywhere in the world, not dependent on anyone else's desires or whims! My fantasies started nationally as I imagined driving to New Mexico to eyeball the magnificent red, orange and purple sunsets while pretending to be Georgia O'Keefe, or journeying to Cape Cod to talk with the ocean and walk naked on the beach. Then I became more expansive, driving across the ocean to kiss the Blarney stone. I also imagined speeding past our family doctor and giving him the finger. As I shared with my mother, tentatively at first, my newfound sense of freedom, and began reeling off all the adventures I might undertake, she shrieked with pleasure and said "Let's go." Her enormous

"She showed fearlessness and perfect confidence that I could do this, I would do this, and I would like it."

enthusiasm surprised me. I suppose I had feared abandonment, that should I truly become independent, she would be gone. But clearly she would not let me go so easily.

When I got my license on the first try, we celebrated with steaks, but as an appetizer, she insisted on teaching me how to get on and off the Long Island Expressway, so that I could drive to her house. The trip to the British Isles never materialized, but it had already served its purpose.

When I drive now, more than a quarter of a century later, my mother, although no longer literally alive, is nonetheless always there, calming me in stalled traffic, beckoning me to undertake outrageous adventures, and warning me against the temptation to be a passenger. ❖

Zena: A very stark, brief memory. I was about 4 years old, playing on the street with my friends. A kid came up, pointed in our direction, and said, “Hey, what’s that?” I turned my head around to see what he was pointing at. Only then did I realize he was pointing at me. Confused, I looked at myself, my body, to see what was wrong. And I suddenly knew...my brace, my short right leg. I was the object of his exclamation.

Naomi: I have a vivid memory of walking through crowded halls at Midwood High School in Brooklyn wearing bells on my ankles, braids in my hair, and a flowing dress, gathering stares from the masses of teenagers around me. My hippie garb was a rebellion against conformity and all things inane in adolescence and society at large. It was also, however, a way for me to express externally how I really felt inside: different from everyone else and proud of it. The reality was, however, that in a school of 3,000, where the student body was not even remotely homogeneous, I had to force the category of “Other” on myself. When I moved to Spain in 1994, I quickly dropped my hippie clothes, for I wanted desperately to blend in. Finally, I was truly an outsider and did not need

superficial markings to prove that.

My mother never had to make an effort to be seen as different; people staring at her 6-inch shoe, sometimes even with apparent shock on their faces, has been integral to her life experience. In my childhood memories, she is bold and defiant, implicitly rejecting people around her before being rejected by them. Unintentionally, she passed this on to me, along with pride, which has sometimes translated into a sense of superiority (different is better). I only now realize how much my mother’s experience contributed to my own feelings of being different. As I get older, I have discovered that for all my rebellion and fighting for independence from her, I’m more like her than I’d ever imagined. Her joy, her strength, her warmth, and even her voice (when we answer the phone it’s impossible to tell us apart!) are all reflected (possibly even mirrored) in me, and so too her disability.

Zena: Hearing what my daughter has said brings back the memory of walking with her through the streets of New York City, having people stare at me (or avoid staring), and then experiencing my own child looking at me, questioningly. I can’t place the exact moment when I realized

Naomi knew I was “different,” nor did I know that I seemed to her “bold and defiant.” Being born different, although feeling normal, created a need to project an exterior appearance that told all others I was “OK.” It’s taken me many years to understand the ambiguities surrounding this focal point of my identity, and I am only now discovering the impact this has had on my daughter. I am deeply moved and humbled to think that my early feelings about myself as “OK” or even defiant (developed with the aid of my parents, I might add) helped produce such a feisty, gutsy, sensitive, introspective and loving human being. ❖



Zena and Naomi at Red Rock Canyon, Nevada, 2003

Musings by Mothers and Daughters

Susan McGee Bailey

Some things come more quickly and easily if your child has clearly recognized disabilities. You cannot consider your child as someone who may be ‘just like you’ or as someone who may, by her wonderful achievements as judged by traditional standards, validate you and your mothering. You must see her as different and while this awareness is filled with disappointment and grief it is also a source of wonderment and joy and an exhausting but strangely exhilarating challenge. If she is not like me, who is she? And if her world is not my world what is it? How much of mine can she find? And how can I find pieces of hers? These questions come, I think, more quickly if you child’s development differs from the usual expected pattern—but surely they are



Amy and her mom, Susan, 2002

every parents’ questions. The sequence and timing may be different, but the questions are not. ❖

Excerpt from *More different than others? Mothering a child with special needs*. Working Paper #171, p. 3, Wellesley Centers for Research on Women, 1987.

L. T.

When I was growing up, my mother didn’t take too well to having a child with a disability. I was one of nine children, the only one who had a disability. She didn’t know how to accept it, so she would always compare me to my sisters, asking me how come I couldn’t be like them. I hated that, wanting her to see me for me. I think now that having a disabled daughter made her feel imperfect.

As the only one with a disability, I’ve never depended on my mom for anything, whereas the rest of my sisters and brothers always have, asking her for this or that. Growing up, I had to be stronger than them, always fend for myself, and never fall on my face. It was a pride thing. My mom didn’t like this. It bothered her that here was the

child that she didn't think would make it, and here was the child that was making it without asking for anything.

I think my mother and I have gotten closer over the years. It's all changed. Now when she has arguments with my brothers and sisters, she's always crying to me and telling me I'm the one who has always been there for her. The tables have turned. I'm surprised because I didn't think that I would ever measure up to my mother's standards. I showed my mother I can survive on my own, I can take care of myself and my husband. And she knows I respect her. I never talk back to her, never raise my voice, never curse. I have only one mother. ❖

Penny Leclair

At six months I was diagnosed as being almost totally blind. It was a difficult time for Mom; she didn't have a support group and knew nothing of blindness. Mom was protective of me, yet I would not be held back from doing what others did. Over the years I grew to be an out-going lady. Mom was always there to provide me with feedback, all



Bernice Donnelly, grandson and daughter, Penny, 1991

the visual things others received by looking in a mirror. She was my mirror to tell me what looked good, when clothing was stained, what the styles were, whether my clothes fit into the seasons, whether I looked my best, things all women want to know.

Later, Mom developed a hearing disability. She started to have difficulty understanding speech, even with hearing aids; she couldn't use the phone, and begin to withdraw from the community. I became her interpreter. Though I had no sight, I helped her with important tasks, going to doctors, the hairdresser, everything. I tried to lessen the

isolation her disability was causing. We had a mutual relationship then, because we both were dependent on one another. It wasn't the same mother-daughter relationship, it was more of a friendship.

I inherited Mom's hearing disability. She saw I was struggling to hear others and demanded to know why I didn't use a hearing aid. How could I continue this denial, when Mom was giving me feedback? With her love, the love of a friend, I learned to accept my deafness.

For Mom and I, our disabilities brought a special bond to our relationship. What we could do for one another was more important than our disabilities. ❖

Sheila Starks

My spinal cord injury was 4 years old when I discovered I was pregnant. What particularly concerned me was how I, as a quad, would care for my baby. After all, I could barely care for myself. Fortunately, I had the support of my Mom who did not have any grandchildren. From the moment my Staci came into the world, everything has worked to our advantage.

At nine years old, my daughter is an old soul and wise beyond her years. She has adjusted well to her quadriplegic mommy and what I have to go through on a daily basis. The experience of raising my Staci has been a blessing and sometimes a curse. Among the blessings is that the child is showered with love. The curses are actually good intentions of my able-bodied support team: there are times when I feel left out of the loop and decisions are made without my knowledge and consent.

Staci is a beautiful, happy, vibrant and well-adjusted child. She has taught me the meaning of unconditional love. I am crazy about her even when she gets on my nerves. I look forward to her teens, young adulthood and hopefully her life as a wife and mother. ❖



Staci at 9 years old with her mom, Sheila

Corbett O'Toole



11 year-old Meecha and her mother Corbett, 2003

I have a disability. My best friend, Linda, does not. We are both single moms and we both have daughters with cerebral palsy. We have a deep emotional bond that profoundly includes the reality of raising daughters with significant physical and speech disabilities.

'Having a disabled daughter in contemporary America means being a full-time advocate.'

Having a disabled daughter in contemporary America means being a full-time advocate. Sometimes it's a simple intervention when a stranger starts asking our daughter nosy questions in the grocery store. Sometimes it's the complicated task of being the sole social worker, advocate, researcher, lawyer, access planner, teacher, tutor and executive assistant for our daughter's various programs and services.

As Linda and I juggle all these roles, we comfort each other, listen to each other's rant and remind each other we are not alone. We help each other out of love for each other but also out of the knowledge that we are performing an important job – helping our daughters become who they are and trying to block as many obstacles as we can that the world places before them. We see our own daughter and each other's daughter as intelligent, wonderful young women whose contributions will make the world a better place. ❖

Close Encounters of a Mother - Daughter Kind

By Laureen Summers

"Mom," my 10-year old daughter asked me one day as we lazily cuddled together, "How many boyfriends did you have when you went to school?"

The sun poured brightness into the morning shadows. The room filled with a merriment I wanted to ignore. I felt sad.

"I didn't have any," I answered softly.

"Why?" Her expression flickered concern; "You were so pretty!"

"Well..." I could hardly stop the tears. I didn't want to make her feel bad. "I think having a disability made boys and girls feel uncomfortable around me." We cuddled closer. "No one talked about it...I felt lonely."

My daughter is beautiful as well as very physically coordinated. "Tell me about it." She touched my face.

"I had girlfriends and lots of crushes on boys. The boys seemed embarrassed when they found out I liked them. I was jealous when my friends started dating and I was left out."

"That's not fair!" My child sounded defiant.

"Well," I tried to rationalize, "people just get scared about disability. They often think it makes a person less than he or she really is. And, there is a lot of conditioning in our world about who is beautiful and who is acceptable and who is not."

She watched me for awhile, "Mom...you're okay."

We snuggled closer and my precocious daughter fell asleep wrapped in my arms.

Does having a disability matter? Of course it does. When my husband and I decided to have a child, I changed doctors three times, until I found one with no preconceived ideas about me. When Melanie was four days old, I told her I had cerebral palsy. I didn't want there to be any surprises.

I worried about what others thought. I expected to be told by someone that I had no right to parent or that Melanie deserved a better role model. I wondered what people thought when they saw us together. Did they think she would walk and talk like me? Did they think I was expecting her to take care of me? Did they think I abused her



Laureen and her daughter Melanie

when she didn't do what I wanted?

One of my early decisions as a parent was to ignore all the books and advice about discipline and schedules and encouraging children to be independent by not demanding too much attention. Melanie was a much-wanted child and I intended to enjoy being with her as much as I could. So, I held her a lot. When I came home from work, I kept her up late so we could spend time together. I was quick to be beside her and listen to her cry when things got tough and I constantly told her how wonderful she was. We encouraged her to try things – to climb on all the playground equipment and go down the tallest slide. We took her to parties, museums, concerts, parks, and on camping trips, en route to visiting friends and relatives. She made friends easily everywhere she went.

Sometimes when we went out as a family, Melanie stayed near her father. She was embarrassed to be seen with me and did not like the stares that accompanied us wherever we went. Not wanting to answer questions about my disability, she would tell her friends, "She's just my mom." I tried to never push the issue.

As she grew older, she seemed to admire me for trying new things and never giving up on what I wanted. She trusted and confided in me, not always, but enough to confirm a closeness that her friends began to envy. Our times together were not always easy, and she was quick to let me know her displeasure. But somehow we forgave each other and returned to the jokes and laughter that was so much a part of our relationship.

Melanie became a wonderful young woman, full of energy and zest for living.

Now in her third year of college, she is excelling academically and is involved with many things. Her friends are devoted to her. We still talk and cuddle and spend time together. She is an amazing daughter and I am proud to be her mom. ❖

Transforming Attitudes: From Shame to Pride

By Nahla Ghandour

I am Nahla, a 46 year old woman with a disability, polio; my daughter, Loulwa is 15 years old. We live in Lebanon in the Middle East.

When my daughter was young, she disliked my taking her to school. As Loulwa explains, "My classmates used to call her a cripple or an old woman. It made me feel ashamed that I had a mother with a disability." Although I tried to understand my daughter's position, I wanted her to think about me in a different way. I started emphasizing the role of good deeds, values and morals in friendships and society as a whole. This helped. As my daughter now says, "If people or my classmates don't like my mom because she has a disability I don't really care. I believe that her having polio shaped the way she is in a good way. I am glad to show people that this is my mom!"

I am pleased with how my daughter sees my disability. Loulwa says, "I think I'd rather have a mom with a disability than one without one. My mom's polio taught me that it takes a lot of courage to bring up two children and give them a home, a place where they are comfortable. Once I accompanied my mother to a TV interview. She sat there with confidence and believed in herself. Her words affected a lot of people in different countries and that amazed me. I was happy and proud and felt lucky that she is my mom. I feel when I grow up, I am going to be a strong woman like her and hope I can affect the world like she has." ❖



Nahla and Loulwa, 1992

by Nadina LaSpina



Mother and daughter at the Church of the Addolorata, 1955

When I was a child in Sicily, my mother carried me in her arms everywhere. She carried me from one room to another in our old house, out to the sun-drenched courtyard to look at the geraniums in the pots, even all the way up the steps to the roof terrace from where you could see the sea. And she carried me into the kitchen, which always smelled of tomato sauce, and to the bathroom whenever I had to go. "I have to pee, mamma." "Oh please, not again, my back is killing me, can't you hold it?"

After I turned five, my mother carried me every day across the street to the convent of the Addolorata where I went to school. There she handed me over to the nuns who carried me to the classroom.

The convent took its name from a statue in its church: the statue of Mary Addolorata — in Italian the word means "grieving," "sorrowful." It was a Sicilian version of Michelangelo's *Pieta*. Mary, the mother, dressed in black and purple silk, sorrow carved deeply into her painted face, held on her lap the dead Christ, red-stained slender limbs draped in lifeless abandonment.

Every Sunday my mother carried me into the church and, before Mass started, she would kneel with me in her arms in front of the Addolorata and light a candle. My arm tightly wrapped around my mother's neck, I was painfully aware of the gazes of the whole congregation.

Sometimes I thought my mother and the Addolorata were one and the same. People seemed to have the same anguished look on their faces when they looked at my mother carrying me that they had when looking at the Addolorata holding her dead son.

"Che bella bambina! What a pretty little girl! Che peccato! What a sin, what a shame!" the town women would say, looking up from their knitting and sewing, when my mother, with me in her arms, would go sit with them in the afternoon sun. The sorrow in their voices made me wish I were ugly. I didn't want my being pretty to make people sad.

"What a cross you have to bear," the women would murmur, shaking their heads."

"What a cross you have to bear," the women would murmur, shaking their heads. Their sympathy usually made my mother's eyes fill with tears. But she never complained to them about me. She didn't tell them how heavy I was getting, or how her back was hurting.

My mother accepted her suffering like a good Sicilian woman resigned to her destiny. After all, in Sicily, all women suffered. They believed that a woman's destiny was to suffer. I sat on my mother's lap listening to the Sicilian women talking about their sufferings: the curse of menstruation, the toil of pregnancy and childbirth, the ravages to the body caused by pregnancy after pregnancy, the exhaustion of raising children, the rigors of poverty... and many of them suffered their husbands - their brutishness, maybe their beatings. My mother, carrying in addition the cross of a crippled child, was the epitome of suffering womanhood. She was the living Addolorata.

When we were alone, my mother laughed a lot. She laughed when the neighbor's cat brought her kittens to our house and I wanted to keep them all, and when the sparrows built a nest under the archway of our back door. She laughed when I spilled the inkbottle on my grandmother's good tablecloth and was so afraid she'd get mad at me.

Sometimes, even while she complained about my being heavy and about her aching back, she laughed. She laughed while we

struggled up the steps to the roof terrace, and when we made it all the way up she would make believe she was dropping me and lay me down on the cement floor and lay down beside me while we both laughed wildly. Every day she would exercise my legs, as the doctor in Catania had taught her to do, and she would tickle my feet and make me laugh so hard I would choke.

She didn't seem at all like the Addolorata then.

When we were alone, my mother seemed happy. She always called me "gioia." I couldn't understand how I could be both her "cross" and her "joy." ❖

Nightbrace

By Ona Gritz

*With the ease of a salesman
she slips my shoe on nightly,
heel pressing her palm.
The brace, cool metal,
buckled near my ankle,
beneath my knee.*

*The pitch,
I could say with her.
"Everybody's got something.
People wear glasses.
Ann Ratshin's daughter caught polio
swimming in a lake upstate."*

*In the dark
I play with words.
Palsy, a tall pansy.
Polio, ring-o-leavio
around the maypole.
When I move my foot
it rips the quilt.
When I feel it itch
I think I may be healing.*



Ona Gritz at age 8, with her mother

moth•er

Beyond Expectations: Being Blind and Becoming a Mother

By Deborah Kent Stein

No one ever told me pointblank that I couldn't have children. Nobody had to say it in words. From childhood on, I heard the message in a subtext of denials and omissions. Nearly all of the women I knew were mothers, but not one of those mothers was blind.... The public generally regards blind girls and women as unlikely candidates for motherhood. First of all we are often perceived as asexual, uninterested in dating, and unattractive to potential partners. Second, we are considered helpless, incompetent, and unable to care for ourselves, let alone tend to small children. We can't be trusted to care for a neighbor's children for a few hours; we certainly can't be responsible for a growing life for eighteen years.

As it turned out, my future was not written in those deadening early messages I received. I married at thirty-one, and at thirty-four I discovered the joys of pregnancy. I felt healthy and happy. I delighted in plans and preparations. And I reveled in the sense that I was joining a new community - the community of motherhood.

Being a new mother had its downside as well as its joys.... The exhaustion and isolation I felt are common to many, if not most, new mothers in middle-class America. Yet I had one added burden sighted mothers did not share. I knew that wherever I went people were observing me, wondering about me, at times doubting my abilities. All too many people, both strangers and acquaintances, questioned my capacity to care for my daughter and to keep her safe... I tried to keep Janna immaculate, cheerful, and of course safe from all the perils of childhood - not only for her sake, but in order to fend off the naysayers, to prove myself worthy for the parental role.

Until Janna was in fourth grade I walked her back and forth to school, which was three blocks from our house. The crossing guard, on patrol in front of the

school building, always made a fuss over me. Day after day, despite my protests he would try to grab my arm and "guide" me across the street. One afternoon it started to rain just as Janna's class filed out to the sidewalk. The moment he caught sight of us, the crossing guard began to insist that I take his umbrella for my walk home. I pointed out that Janna and I would be home in a few minutes, whereas he had to stand in the rain for another half hour. Clearly he needed the umbrella far more than we did. He continued to argue and cajole as I walked away with Janna, the rain pelting down upon us. "What was the matter with him?" Janna asked as we headed home. "How come he wanted to give you his umbrella so much?" "Oh," I said, "he thinks blind people melt when they get wet. He wouldn't want me to melt away, right?"

Over the years, "melting" remained part of our shared vocabulary. Janna referred to our more anxious, patronizing acquaintances as "melty." If someone tried to whisk me to the front of the line at the post office, urged me to pay half fare on the bus, or congratulated Janna for "taking Mommy for a walk," Janna would listen politely. But as soon as we were alone she'd lean over and whisper to me, "Melt!" with a conspiratorial giggle.

I hope that when she looks back Janna will feel that she had a happy childhood, filled with fun, friends, and opportunities. I would like to think that she grew up with no more than the usual childhood trials and disappointments, that my blindness did not impose any extra hardships upon her. As her mother, I'm hardly in a position to be objective. Maybe some day she will tell her own story, and will try to answer the question her friends so often ask her, "What's it like to have a mother that's blind?" ❖

Excerpt from "Beyond Expectations: Being Blind and Becoming a Mother," *Sexuality and Disability*, Vol. 20, #1, 2002

daugh•ter

"You're So Brave"

By Janna Stein

I got my understanding of blindness from my mom. Blind since birth, my mom has always tried to show me how truly capable, intelligent and strong she is. She taught me that being blind wasn't a reason to pity or praise someone, or treat them specially. What matters is a person's character.

'she hasn't let people's attitudes about her disability intimidate her or hold her back from accomplishing anything.'

When I was little, we came up with the term "melty." It describes anyone who treated my mom like she would melt if she had to do things on her own. This included waitresses who gave the check to me, an eight year old girl instead of to her, crossing guards who would offer my mom their umbrella in the middle of a rainstorm, and a wide array of other people we encountered. After one of these people had left, I'd lean over and whisper, "melty".

I'm glad my mom raised me the way she did. I know my mom really is "so brave," [as total strangers sometimes say to blind people] not because she's blind, but because of the way she hasn't let people's attitudes about her disability intimidate her or hold her back from accomplishing anything. She's brave because of the wonderful example she's set for me, not just as a blind person, but as a person in general. ❖

'I knew that wherever I went people were observing me, wondering about me, at times doubting my abilities.'

My Three Daughters

By Mary Somoza

As the mother of four children, three of them girls, I feel I am particularly lucky. My son is the oldest at twenty-one, followed by my twenty-year-old twin daughters (Irish Triplets- all born in one year!) and my youngest daughter, who will be seventeen in May. My twins have cerebral palsy and are both quadriplegic.

Needless to say that when the twins were born and diagnosed, our life went into turmoil. We somehow survived the first two years of constant hospitalizations and health scares, and it was around this time I had an enormous desire to have another child. Of course everyone thought I was mad!

One year later, when our pediatrician came to visit, I asked if there was any physical or genetic reason why I could not have another child. He said that he did not think there would be any problem, and the following May, Gabriella, our fourth child was born. As parents we vowed to make time to spend with each one of our children. The twins demanded the overwhelming majority of my time, so it was always a struggle.

Today, my relationship with my three girls is that of any mother with several daughters. I have always pushed for my twins to be independent. Currently, Anastasia attends Georgetown University and is an intern at Senator Hillary Clinton's office on Capitol Hill two days a week. Alba is studying art at Queens College, commuting back and forth every day, and Gabriella is a junior at the Dwight School.

I would say that my relationship with Anastasia, the oldest of the girls, and Gabriella the youngest is very similar. I had to be very involved in Anastasia's entry into college, working closely with the university's disability coordinator, yet I kept in the background as much as possible. Everything Anastasia and I learned is helping Gabriella in her search for a college for next year. The two of them talk frequently, comparing notes on college and everything else.

My relationship with Alba is different. Alba is non-verbal, has a feeding tube and requires total care. I am extremely protective of her, perhaps sometimes even over-protective. She is an amazing young per-



Mary and her three daughters

son. Despite her significant disabilities, she wants to do everything, go everywhere, be involved in every single activity, and is completely fearless.

Because Alba is so dependent on help for everything she does, I think we have a bond that ties us together in a special way. I know that Gabriella will go out into the world and eventually begin her life away from home. I feel the same about Anastasia. With Alba I sense that my close, day-to-day involvement binds us together in a different way. Most twenty-year-olds are quite independent, leading their own lives, no matter how close they are to their mothers. Given her need for care, Alba and I have no choice but to be together, although I help her cultivate friendships with others. Years of experience have shown me that nobody will give Alba the level of care and attention that she receives from me and her family. While I would like to believe that I have the closest relationship with Alba, I know that her twin holds this place. The bond between them is unique to twins, sometimes telepathic.

In summing up my relationship with my three girls, I would say that for the most part disability has in no way altered how we feel for, and interact with each other. While I worry about my twins' social life more than I'd like to, I have learned that things sometimes have a way of working themselves out. I have to admit I am extraordinarily proud of all three of them, and truly enjoy sharing their company, hearing their stories, advising them, lending a helping hand with homework, shopping with them; I love every minute of being with them! They are terrific girls, each in their own way, and I am one lucky mother to have been so blessed. ❖

About the Writers

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Harilyn Rousso is an educator, social worker, psychotherapist, writer, painter and disability activist.

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