CHAPTER VI

A PARENT SPEAKS

by Lotte Moise

What made our small house in rural Western America into a home? What insights did we—a father, a mother, and three children—gain so that our home worked and we became a family that 'hangs together'?

Barbara, our third and handicapped child, contributed significantly to the subtle changes in our heads and hearts—changes which have taken twenty years to come into clear focus.

When she was born we were a rather achievement-oriented, middle-class family. Intelligence was expected; stupidity was a dirty word. We were hardworking, super-responsible members of the community—never too busy to put up downtown Christmas decorations in a howling gale or preside over the PTA. Karen and David, at the ages of four and two, lived up to all our expectations in line with Gesell and Spock. Then Barbara was born and changed the tenor of our home. Karen was the first to voice her doubt when almost accusingly she asked me one day: "Why doesn't our baby DO anything? Keith (our friends' baby) rolled off the bed today." And this was the beginning of months and years of doubt, ("She'll be okay—My cousin didn't walk until she was three")—guilt ("Maybe that rash I had last year WAS German measles and I should have checked it out")—fear ("What will become of her when she grows up?")—resentment ("Why did this have to happen to us? I had such plans for our lives")—prayer ("Dear God, if only she'll learn to talk, please!").

There were times of terrible tension. While I was aware of Barbara's noticeable early deficits and was soon to be caught up in the rigid clinical prognoses of the early 1950s, Al, the papa, seemed to be dodging the problem by refusing to admit that anything was wrong. "Don't be nervous," he'd say, "she'll catch up if we work with her hard enough." I remember many a furious argument when I defended the reality of her physiological impairment and could see only limits in her future, while Al defended his irrational belief in unlimited potential. Barbara, in the meantime, responded to the warmth of his love and optimism and squirmed ecstatically whenever he came into her range of vision.

We luckily had good allies to help us over the rough spots. Our 'primary physician' was frank, warm, and supportive and we trusted him. Karen and David heard the simple advice of Barbara's pediatrician who said "Help your sister grow, but don't help her too much!"

Slowly at first, but accelerating all along, Barbara taught us to listen to and learn about her needs. Like a Jack-in-the-box she popped out of the confines of the 50-IQ trainable cubbyhole and blew all my neat professional pre-conceptions, labels, and limitations to the four winds. And with these restraints gone, I can now recognize the SIX R's which helped our house become a home.

RIGHT TO RESPECT

Respect means "value"—"to be worthy of esteem." Between mates in marriage it is considered a solid plank and a foregone conclusion. Respect can grow, even when passion and romantic love have cooled. But how about the children? Although we cuddle and love, bathe and feed, spank and tease, and play and help with homework, is it ever too early to express our respect for them?

Once I came into David's room and found him sitting, just sitting, on his bed and doing nothing at all when he was supposed to be changing his clothes. When I burst out angrily with my displeasure at his apparent laziness, he looked at me earnestly and said: "Mom, I need to have some time to think."

Karen, the A student, doggedly tried to overcome her poor natural coordination. Starting with her tiny two-year-sized tricycle, then stilts, later a bike, then tumbling, diving, and mastering her big stubborn horse, she irritated us to a point of anger with her persistence—until we recognized why and how valiantly she was striving.

I only hope that we spoke clearly of our respect to them, for all children need such solid stepping stones on their way to self-esteem.

Barbara's geared down rate of progress led us naturally from taken-for-granted high expectations to generous praise and applause. I still see her—age two years and three months, feet straddled wide, hands clutching the clips of her coveralls

—taking her first real steps. That and each new word in her limited vocabularly became causes for family celebration.

And from this we graduated to a dimension of respect which surprised us. We discovered that Barbara was aware of her handicap and that, if we truly respected her as a human being WITH her impairment, we owed her frank explanations and discussions of her handicap and its implications on her life. We also recognized that not long could she live her life as a girl without an awareness of boys and that true respect of her as a human being would grant her the right to a heterosexual life.

REGARD FOR OPINION

Regard for differences of opinion was not easily come by in our marriage. Broad areas of agreement existed in our relationship, such as in politics, money management, and music; BUT we disagreed on such sensitive issues as whether claiming a veteran's exemption is honorable or whether children must eat hot oatmeal every morning. At first we thought we must present a united front to our children on all issues, and we expected them to echo our opinions in important matters.

SHOCK! They didn't. David, the product of two parents who had taken an active part in World War II, was an avowed pacifist at age eight, and at ten he caused a hot discussion around the supper table when he challenged the value of daily pledging allegiance to the flag. Differences of opinion became the order of the day during the children's adolescence and ranged from hitchhiking to hotpants, from beards to booze. Then we began to recognize that home is a good place to air your views, be they ever so outrageous and shocking. Barbara soon joined the dissonant chorus by balking at baths, wanting to grow her hair long, and stating that she hated school and home. Gradually we began to hear each other out—to listen—and to accept. As we heard our children's different opinions on a variety of subjects, we learned that they were indeed widely differing people and that we had to prepare them for life in an ever-shrinking world of infinite variety.

Many "normal" young people came to our "Youth Hostel" during those years. It soon became apparent that these visitors did great things for Barbara's self-esteem, for she felt one of them. Many young people became profoundly moved by her, and some chose to enter a field of human services.

ROOM FOR DIFFERENCE

Our home was well regulated during the children's early years—regular naps, regular chores, much urging on regular elimination, and almost iron-clad bedtime hours on school nights—until Barbara came along. She seemed to crave irregularity and noticeably blossomed whenever we packed her with us to a potluck supper or school program. Late bedtime hours and strenuous trips seemed to spurt her rate of growth, and in this way we began an informal program of "infant stimulation." It was scanty and haphazard. At times the busy mother of a three and a five-year-old was glad of her quiet child. Looking back on those years I wish that Barbara could have had then the kind of preschool program we can provide now. We also stumbled onto an awareness which I now recognize as a "developmental profile." While she was slow at gross motor skills such as crawling and walking, she did an excellent job of feeding herself at an early age, and she had an uncanny understanding of complicated record players and operated them more competently than her sister. She spoke late and unclearly for years, but had a highly developed sensitivity for people's moods, and a startling extra-sensory quality. As we reinforced her assets to bridge the gaps of her deficits, we grew in tolerance of each other's short suits. It became acceptable for Mom to be poor at sewing and dense at threading movie projectors. Karen was rated as sloppy, but a venturesome cook. David's spelling was purely phonetic, but he was a fine mechanic. Father—well -—father remained 'perfect'! Our house—furnished in a variety of styles, textures, and colors—was beginning to have space for different people, too.

RISK-TAKING

On the day Karen climbed up a tall slide for the first time, I experienced my first pain of risk-taking. At the bottom I could support her. Then she was out of my reach. She teetered on the top rung—then sat and looked fearfully the long distance down—then back at me. I would have climbed up and brought her down again, but already other children were impatiently waiting for their turn. So down she slid. Triumph reigned, and I knew then that other moments just like this one were waiting for me.

There were many. She and her brother left for kindergarten—they spent a first night with a friend—rode a Greyhound bus alone—went on their first date in a car—got drivers' licenses. What made it so much harder to watch Barbara take chances? Since "normal" children had conditioned us to success, Barbara's diagnosis of mental retardation had scared us into expecting failure. Once we recognized that risk-taking is essential for learning, we were better able to let go. So she learned to light her father's pipe and later the fire in the grate. To go on errands to the neighbor and later on the Greyhound bus. She swims in deep water and pours hot coffee. More nerve-racking learnings, such as crossing busy intersections and riding escalators, we delegated to someone less personally involved. Of course we worry that someone might hurt her feelings, cheat her when she shops, or take advantage of her trusting affection; but we also recognize that we cannot let OUR worry become HER straightjacket—that we must not cheat her of her right to failure, which is as integral a component of growth as is success. For Barbara was learning about freedom and the risks it entails. She most clearly expressed her own feelings about this when she was sixteen. A friend of the family had died, and it was a first and very upsetting experience for Barbara. We explained as well as we could and hoped that she was feeling better. A few weeks later she and I were having a round-and-round. I nagged. She balked, and suddenly she looked at me and asked: "When are you going to die, Mummy?" I was shocked. She was worrying about the one condition which we cannot change for our handicapped children. As I put my arms around her shoulder, I assured her that I was feeling fine and should be good for a long, long time—"But why do you ask, Barbara?" Her answer was: "Because then I will be free . . ."

RESPONSIBILITY

RESPONSIBILITY was an "all-cap" word in our household. It applied to daily school attendance, Sunday School, scout meetings, and concerts. A promise meant total commitment. We expected our children to abide by our standards of responsibility. In desperation David once turned to his father and said: "But what if I don't WANT to grow up to be as good as you, Dad!"—and with that we realized that a sense of responsibility must be learned and cannot be dictated. Everyone must experience the consequences of irresponsibility in order to opt for the opposite.

Of course we were overwhelmingly concerned that Barbara learn responsible and appropriate behavior in the framework of our home, and gradually she did. At first she was clumsy and destructive. Favorite trucks lost wheels. Dolls found themselves decapitated and card games disappeared. It was difficult to referee between irate "normal" older brother or sister who took care of their possessions, and their young retarded sister who was exploring with a vengeance. Later she learned to leave their things along; and although she occasionally still probes the innards of her transistor radio, she is generally better organized with her personal belongings than the rest of the family.

No secret formula aided this learning process. She was exposed to the same group dynamics as were her brother and sister. We praised and scolded, rewarded and punished, hugged and spanked. We learned that many concepts needed to be explained with greater patience and in great detail. Flip answers instead of the 'honest truth' had to be dealt with, and still do. The need for an occasional 'white lie' as opposed to a 'black lie' was hard to explain.

Becoming responsible involves many small steps. From individual tasks such as personal cleanliness, taking messages,] and wrapping presents, she has had to learn to take part in group-oriented tasks such as folding clothes, washing dishes and dusting. She is not much of a self-starter yet, but is becoming more aware of her responsibility toward the group she lives and works with.

When she was little, liquor and sex loomed as tremendous worries on the horizon of her adulthood. But the first time she observed a drunk in a downtown gutter, she commented aptly, and she herself has decided to turn down alcoholic drinks in! favor of diet cokes. She learned about sex in our home in the! same way in which we all learned—by asking questions and getting straightforward answers, by observing animals and humans, and by watching television. She is well able to express one of the most basic of all human needs: to have a person to love her for herself—just the way she is—and she thinks well enough of herself to expect that some day this will happen. Our goal and hope for her is that she could hold up her end of a one-to-one relationship, be that in friendship or in marriage,

READINESS FOR ROLE CHANGES

We had a letter from our son recently. '"Dear Al and Lotte," it began, as he told us his latest news. Then came a subtle switch. "Could you do me a favor, Mom, and look for something in my closet, please." The twenty-two-year-old young man, very much his father's respected colleague and his mother's friend, had unconsciously slipped into a former, more dependent role, where he called me Mom and asked for help.

The see-saw patterns of maturity and childishness are strangely unpredictable. Transition from childhood and dependence to adulthood and independence, later to old age and a return to increased dependence, rarely happens smoothly. Yesterday the children piled into our bed to snuggle. Today they pull away from hugs and kisses. A few days ago the child bristled at Mom's insistence that she wear snowpants. Today SHE wants pantihose and claims that her legs are cold. Small bids for adult status may alternate with regression into childish behavior, but overall most children dream of becoming grown-ups, and mentally retarded children are no different.

Barbara longed for THE status symbol of maturity, her monthly period, when she was only eleven. She could hardly wait to be eligible for Aid to the Totally Disabled at eighteen; and when we asked: "Why are you so anxious?" she informed us that she could then help pay for her sister's hospital bill. She would be proud to have her own money. The acquisition of a non-driver identification card was also a source of tremendous pride to her. With Karen and David we expected adulthood, but with our handicapped child it took jolt after little jolt to shake us out of our overprotective parental attitudes.

One day, about a year ago, Barbara complained of a little headache. "Want to take an aspirin?" I asked. "I already did," she replied, and with that I jumped all over her. "Don't you remember," I bellowed, "that we have a rule in this house that you must NEVER take any medicine without asking?" Her lower lip drooped. "But I KNOW aspirin"—and she promptly went to show me the bottle. I suddenly thought of three things at once: "My child is eighteen and a young adult. During our visit to Denmark where Barbara lived in a group home for a month, the director told us that all her mentally retarded residents learn to take their own medicine. And here we are planning to let Barbara move away from home, while I can't unlearn my 'mother' role."

I apologized to Barbara: "We will have a new rule now—a rule for young adults—who KNOW aspirin."

At this point you may say "yes, but . . . my problems are quite different"—and right you are. I have no illusion that our family's SIX R's—the six principles which seem to have worked for us—will magically turn into a blueprint for homes for all families with a handicapped child. It would be smug and simplistic to assume that I have given all the answers.

Some families appear to have the same resources—access to schools, counselors, medical services, and supportive neighbors—and yet can't make it. Marriages have split over a mentally retarded child. Parents have abandoned children in state hospitals or placed them in foster homes and rarely visited them. Some capable young retarded ladies are not allowed to walk alone to the corner mailbox. I know men and women who may not hold hands. Some parents forbid their adult sons to have a beer. One mother found it so overwhelmingly difficult to teach her retarded daughter to use a knife and fork that for years she took her to the corner lunchcounter and ordered a hamburger and malted milk for her supper. As a result, this girl's teeth are in terrible condition. I knew a young man with Down's Syndrome whose mother did not let him go to school, and every time we approached her she wept. Another young man has never gone to summer camp because his mother fears that he might go into insulin shock. Her only other child—a talented older sister—died of diabetes complications. I remember urging one father to allow us to refer his young son for a tonsillectomy and adenoid operation. The boy had significant hearing loss in both ears, and the physician warned that it would get worse. The father ran me off his land with a shotgun. Recently an elderly mother, herself in a nursing home, refused to give permission for her adult son to leave the State Hospital and move into a community that offers fine homes and support programs for its handicapped citizens.

Why is it that similar problems challenge some families and defeat others? And granted that it is so, how can we solve the problems resulting from the past and prevent new ones from arising? Do we label families with problems "failures" and categorically place their children into community group homes, or can we help these families view their human experience of fear and fatigue in another light? Unfortunately, as Virgina Satir observes: "Family life is something like an iceberg. Most people are aware of only about one-tenth of what is going on." Perhaps the parents' inability to ask for help or respite, their unwillingness to let their handicapped child off the "short leash" of dependence, their need to perpetuate their disabled son or daughter in a retarded or sick or eternal child role is due to a very private need of their own. Perhaps with counsel and support they can reevaluate their home in the light of these unmet needs. The discovery of the cause of their own hurt feelings and fears may unleash new energies and the capacity of coping with the presence of a handicapped family member.

That not every family will cope in the same manner is essential to our American tradition. People feel that they have the right to raise their kids the way they want. Although it may have served our pioneer forefathers better than it does us now, rugged individualism is still held in high esteen. While in some areas of the world handicapped children are registered at birth, then followed up, treated, and provided habilitative programs by Government, we must first create family understanding of handicaps by public education and awareness. I believe such awareness is well worth pursuing and will result in full citizen status for our children.