

The Evolution of a Parent: A Gradual Process

by Alexandra Jacobs as told to Betty Binkard

Part One

Today, I believe, ours is a healthy, happy family. We have five children. All are enjoyed and appreciated for the very different types of pleasure and gifts each brings to our family.

Some twenty years and three children ago, we also began as a happy family. It was a more unquestioned kind of happiness. We already had one little boy, a strong, clever youngster, and now we had a baby girl. Eight pounds and five ounces of pink skin, dark hair, and healthy joy. We thought she was perfect.

Three months later, we were dealing with a sick infant, who had an episode of unknown origin, seizures and a coma. From what? No one could really tell us.

Sheila's first year was one of uncertainty. Her face was as animated as other babies', smiling when we approached. But she did not roll over until she was nine months, and she could not sit straight in a high chair. I needed to stuff each side with towels when I fed her. Her left hand was drawn into a tight fist and did not move with her right.

We were told it was a stiffness that would subside.

The years since that point and that very inadequate advice have been ones of hard questions. First, there was the search for someone who could tell us what was wrong so we would know how to help her. Then, there were the tough mental questions I found myself asking — about love, myself, and what it means to be a parent.

I'd like to share some of the answers we found with parents who are just beginning to ask their questions.

Faced with our own doubts about the diagnosis of stiffness, we took her to an orthopedic specialist. After his exam and learning about her coma and seizures, he simply said, "I think she has cerebral palsy."

I felt shaky inside but managed to leave the office to return to my husband's waiting car. Tearfully, I told him what had been said. Someone had finally, at last, told us that something was wrong!

Yet while we now had a label, we were to discover over the years that cerebral palsy simply identifies a condition of the muscles with a wide range of conditions. We found that each child is different, having individual similarities to others with cerebral palsy, yet unique in themselves.

We had another difficult diagnosis yet to face. That Sheila was retarded seemed obvious to me by the time she was two. We had another evaluation done, and as the lumps in our throats reappeared, we were told that this, indeed, was probably true.

Some of the uncertainty was now gone. And there were positives, even then, although they're easier to appreciate in retrospect. My husband seemed completely accepting of what we were facing, even at the beginning. He took an optimistic outlook, trying to ease my worries and help me to understand that we could simply try to handle each day's difficulties without bogging down in anxiety about what might happen — or might not - in the future.

Also, our family's financial security has meant we've never had to be dependent on public services. There have been options for ourselves and Sheila that not all families have. Yet so much of the experience has been the same as for everyone else.

I found myself at first feeling things I didn't always like myself for feeling. There was a kind of instinct to reject — not Sheila the person perhaps so much as the problems of Sheila.

I came to think often about the kinds of expectations we may have for our children. As I examined myself and listened to other

mothers and fathers talk about their children and their achievements, I realized that children are often expected, perhaps subconsciously, to serve as mirrors of ourselves, to make us proud and accomplish the kinds of things that will lead others to say, “Your son or daughter is so talented,” implying “What a good parent or person you must be.”

What happens, then, when a child we have “made” is less than perfect? Not able to function as we think normal is? In our young lives, what had we experienced to prepare us for Sheila?

The answers to many of my questions were not to come for years. I know now that I wholeheartedly accept and love Sheila, but I can't say exactly when it happened. It was a gradual process.

First, there was guilt. Had I done something, somehow, without knowing it, that caused Sheila's problems? The guilt eased as I accepted that there were to be no solid answers, that it was healthier to concentrate on what we could do now than to dwell upon unlikely past scenarios. I knew that there was certainly nothing in the past that we had ever done wrong knowingly, but that what we did in the present could have great effect.

I worried, too, about my love for Sheila. Could it be the genuine thing that usually comes so naturally and freely with children? Or would it only be the burdensome kind, the feeling that I had to love her, because she was my child?

There were also the fears — of the future, the unknown. What would happen to our child? To our own lives? To our family? Some of the fears began to leave as we acted to help her in whatever ways we could and as I realized that “the worst” wasn't happening. Being honest, I must admit that even today, my thoughts about Sheila and her future are not fear-free. There are still unknowns.

But as in the past, we've found that the important thing is to make plans and do whatever we can to make sure that Sheila's chances of having the unknowns work in her favor are as high as possible. The actions we've taken in the present phase of her life include having her brother formally appointed her guardian so that when her father and I are not here, someone who loves and cares for her deeply will be there and responsible for watching her progress and seeing that all goes well. We began early in Sheila's high school years to plan for her adult life.

When she was a toddler, it seemed vital to start her in a program that would stimulate her, physically and mentally. We wanted her to be given every chance to develop all the abilities and strengths she did have, as early as possible. I'm convinced that she's advanced as far as she has today because

of her early intervention program.

We learned it was important for us as well as for Sheila to research and investigate every possibility there was out there for her and then not to let ourselves persist in second guessing our decisions.

Still, there were many years of frustrations. She did not walk until she was about eight, but kind of waddled on her knees with her back as straight as could be. I saw others with a higher degree of spasticity who could walk fully on their feet and couldn't understand why Sheila wouldn't or couldn't stand up.

She was a mystery! It seemed as though she only made advances when she alone felt like it.

In a way, the puzzle about her walking and the realization that Sheila had her own agenda symbolized my own continuing questions about acceptance.

We parents are told, time and again, that we must accept our child, that we must not have false expectations.

I agree with this — for the most part. Certainly, not until we accept a situation can we be effective in dealing constructively with its realities. Acceptance means you can shift away from concentrating on what the child cannot do and on where she falls short of advance expectations and can focus instead on the positives of what she is and can do.

I've also come to understand that accepting a child for what he or she really is absolutely crucial — both for the child's sake and for the parents' peace of mind. It's impossible for children to have a very good picture of themselves if they sense — and children who are retarded can sense this, too — that their parents aren't quite satisfied with them, but are always wishing, even when they don't express it openly, that something about them were different.

Yet I see the acceptance as one that requires a very fine balance. It should not mean that we have no hopes, no expectations for our child who is retarded or handicapped in other ways.

Sheila has taught me that she does have her own agenda and strengths that have carried her far beyond what I would have thought possible during her early years. I've learned to keep an open mind about the possibilities her life presents.

I've also learned to keep my own ego out of my hopes for her. She will not have the kind of worldly accomplishments that make every parent's heart beat more warmly.

But, along the way, Sheila has taught me about keeping the goals we have for our children in perspective. When I think in terms of happiness as a goal, then Sheila has perhaps

attained more personal satisfaction in her life than our other children.

Our hopes for her are modest in some ways: that she can retain her self-respect and dignity, that she can continue to live as an adult in a surrounding with friends who value her, and that her own sense of self as a valued person is maintained.

She is an upbeat young woman with an endearing personality. My early doubts about whether my love for her could be the genuine, natural kind disappeared many years ago.

Part Two

One year later, I find that another article can be written as Sheila begins her adult life. It must be about evolution, the changes she is undergoing as she leaves her childhood. For we are discovering that the “whole” of Sheila is far from having all her parts set and in place. In her early 20’s now and just graduated from high school, she continues to grow and mature in ways that can be startling.

Watching Sheila enter adult life is different from our experience with her sisters and brother, whose basic personalities and abilities were well formed by the time they left our home. With Sheila, we’re learning not to take anything for granted, including some of her limitations that had come to seem like permanent plateaus.

We know that Sheila will always face certain restrictions. She has left high school — not to attend college — but to go to work in a supervised setting. Her very limited use of one arm and her tendency to fall have placed limits on her physical performance. Her health is good now but some past complications sometimes still make me question what her medical future will hold.

However, in her earlier years, we’d already learned the necessity of looking also at Sheila’s strengths when thinking about her education and development. Now we’re learning something else — that she’s not through acquiring new strengths upon which plans can be based.

Her language skills are developing. She’s using new words and speaking in longer and longer sentences. Friendly as a child, she’s becoming even more social now. She cries now as an adult cries, not in the frequent outbursts characteristic

of a very young child.

The other weekend morning, she went outside to remove our new puppy from his kennel and began playing with him by herself. This is an independent act that Sheila would never have initiated even a year ago.

Her confidence in herself is building after what may have been overprotection on our part as parents. We didn’t know what the future would bring upon her. We’ve changed, too, and eased up as we learned more about her capabilities. She isn’t so dependent upon her father now, and I sense this may reflect our own increasing confidence in her and what she’s able to face.

We know, on one hand, that we as parents need to continue to be very involved in her life and to make careful plans, a process in which we received valuable assistance from Sheila’s excellent teachers and administrators in the Buffalo district.

On the other hand, we know that those plans should not be written in indelible ink. Much of what Sheila is now at age 22 is not going to be the same at age 32. We have laid careful groundwork, finding out about all possible support systems and programs for her. We continue to learn about vocational possibilities. Her older brother has been officially appointed to be her guardian when her father and I can no longer make crucial decisions. She presently is at home only on weekends, having left our house to live in a type of foster arrangement in a family setting.

Some of these arrangements will likely remain in place. Others will change as Sheila continues her evolution and new needs and interests become apparent.

Sheila is very interesting to me. I often sense that she knows much that I don’t understand. She seems to know many of the words she just can’t say, to understand ideas that she can’t state.

Sheila Jacobs has certain personality traits that are unique to her, and they would probably have been there regardless of her disability. I think it’s very important for parents to recognize and respect these traits and also the untapped, or maybe untappable, capabilities of our sons and daughters with mental retardation.