

inflicted with cancer and have cared for them. To us, life is what a person makes of it. It is the positive attitude that surrounds any child or person that is so important. One can only try to make the best of things and live each day to the fullest.

We are concerned for the babies that have doctors who perceive spina bifida as a dreadful defect/disability and make the decision of whether to treat or not. Cindy was not treated at birth but survived. Thoughts arise as to what more she could do had she been treated. Would her degree of paralysis and the kidney damage be less severe? We'll never know. Some doctors hesitate on treating babies born with spina bifida, but wouldn't give a second thought to treating victims of automobile, industrial or other accidents even though the outlook may be very bleak. An example of this is the president's aide, James Brady. What makes the difference?

Another concern lies in the high cost of the medical supplies and equipment she will need the rest of her life. It doesn't seem fair that urostomy bags bought 11 years ago cost \$13.95 and today are \$42.50, that a set of full braces is \$5,000 or more, that a wheelchair is over \$1,000, that vans with lifts are \$20,000, or that urine analysis that were \$2.00 are now \$10.00. Most of the people with physical problems have limitations in job opportunities. Very few will be able to hold high paying jobs. Where will the money come from to pay for their needs?

Some places now want the money first and then they will bill your insurance. Where will she get the start to save money when she needs something? What happens when our 80 percent group insurance coverage lapses because she is an adult and then she cannot get insurance of her own because of her medical/physical involvement?

Cindy feels good about herself and has ac-

cepted her handicap. She realizes that she has limitations but that these should not preclude her from being able to achieve the goals she sets. The fact she is paralyzed from the waist down and requires orthopedic bracing brought Cindy to the realization that she would have to work very hard for what she wants very early in life. She knows that nothing is going to be handed to her on a silver platter and does not think that she deserves special treatment because she is "physically challenged." All she wants is an equal opportunity to contribute to society and earn her way.

Cindy has been a constant source of strength, love, and courage for us. As we watch her grow and see her achieve, our admiration for the child/young lady/soon-to-be woman grows. We truly believe that we have been more dependent on Cindy than she has been, or ever will be, upon us.

We have been very fortunate in having benefited from the professional services of very dedicated, talented, competent, and caring people in the areas of medicine, education, and orthotics. Yes, there have been differences of opinions between themselves as well as with us. There were goals that took longer than anticipated to be reached. But, can't we all say this happened to us also in our "normal" lives.

It is one of our dreams and goals to see more medical professionals get involved with the National Spina Bifida Association of America and its local chapters. We don't need people to be afraid of spina bifida. We need help to spread a positive image, to achieve the establishment of a hospital for research and for the needs of all people with spina bifida. People need to know that children who are physically challenged don't need sympathy and things done for them. What they need is the opportunity to live, learn, grow in love and be loved—just as we all do.

A Personal Experience

by Cynthia L. Cuchna*

Most people would say, "It would be terrible to be born with a birth defect." Well, I know

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firsthand that it really isn't so terrible. I have been blessed with family and friends who have not let me feel that my disability should get in the way of reaching my goals.

My parents have never let me use my handi-

cap as a way of getting out of responsibilities. I have the same responsibilities around the house as my sisters and if I don't take care of them I am equally disciplined just as my sisters would be if they didn't do their share of the work. I feel my oldest sister, Sherri, has helped me the most in believing that I am just as capable as anyone else in doing things for myself. If I would ask her to get me a book or a glass of water or something, Sherri would probably say something like, "Get it yourself, you aren't helpless!" I wouldn't want it any other way between us.

People have asked me if I feel my sisters are allowed to go more places and do more things than me. I don't feel that I've missed out on any of the experiences my sisters have had. I go to football games, movies, go shopping, and go to the local disco just like my sisters.

The only problem I have is that most of my friends live too far away from me to just "drop by" whenever they feel like it. My friends are my classmates from the high school I had to attend, which is outside my local school district and is the only school in the county capable of handling my special problems. We can't even call one another very often because it is long distance.

Hospitals have been a very important part of my life, since I was in and out of them quite frequently when I was young. I never really minded going into the hospital because the doctors and nurses were always nice and I knew they would take good care of me. Along with hospitals comes bills. Our family has never been eligible for financial aid because my parents always made "too much money." I know that at times it has been tough for my parents to make ends meet because I am such an "expensive kid." Sometimes I feel guilty about having

my parents pay such big bills just because of me.

I have been in braces ever since I was four years old. I know that they have helped me considerably, but I often have negative feelings about my braces. There was a time when I was unable to wear my braces due to pressure sores. I like being out of them because my clothes weren't torn by the locks on my braces and I liked getting dressed faster. I thought I looked prettier without all of that plastic and metal sticking out of my clothes. I am finally starting to realize that I look better in them because they make me straighter. I don't look like I'm a "pretzel" when I'm in them. I have greater mobility in them, which enables me to do things and go places that I couldn't in my wheelchair. Even though the negative feelings may resurface in the future, I plan on wearing my braces a lot more than I have for the past two years.

When I go out to a movie or go shopping, sometimes people stare at me. This has never really bothered me. It just shows me that they are interested in my disability and are curious to see how my braces, crutches and/or wheelchair works. I especially like it when little children come up to me and ask, "What happened to you?" I am glad that children aren't afraid to ask questions. I wish that adults would open up and ask, because I would be more than willing to tell them about anything they would want to know.

My plans for the future are to graduate from college with a degree in psychology. I think that I would like to be a school psychologist because I love children. I know that the road ahead will have some rough spots, but I know that I can make it with the love and support of my family behind me.