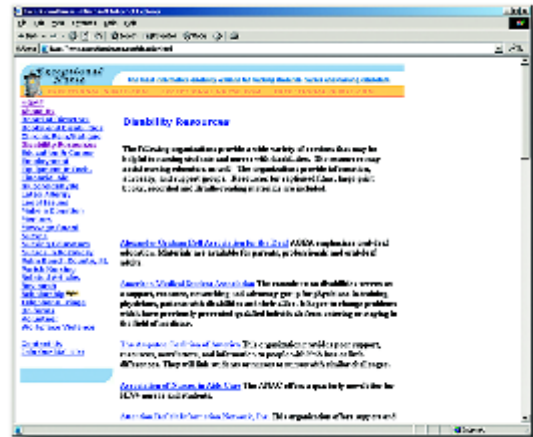




Empowering Persons With Disabilities

How Nurses Are
Changing Perceptions at
www.ExceptionalNurse.com

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We all do a lot to prevent birth defects—health care providers, the media, specialty organizations, the scientific community, the government and many others all play strong roles in advocating preventive measures so that most children are born relatively healthy and whole in the U.S.

Genetics research has even given some parents the option to pre-select the sex and the genetic makeup for their offspring. Then reality sinks in . . . even if a child is born perfect, it doesn't mean he or she will stay that way.

So, when an infant is born with a birth defect or develops a problem or disabling condition later, his or her parents are subjected to the reality of what their child may face throughout their life. This can be disheartening. A death happens; a death of dreams. Parents are often left with a loss of hope for their dear child.

Society callously places perceived obstacles in front of children born with disabilities, rudely diminishing the life experience of a person who has a handicap because it may not

perfectly parallel the social norm. We also do this to children of normal abilities without even realizing it. Take, for example, Robert McMillen's story. He was born in 1942 and, as a distance runner, he failed to make the high school track team. Once he and his father and brother realized that the coach was building his team by testing students as sprinters in the 100 yard dash, they asked the coach to consider a different approach. The coach then offered Robert the opportunity to run the mile, and voila, he made the high school track team. Ten years later, he won a silver medal at the 1952 Helsinki Olympics as a distance runner.

The lesson to be learned is that we all face obstacles, and those faced by people with handicaps are no different than those faced by persons with normal abilities. And here is where nurses can make a critical difference in the lives of parents who have just birthed a baby who has a birth defect, or who may go on to develop a disability or disabling health problem. Nurses can help parents see that their children will often have many, varying roads to live

By sharing information and resources, ExceptionalNurse.com hopes to facilitate inclusion of students with disabilities in nursing education programs and foster resilience and continued practice for nurses who are, or become, disabled

a full life and achieve their dreams. Nurses can play an important role in empowering parents so that they can in turn empower their children. Here's how two nurses, who met through the issue of disabilities, are working with their colleagues to change perceptions regarding persons who are different from the norm.

Susan: One Nurse's Story

Consider my story: When I was 5 years old I became acutely aware of my differences. When I entered kindergarten, I realized that I was missing my left hand. In effect, I had not paid that much attention to the fact that I didn't have a left hand until others began to point that out to me. Until this time my interactions among my family, friends and neighbors had not emphasized this difference in me (see photos 1 & 2).

During this time, I vividly recall seeing a television commercial "calling" others to help the handicapped. The commercial featured sev-

Photo 1.

Here I am doing what all little girls love to do, hold their doll babies. It was apparent to me then that I "didn't have a left hand" (Susan Fleming).



eral children with sorrow on their faces—all with various handicaps. And there she was, a little girl, just like me missing a hand, a pitiful portrayal. "Help the handicapped," the commercial demanded.

My little mind began to wonder, "Was this my destiny?" When my mom came home, I asked, "Am I handicapped?" My clever mother answered, "Only if you want to be." Right then a huge sense of relief hit me. I had a choice. I could choose to be full of sorrow or I could go on outside and have fun. I chose the latter.

These early experiences in my life empowered me. They gave me the boost to go on when the road that I traveled got bumpy, like when I first applied to nursing school and was turned down. I knew that I could take a different road to reach my goal. I just needed to be patient. I learned a big lesson: don't let someone who has only known you for 10 minutes make a decision that will change the course of your life. Patience paid off. I became a nursing assistant, and I was finally admitted to a nursing program after receiving tremendous encouragement from the doctors and nurses with whom I had been working.

Then a new fear struck me: I began to fear failure—being unable to demonstrate a skill or task that would result in dismissal from the nursing program. By myself, I would have wallowed in my fears. However, sensitive nursing instructors sensed my uneasiness and offered me counsel. A pediatric nursing instructor sat with me and said, "You are waiting for the big one, the big one to kick you out of school, but it won't end here. Next, it will be the big one to keep you from getting that job, then the big one that will get you fired. You must get over this. It won't end."

At that moment, I knew that somehow I had veered away from that initial encouragement my mom had given me so long ago. I regained my strength and determination, graduated from nursing school and I have spent the past 20 years working as a staff nurse in many hospital settings. Persistence pays off. I know this because Olympian Robert McMillan was my uncle as well.

Donna: Another Nurse's Story

I, too, am a nurse. From my earliest recollections, I wanted to be a nurse. I grew up in

Rather than focusing on that defect and letting it serve as a limitation in the child's life, teach the parents to empower their children as they are, and to build on their own unique skills and abilities



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Hartford, CT, and worked as a “candy striper” at Mount Sinai Hospital. Later, I attended nursing school and pediatrics became my love. During the years, I developed a passionate interest in working with children with special needs. Today, I teach nursing at Florida Atlantic University in Boca Raton.

My daughter, Lauren, was born in 1986 at the stroke of midnight. Ironically, months later, I learned that she would be one of the countless special children for whom I would provide care. Lauren is mentally disabled and has a host of additional problems including autistic tendencies, obsessive compulsive disorder and seizures. Her care is extensive and requires total assistance with bathing, grooming and dressing.

Soon after learning about her challenges, I began to search for information, and failing to find all that I needed, the seeds of a life of advocacy were planted. Two other parents and I started a parent-to-parent support group for parents of children with disabilities in our community. I wrote, I spoke and I worked tirelessly for Lauren and other children with disabilities so that they would have equal access to school, community and recreational activities. I nurtured countless new parents of children with differences and empowered them to advocate for themselves and their children.

Professionals told my husband and me that Lauren would never walk or talk. Surprise . . . Lauren continues to defy all early predictions. Thankfully, she has never read the books that those professionals read! Lauren now walks, snow skis, swims and talks with short sentences. Countless hours are spent working on self-help skills to empower Lauren to be as independent as possible.

In my “spare time,” I completed a doctoral degree. It was in focusing on my dissertation, which examined the experiences of nursing students with disabilities, that I created a nonprofit website for nurses and nursing students with disabilities called www.ExceptionalNurse.com. And then I wrote a book called “Nursing Students With Disabilities Change the Course.”

Susan and I connected when she e-mailed me after visiting www.ExceptionalNurse.com. We quickly became friends, colleagues and coauthors. Today, she serves on the board of

ExceptionalNurse.com and she works with me as an advocate and mentor for other nurses and students with disabilities throughout the world.

The Importance of Empowerment

ExceptionalNurse.com is a nonprofit web-based network committed to inclusion of more people with disabilities in the nursing profession. By sharing information and resources, ExceptionalNurse.com hopes to facilitate inclusion of students with disabilities in nursing education programs and foster resilience and continued practice for nurses who are, or become, disabled. ExceptionalNurse.com began as a grassroots effort to address the needs of nursing students and nurses with disabilities. Currently, there is a paucity of information available for this growing group of nurses.

Empowerment is a catchy word. However, it holds a lot of truth. Nursing educators need to be open to admission of more students with disabilities. All nurses, educators and administrators can make a difference in the success of students and their perception of themselves as a valued member of the nursing team. We need to encourage all nursing students to know their strengths and build on them.

Next time you hear that a child has been born with a birth defect, let the parents know that they can make a difference in their own lives and in the lives of others. Rather than focusing on that defect and letting it serve as a limitation in the child's life, teach the parents to empower their children as they are and to build on their own unique skills and abilities. Tell them their child can have an amazing life full of wonderful friends, a life rich in skills and abilities. And that when faced with real or artificial obstacles, they can challenge the status quo and simply “reinvent” themselves as often as needed so that they can have the life they've always dreamed of having. The child could even grow up to be a nurse!


Parents can make changes for their child or they can empower their children to make their own changes. We suggest the latter. 

Photo 2.

A Memorable Childhood

I fondly remember focusing on what I could do during my childhood, not the fact that I didn't have a left hand. Eventually, I graduated from nursing school (left bottom) (Susan Fleming).



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