

# GROWING UP WITH A DISABILITY:

## What Children with Physical Disabilities Need from Their Parents



by Melissa Crisp



Top (l-r): Melissa's parents, Beverly and Howard Crisp, with Rudy Costruto, Superintendent of the Santa Ana Unified School District, and Melissa at the Senior Awards Ceremony. Above: Melissa hitting the slopes in 2000.

I have always wondered what my parents were thinking on the day I was born. My dad recently told me he was expecting an experience similar to the birth of my sister four years earlier. Then he and my mother learned that an emergency C-section was necessary, and that this was not going to be a typical birth. I often wondered, did the doctors scare them with phrases like “blue baby” (lack of oxygen) and “cerebral palsy?” Did my mom and dad instantly forego dreams of their new baby daughter taking her first steps? Unfortunately, I never had the opportunity to hear my mom’s perspective on what must have been a very frightening day. She died shortly after my third birthday.

While cleaning out my grandparent’s house several years ago, I found hints of her thoughts regarding my infancy on a typed piece of yellowing paper:

*“She was so floppy. No muscle tone—hypotonic they called it...The only clue to ‘normalcy’ (I always put quotes around ‘normal’ because what really is normal? Normal for one is not necessarily normal*

*for another.) was the sparkle in her eyes and a bewitching smile she always seemed to respond with.”*

As parents of children with disabilities, you may have questions and concerns about raising such unique children. You may wonder what the future will hold for your son; or you may worry about who will care your for dependent daughter when you are no longer able to do so. Although I cannot speak from the perspective of a parent, as a young woman with cerebral palsy, I can provide a special insight on what it means to have physical limitations, and offer specific strategies for coping with unexpected challenges.

The following suggestions were gathered from a variety of sources. Some are based on reflections from my own childhood—what my parents did or what I wish they had done. Others come from friends with various types of disabilities,

their parents, and people who work within the disability community.

### Let go—a little

Remember, first and foremost, that a child is still a child. In addition to their parents’ love and acceptance, children need to experience as normal a childhood as possible. This may mean becoming involved in after-school activities, doing household chores, going to slumber parties, attending summer camp, participating in adapted sports, and yes, even dating. Consider letting your child spend time away from home.

These brief periods away from the safety of home will teach him or her how to trust others for personal assistance, and aid in the development of social skills.

By spending time away from home, I learned what I was physically capable of doing independent of my parents, and specific ways of asking others for help. I attended summer camp every year between the ages of 9 and 12. I loved the freedom of being away from the protective eyes of my parents. At camp, I learned that asking for help from unaccustomed individuals means more than just saying, "Can you help me?" It means explaining how to unfold the wheelchair, set the brakes, and push the chair over large cracks in the sidewalk. I also started to feel comfortable around large groups of people without disabilities for extended periods of time. These are valuable skills while learning to cope with the world at large.

One of the best aspects of childhood is the unshakable belief that absolutely anything is possible. This is not to say that we should encourage

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children to have unrealistic expectations of their physical abilities. After all, Susie may never leap from her wheelchair and jump rope. It is simply a belief that every child should be allowed to take risks, and perhaps fail. This may seem like a scary prospect for some parents. I am sure my own parents encountered sleepless nights during my first few months living in the college dorms. However, they understood my need to push beyond any previously established limits in order to uncover my full potential, both physical and mental.

Failure has taught me that there is always another door to open. If I had gotten the first job—or even the tenth job—that I applied for after earning my bachelor's degree, then I probably would not have pursued a career in writing (my first love). I also see failure as part of achieving independence. As I was growing up, my (step) mom's mantra was, "If at first you don't succeed, try, try, try again." She sincerely believed I was capable of a great number of

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accessibilities  
expo

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things. She pushed my boundaries when I found it easier to accept my limitations. I owe my current independence to her more than anyone else.

As an undergraduate student, I lived in the on-campus dorms for three years. I remember the first day my parents helped me move into my

dorm room. They waited for me to take a bath. They said they just wanted to make sure I would be okay getting in and out of the bathtub, but I could tell that they were just nervous about leaving. I was equally worried about them leaving, but they did and I was fine. My dad called me quite frequently for awhile. He told me later, "We were

very apprehensive during your first few weeks at school. You had been with us for 18 years. We knew you'd be okay, but we were still pretty worried. After about a month, you told me that you'd let us know when you wanted to come home. We didn't see you until Thanksgiving!"

### **The importance of being mobile**

As a person with an ambulatory limitation, I feel the same way about using my wheelchair as a person without such limitations feels about walking. I got my first manual wheelchair at the age of 4. If the user and wheelchair (or any other type of mobility device, for that matter) are properly matched, there should be a natural connection. This is why it is critical to choose the right device. I feel that the goal in choosing a mobility device for a child should be to provide the greatest amount of daily independence. I use a power chair for my everyday mobility. I can't imagine my life without this chair. It has given me amazing freedoms, like the ability to "hop" on a city bus, go shopping, or simply go for a "walk" on a sunny day. Since most cars are not equipped for power wheelchairs, there are many situations when using this chair is not practical. For instance, when I attend outings with friends and family, or run errands with my part-time attendant, I generally use a manual wheelchair. The loss of independence while using my manual chair is usually compensated for by valuable social contact.

Since it is such a personal piece of equipment, choosing a wheelchair and its accessories should be done with as much input as possible from the child who will be using it. The overall comfort of the child should be a major priority for everyone involved. A quality cushion is a must! Sitting on one's bottom all day, every day, can become mighty uncomfortable! It can also lead to pressure sores. In addition, properly adjusted footrests will not only keep the child comfortable during a typical six-hour school day, but will increase their functional abilities. When I got my current power chair, the footrests kept falling off. Not only did this drive me absolutely insane, it threw off my posture and my ability to control my chair with precision. It was a little like sitting in a chair where your feet don't touch the ground for six hours.

I also recommend allowing children to choose the color of their chair. If this prospect gives parents visions of their teenage rebel zooming around

universal motion

high school in a neon green or orange chair, try having the child choose from a set of predetermined colors. My parents insisted on a black chair, saying that I would grow out of my desire for a purple frame. I think they were wrong, however, because the first chair I picked out completely on my own, at the age of 25, had a purple frame.

Remember that ultimately the chair does belong to the child and he or she needs to develop a sense of ownership and pride. Hopefully, it will serve as the child's most loyal companion and he or she will care for it as many adults do for their cars.

### **Teach your children, and yourself**

There are a variety of ways both children with disabilities and their parents can gain knowledge and insight about life with a disability. Since the vast majority of individuals with disabilities actually enjoy talking about their lives, parents should not be afraid to ask questions of any they meet. Be nosy, but respectful. I have found that speaking with older individuals who have physical disabilities can be very informative and comforting. This was especially true for me as a college student, when for the first time I found myself in the midst of a community of intelligent individuals with disabilities. My older friends often serve as my mentors, providing both advice and empathy. It was through their dreams that I discovered my own future ambitions. It was not until college that I had my first contact with a professional adult who had a physical disability. Patty, my main advisor, continues to be my role model.

I would love to see the creation of a national mentoring program, where families of older children with specific disabilities are connected with families who have younger children with the same disability. Until this concept blossoms, parents should encourage friendships between their children and older individuals with similar disabilities and welcome ideas from families who have already jumped a few of the hurdles. Practical experience often proves much more valuable than professional theories. Read and network with other families; network with families who have children with similar disabilities. You can locate these families through your child's school, on the Internet, or by asking your family doctor. They will not only serve as a support group, but also a great source for references and referrals. Parents may be able to locate these families on Web message boards,

since virtually every medical condition under the sun has a site on the World Wide Web.

My dad always teases me (and sometimes becomes annoyed) because I startle quite easily. I never knew why I sent my Cheerios flying each morning when he walked into the kitchen. I just

figured it was another one of my goofy characteristics. Then, one evening, while listening to a special education lecture on cerebral palsy, I learned that this was a common reflex in people with CP. Allowing children with disabilities

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### enabling devices

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access to age-appropriate medical information and research may give them a better understanding of their physical limitations, show them that they are not alone, and help them see what aspects they have control over.

### Public awareness

After you educate your child and yourself as a parent, you may wish to share what you've learned with others. Members of the general public will not know how to react to your child. They may feel uncomfortable or embarrassed by their

own curiosity. Speak openly about your child's disability. Welcome questions. If possible, try using humor to put people at ease. This type of interaction will help them gain a better understanding of the disability, and show children with obvious physical disabilities how to deal with strangers' questions. Remind children that strangers only stare because they are curious, and ignorance is correctable.

Jennie Benson, my best friend, is blind. Jennie finds that some people have a tendency to speak loudly to her, as though she has a hearing impairment. She and her mom point out, "We must teach people that blindness is not deafness!"

I believe that parents can and should become their children's advocates. As parents, you probably spend the most time with your son or daughter. Therefore, you probably know their abilities and needs better than anyone else does. Doctors, teachers, and other professionals may seem intimidating, but your voice is truly important when making decisions that will affect your child's life. As they mature, think about letting children advocate for themselves as much as possible. This may mean allowing children to attend Individual Education Plan (IEP) meetings, or having their voice heard during the making of medical decisions.

### Take it easy

Practice patience: Absolutely nothing will frustrate a child more than when parents become agitated because they cannot perform a task with the speed and accuracy of a non-disabled child. This can make the child feel that the inability is somehow his or her fault. (And my parents wonder why I never learned how to tie my shoes!) Try encouraging independence, not perfection.

My grandmother once told me about a phone call she received from my dad. He called shortly after my first birthday to tell her that I had just rolled onto my stomach. Grandma said that the excitement in his voice was unmistakable.

Raising a child with a disability can be quite challenging. Yet the smallest accomplishments can yield the greatest rewards! ■

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