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# How to Explain Your Child's Disability to Others

**Donna G. Albrecht, Medical Writer**

## Introduction

When Bonnie Russell's 8-year-old son Randen asked her to explain [his learning disability](#), she came up with a novel approach. "Using San Francisco as his brain, and the highway as the way nerve endings travel," Russell recalls, "I told him a lot of people's nerves route them to the freeway--to their brain crossing over the Golden Gate Bridge--but his nerves take the ferry."

Russell's explanation was easy enough for a child to understand. It was an honest way of saying that her son's [brain learns differently](#) than other people's. It let him take control of questions and handle them in a way that was comfortable for him.

## Making Differences Normal

Dr. Irwin Siegel, codirector of the Muscular Dystrophy Association's clinic at Rush-Presbyterian/St. Luke's Medical Center in Chicago, has worked with children with muscular dystrophy or neuromuscular disease for more than three decades. He says he believes that "honesty is the best policy" in all communication about a child's disability.

Dr. Siegel says it is up to a parent to ensure that a child knows and understands his or her disability. One way is to tell the child that everyone is different somehow: Some kids wear glasses, some have allergies, and some have weak muscles. Pointing out successful people who have achieved their dreams while living with a disability, like President Franklin

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Roosevelt (polio), scientist Stephen Hawking (amyotrophic lateral sclerosis), and Miss America 1995 Heather Whitestone (deaf), can help. When your child is adjusting to a new class or a change in physical condition, Dr. Siegel suggests that parents hold a classroom session so that classmates are aware of the situation and have an opportunity to ask questions. He has found that their questions are often simple, but serious, such as how they should react to their disabled classmate and whether the condition is contagious.

## Who Does the Talking

Whether your child's disability is obvious or hidden, there will be times when other people ask questions. "It is the tendency of most parents to answer for their child, feeling as if they are protecting the child," says Carla Amrhein, a child-life specialist with the Shriners Galveston Burn Hospital. Amrhein advises parents to pay attention to their child's readiness to talk about their disability and allow their child to answer questions if the child wants to.

If your child does not feel comfortable answering a question he's been asked, be sure he has a response like, "Please ask my mommy [or my teacher, babysitter, etc.] that question. I have to go now." You can create practice situations at home where your boy or girl can try using that response. Unfortunately, rude or inappropriate questions in real life are inevitable. Your child must have a way of handling it. You need to make it clear that your child does not have to share personal information with others.

Tracey Flourie, whose 13-year-old son Skyler has a seizure disorder, tries to explain Skyler's disability simply and honestly. "It really depends on my target audience," she says. "For example, for school purposes--where people know what a seizure disorder is--I would be more inclined to give a description of what Skyler's seizures look like, where and when

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they're likely to occur, and what kind of first aid needs to be rendered. To family members who don't have a lot of medical knowledge, I might just say he has epilepsy--we don't know why."

Elizabeth DeVault of Easton, Pennsylvania, has found that it is sometimes necessary to approach people like sports coaches and parents of her children's friends and offer information they haven't asked for. Her 11-year-old, Colin, and 9-year-old, Bethany, both have spina bifida and use braces and crutches. "I usually bring up the subject to others," she says. "They may try to be so PC [politically correct] they pretend it doesn't exist."

## Special Help

There will be times when you want professional help in explaining your child's disability. This could be anything from a presentation for the staff at your child's school or day care to educating your child's scout troop or sports league about their medical condition.

There are excellent resources available for this purpose. Many organizations have everything from brochures to films that explain different disabilities. They may have specially trained facilitators who will come to the school or meeting to do a presentation and answer questions. You can also check with your child's physicians, occupational or physical therapists, visiting nurses, or other professionals who know your child well. Often these people will take the time to come to a meeting to answer questions and educate people so they will be more comfortable around your child.

## Resources

Many Web sites offer information on helping you and your child learn more about explaining and handling disabilities. Not all of them are authoritative and accurate. Look for sites that are affiliated with medical institutions, health organizations, and governmental departments for information and advice you can trust.

Here are some good places to start:

<http://www.easter-seals.org/>

Easter Seals offers information, support, and services for children and adults who have disabilities

<http://www.mdausa.org/>

The Muscular Dystrophy Association offers information, support, and services for families dealing with neuromuscular diseases.

<http://www.nichcy.org/>

The National Information Center for Children and Youth With Disabilities has a national information and referral center that provides information on disabilities and disability-related issues focusing on the needs from birth to age 22.

<http://www.shriners.com/>

This home page for the Shrine of North America offers information about their hospitals in the United States, Canada, and Mexico that offer free services to children who need care for orthopedic problems, spinal cord injuries, or burns.

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