

Developmental Disabilities Awareness Month: Opportunities and Misconceptions

By Margaret Graham, Esq.

March is Developmental Disabilities Awareness Month. Owing to parent advocacy and landmark legislation, communities have become significantly more responsive to the needs of people such as my daughter, Emily, who has cerebral palsy and autism. But challenges remain, and families continue to band together throughout the U.S. to help one another, increase general understanding and lobby for change.

Everyone deserves a chance to reach their potential. Here, Emily asserts her independence at the pool.Here in Albuquerque, I belong to the Cerebral Palsy Parents Association (CPPA), a nonprofit that's affiliated with the University of New Mexico's Carrie Tingley Hospital. The group was founded back in the nineties so that families could learn from and support one another. Due to the hospital's central location, our "local" self-help group counts families from across the region among its members.

The CPPA meets monthly and maintains an extensive mailing list. Many of our efforts focus on distributing information and connecting families to services that meet the changing needs of their loved ones. Parents of new-borns, who have just received a diagnosis, are usually overwhelmed and wondering what to do first. Once a child reaches school age, families must learn to negotiate for Individualized Education Plans (IEPs), arrange transportation and navigate the sometimes harsh social landscape of the classroom. Then there are the years immediately after graduation, when the public support system changes dramatically and individuals are entering adulthood. Given improved health care and longer life spans, aging parents increasingly wonder how to ensure a child's security when they are unable to personally advocate and care for them.

Kids with CP want to be treated like everyone else, but there are still too many misconceptions. I don't object to people asking me what my daughter can and can't do. It's their limiting assumptions that I mind. Our support group talks about how CP affects entire families, including siblings and grandparents- such as a sibling acting out in school on the day that a brother is having surgery. Thoughtlessly cruel language, such as use of the "r" word, is deeply offensive and hurtful, not only to people with disabilities, but to those who love and care for them.

Today, there are far more support options than were available when our group was established. There's more assistive technology every day, and federal regulations have

vastly improved wheelchair accessibility. A growing focus on self-advocacy means that people with CP are making more of their own decisions with regard to the services provided to them.

There are more job opportunities, too, but far from enough. People with disabilities have skills and enthusiasm to offer. Employers would be well served to make creative adjustments to their operations that would both benefit their businesses and accommodate this talent pool.

As people throughout the U.S. consider the meaning of Developmental Disabilities Awareness Month, I ask them to remember that, just like other individuals, those with disabilities have unique capabilities and interests. As a society, we owe them a chance to achieve their personal potential. My Emily, who loves to swim, recently received special "floaties" that were recommended by another family in the CPPA. Now she can be more independent in the water-and she loves that.

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