

AFTERWORD: DISABILITY CULTURE

John D. Kemp

BORN WITH ARMS ENDING just above the elbows and legs ending near the knees, I didn't know I was different until about age three, maybe four, when a young boy, very angry at me, said something hurtful. I went immediately to my dad for comfort and protection. For the first of many times, he told me that I was different—not better, worse, or special—than other children and that other children who couldn't accept me for using prostheses had problems, not me.

Thank you, Dad, for giving me the gift of pride in being equal as well as different. My dad is my hero for his life of devotion to family and faith, public service and advocacy, and personal values and beliefs.

Our natural mother passed away three months after my younger sister, Mary, was born, leaving Dad to raise three children. Kathy, my older sister, was then five, and I was fifteen months old. At age thirty-two, my dad restarted his life—with three young children, two master's degrees, a deep Catholic faith, and without his partner. He committed then to a life of quality parenting and love, public service and advocacy, and improving the lives of people with disabilities. By the time he decided not to seek reelection to the City Council of Prairie Village, Kansas, in 2001, in his eighty-third year of life, he had completed sixty consecutive years of public service—from a county public roads worker to Kansas's Secretary of Transportation for eight years in the 1980s.

He spoke to us often about his career, stressing the importance of service to our fellow citizens. In addition to civilian and military service with the U.S. Navy in World War II, Dad was a volunteer leader with Easter Seals, long before, during, and after I had been chosen to serve as its 1960 Poster Child.

Dad felt it was an honor to serve others. From his days growing up on the homestead land of his parents in northeastern Montana, he always believed it was a privilege to live in America, that freedom needed protection, and that volunteerism required nurturing. He expected all his children to volunteer at community-based organizations, and we did—Scouts, Easter Seals, candy-striping at the hospital, and serving Mass at our Catholic Church. Dad practiced as he preached—providing a wonderful role model for me.

Dad used his wisdom, charm, and good fortune to find and marry Joan, our stepmother—our mother—in 1970. Dad now has Parkinson's disease, and he addresses its challenges with all the skills he has acquired—managing it and never letting it defeat him.

I was given the gift of love and self-worth by my family—Dad and my two incredible sisters. Inclusive school settings from kindergarten through Washburn University Law School also contributed to my self-worth. Dad's successful argument was not how much inclusion would benefit me; rather, it was how—as a result of my participation as the only child with a disability—all children in the school would learn that there are children with disabilities who belong in our communities, with their families, and in local schools.

My disability has given me both insight and perspective on human behavior. A simple social “handshake” with me because I wear prostheses (hooks for hands) has sent ordinary people into states of total confusion. I know I must guide people at these times.

As I travel by air frequently, giving speeches and serving my law clients, I find myself answering strangers' inquiries about what happened to me. The answers lie in my identity as a person with a disability and as a member of the disability culture. I am proud to be a person with a disability. While my experience as a person with a

disability does not completely define me, it is an important part of who I am today.

People with disabilities have a culture of their own—just as African Americans, Hispanic Americans, women, and so on do. The notion that a culture of disability exists is anathema to some people; yet, it is fully understood by most adults who have lived with their disabilities for years. Typically, cultural phenomena are transmitted down through families, as lore and legend, and at places of worship. Our disability culture is transmitted from one of us to another, peer to peer. Yet, parents and families can nurture it. When my dad gave me my pride in being a person with a disability, he was nurturing a culture of disability within me. I urge parents and families to nurture our culture.

Carol Gill, Ph.D., an assistant professor in the Department of Disability and Human Development, College of Applied Health Sciences at the University of Illinois at Chicago, has articulated the core characteristics of our disability culture as follows:

- People with disabilities have a heightened acceptance of human differences—whether social, racial, economic, or class.
- People with disabilities consider interdependence an essential aspect of our lives.
- People with disabilities use humor—the ability to find something absurdly hilarious in almost anything, however dire—without it becoming self-deprecatory.
- People with disabilities have an ability, acquired over time living with our disabilities, to read others' attitudes and conflicts in order to sort out, fill in the gaps, and grasp the latent meaning in contradictory social messages.

We are connected as a culture because of shared indignities inflicted upon us by poor architectural planning and design and by others' stereotypically negative assumptions about us. We are also connected by the frustration and anger that wells up once in a while

when we tire of dealing with prostheses, scooters, and sores—and that makes us search for understanding by someone who has been where we find ourselves. Anger, frustration, and hurt are managed quite well by many of us . . . and poorly by all of us once in a while. But how do we handle these emotions?

In his book *Emotional Intelligence: Why It Can Matter More Than IQ* (Bantam Books, 1995), Daniel Goleman, Ph.D., describes a core of emotional competencies: controlling impulses, managing anger, and finding creative solutions to social predicaments. Goleman estimates that only 20 percent of life's success is attributable to IQ points. The other 80 percent is emotional intelligence—the ability to rein in impulse, to read another's innermost feelings, and to handle relationships smoothly. I know I had the hardest time managing my own anger and frustration until I read something by Aristotle. Aristotle suggested that it is a rare skill to be angry in all the right ways (at the right person, to the right degree, at the right time, with the right purpose). I have been working on this skill, and I suggest that parents and children with disabilities consider it as they deal with the frustrations and anger that are part of our cultural experience. It is OK to be angry for a while. Then address the cause(s) of frustration and anger and fix it—or accept that you cannot change it.

I empathize with parents. From the beginning of pregnancy, you've prayed for and dreamed of "a healthy, happy, normal" baby. Your world flips over when your baby does not meet this standard. You might think, quite wrongly, it must be something you did or some genetic factor. Please be assured that it is not your fault. My dad and mom had similar concerns.

After Mom died, my dad's three sisters and his mother came to help. Dad left each of us with a sister for three months—to examine how his life had changed, why this tragedy would befall us, and what he could do going forward. None of us has ever known where he went, what he did, with whom he spoke, or what progress he

made. When he returned, he gathered us up and we began as a family of four. He never looked back, other than to honor our mom and tell us what a kind, loving, and beautiful woman she was. Dad has never blamed her—or himself—for my disability.

Please don't blame yourselves. Come into this new world of people with disabilities with curiosity, criticism, and your own set of values for parenting your child. Find a new friend who is going through or has just completed such a journey, and then, with your friend's guidance and suggestions, enjoy parenting.

I believe that inclusion works, even for most children with severe disabilities. Sometimes, however, caring parents decide that more intensive services and supports in a separate, segregated setting are necessary. Such parents need not apologize. My philosophy is that "choice," the fundamental value of the disability civil rights movement, affords parents a full spectrum of options—including separate services. Families and children have the right to make that choice—a choice that must be respected by all.

Take care of your marriage. Raising a child with a disability or serious health concern can add stresses to any marriage. If divorce should become the solution, and I hope it does not, financial stresses will increase and all children must be protected from the pains that follow. Each child must always feel special and not a burden. Be sure to tell your children that your divorce is yours—they are not responsible for such parental decision making.

Finally, get a life! Keep the laughter and joy flowing and set and celebrate goals achieved as victories of life. For almost all children with disabilities, there will come a time when parents have to let go. So, teach them early the way to become independent and maintain that independence as well as their pride in themselves—pride in the differences and similarities of all people—and you will have done a terrific job as parents.



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A graduate of Georgetown University (1971) and Washburn University School of Law (1974), John was awarded an Honorary Doctorate of Law from Washburn in 2003.

John has served as chief executive officer of United Cerebral Palsy Associations, VSA Arts, HalfthePlanet Foundation, U.S. Business Leadership Network, Disability Service Providers of America, and The Abilities Fund. He has also served as a member of several nonprofit boards of directors, including the American Association of People with Disabilities (co-founder), Independent Sector (vice chair) and the U.S. International Council on Disabilities (chair).

In 2006, John received the Henry B. Betts Award, America's highest honor bestowed for disability leadership, service and advocacy.

A much sought-after keynote speaker and humorist, John delivers many major addresses each year at conferences, conventions, and annual meetings.