

## **HOW COULD ANYONE EVER TELL YOU, YOU WERE ANYTHING LESS THAN BEAUTIFUL?**

Reverend Nancy J Anderson

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### **The Whole Human Family –**

I grew up in a family where everybody was pretty much healthy and able to walk, talk, listen and see. We could all function within optimal range most of the time. Well, except for my dad's migraines. That laid him out occasionally and we were careful not to disturb him.

And well, except for my Uncle Chet who was born tongue tied and lived his entire life unable to speak clearly. As a child, I was the only person who was able to understand what he was saying. He was my favorite uncle.

Oh, and of course there was my cousin Keith who was deaf. At the Iowa School for the Deaf he learned to read lips and speak, so we could communicate fairly well. Keith helped me tie the bow on my Sunday dress.

Then there was my uncle Maynard who had Parkinson's disease. He was in constant motion. He couldn't speak very clearly either, but he was very kind to us children. We used to love doing errands for him.

I never thought of any of these family members as disabled. They were just part of my life, differently-abled if anything. And so when at school, I had a friend who had a cleft palate, played with a neighbor child crippled from polio, and encountered a whole variety of children in our school's special education class, these children were also just a part of my life. While the term differently-abled was not *au courant* at that time, that is how I saw them.

And it never occurred to me that I myself had a disability! Even though I was deaf in one ear as a result of an ear infection. It was just something I learned to live with.

When is it that we human beings learn to discount and fear those who are different from us? How is it that we do not naturally make room for everyone? This is a mystery to me, for disability is all around us. Very few of us function perfectly at all times. How many of us in this room have impaired vision? How many wear hearing aids? How many need the assistance of canes, wheelchairs, oxygen tanks, or other paraphernalia? How many live with unseen conditions like Attention Deficit Disorder? Or depression, or those debilitating migraines?

My experience as a child helps me to understand that when we know and care about someone, we have no fear of their difference, disability becomes normalized. We accommodate and include everyone as best we can.

Today we have opportunity to get to know some folks in our congregation, perhaps in ways we have not known them before.

We have opportunity to open our minds and hearts to see us all as just part of the human family.

### THREE VOICES on Disability and Inclusiveness

#### Voice I

When I was a high-spirited 19 year old I became involved with an older man and my parents became involved in Intervention. Over several months our relationship deteriorated and they saw fit to have me hospitalized. I would say committed, but I had the foresight to agree to sign myself in, reasoning I would have a better chance of signing myself out if I did. The facility had all characteristics associated with the movie version of a mental hospital. Women zonked on thorazine; patients dreading their next electroshock treatment.

It took almost a week, but I negotiated my way out of there by agreeing to go to a modern facility in Chicago, to an unlocked ward of folks pretty much like myself, neurotics with problems, some with depression. I figured I'd make the most of this time by treating it as an unusual experience to be lived to the max. And I made friends with the people on this ward. I learned about their experiences of being committed by spouses (read Husbands) through Cook County Hospital, where the indignities they suffered included having no forks, no eye-glasses, no shaving equipment, just to name a few.

Seeing ourselves as more like each other than not, not that different from those "outside", we formed a pact, like kids being "blood brothers", to tell the truth and fight the stigma of mental illness when we got out. I tell you this sordid little story in their honor.

Fast forward to my "Real Life." During that time they had a hard time pinning a diagnosis on me, but over the years I discovered what it is like to live with a real diagnosis and one that is not easy to poke fun at: depressive disorder. At first it was denied but eventually it could not be ignored or wished away. I was hospitalized again in my thirties. Ten years later I started taking medication and thinking of this illness, not as "mental" but as "chemical". Well, considering the makeup of the brain, what's the bloomin' difference except that one sounds less stigmatized than the other.

This fall I saw a psychiatrist for the first time in many years to get a meds check. He changed all my meds and the adjustment has been rocky. For a time, I thought he diagnosed me as bipolar. That was a blow. I felt the force of the stigma I denied. Recently I clarified and found my diagnosis is limited to depressive disorder, but I am grateful for the insight I gained while I thought it was more.

Recently I have experimented with answering people honestly when they say "how *are* you?" I've said "Oh, I'm a little depressed." I am shocked at how few people are equipped to respond to that simple statement. I mean I didn't just say "I have a fatal contagious disease." One person actually signed off with "Oh, that's great" or some such words. If you would welcome people with my illness, learn to listen without being threatened; learn to reply from your heart. **acknowledge the statement.** You could ask a question ("Does that come over you often?" for example). Or simply say "I'm so glad you came anyway."

Stigma is at the center of our response to this illness. Like homophobia, it can be internalized, as I demonstrated when I didn't share my story, or external, as when people are embarrassed by my sharing. And, like homophobia, it evaporates when we realize that the person sharing is just a unique human being like everyone else.

## Voice II

My first born child was a beautiful little girl named Denise. When she was born the umbilical cord was around her neck. The doctor said "Don't worry, the cord is loose and her responses are good."

A year later we took her to a specialist when it was apparent that Denise was not developing normally. He said that the umbilical cord might have twisted while in the birth canal, cutting off the oxygen to the brain for a few seconds. There was no way to tell then if Denise might just be slow to develop or if it might be more serious.

It was more serious. She did not learn to walk until she was three, had a stroke, learned to walk again, had another stroke and didn't walk again. She never learned to talk, showing her emotions much like an infant would.

When she was five we had her committed to the District of Columbia Home for the Retarded. Denise stopped growing when she was five and I learned that children who stop growing at an early age usually do not live through adolescence. She died when she was 16, bed ridden but still responsive and able to smile or laugh when I visited her.

We were lucky that there still was a public institution then. Today most children like Denise have inadequate care at home or in a foster home. The public institutions have been closed down without adequate provision for community care.

Because Denise looked normal I sometimes got inappropriate comments; for example, the woman who said "You shouldn't spoil her by carrying her around. She's old enough to walk."

And then there were the Congressmen on the District of Columbia Budget Committee. Taking care of the retarded in D.C. didn't get them many political points back home. For over ten years I would go to the hearings and plea for more staff and higher salaries. One congressman told me that his sister was a nun who worked with retarded children and she never asked for more money.

At an evaluation clinic for crippled children the doctor was brutal when he said "She's not crippled – she's retarded." I was not comforted by the social worker telling me that Denise would be happy in her own little world. I wanted her in my world.

What helped me the most was a friend who burst into tears and said "This is terrible." Her expression of grief lightened my load.

There were many who helped me bear the strain and grief. When Denise had her first stroke the U. U. minister who came to comfort me said "Aren't you glad you don't think that someone up above did this to you?" Yes, at times being an atheist is a comfort.

Denise spent a year in a nursery school for handicapped children and was treated with kindness and care even though there was little hope of improvement.

The director of the nursery school helped me through the decision to have Denise committed. The doctor who had to certify that Denise was eligible was very compassionate. He visited the District Home to check out what Denise's ward would be like. He assured me that it was excellent. The nurses and nurse's aides who took care of Denise over the years were angels.

When Denise died I reserved the Children's Chapel for the memorial service rather than the sanctuary. Since no one at that church had ever seen Denise I assumed few would come. It was packed, because, of course, they came for me.

A relatively new minister did the service, spending time with me to plan it. I knew that he had been sick recently but didn't know that he was dying. He pulled himself together to perform his last ministerial service before his own death.

Some disabled people would gain little or nothing by coming to church. We can still make a difference by giving our love and support to their families. I know this from experience.

*How could anyone fail to notice that your loving is a miracle? How deeply you're connected to my soul.*

### **Voice III**

#### Personal Observations on the Sociology of Wheelchairs

I have osteonecrosis ("bone death") in my knees and hips, and probably my arms as well. It is a progressive disease, with the dead areas suffering microfractures when I stand. In most cases, continued walking leads to collapse of the bones, but high pain levels have protected me from this mistake.

#### **Pain and Grief**

People can see a wheelchair, but the problems are often invisible, so the story needs to be told. In general it is futile to persevere while in pain—it seems that pressing on creates anger, and then sadness. I have good days, but things are easily put out of balance, so that pain prevents sleep. In social circumstances I seem to unconsciously suppress pain, until I suddenly realize that my mood has turned foul and I am treating myself and others harshly. At this point I am suddenly unable to do any more. This makes schedules and commitments difficult.

Mourning is also invisible, and the loss of your ability to walk might have the same kind of impact as the death of a close relative. This means that trying to be friendly to someone in a wheelchair can be risky. My wife and I visited one of our favorite campgrounds in Minnesota, on the north shore of Lake Superior. It was our first camping trip with osteonecrosis, and I found many joys were now inaccessible to me. We took the wheelchair up a paved path to the immense waterfall and looked upon it. I was very sad to be sitting on the sidelines, as it were, when only a few years back I was *climbing* those falls. A woman smiled at us and said, "Isn't it good they have a path here for people like you?" Well, I thought, "people like me" are capable of tossing "people like you" right over the rail, as a matter of fact! I can see the headlines now: "WHEELCHAIR MAN GOES BERSERK OVER KINDLY COMMENT: INSANITY SUSPECTED." In all seriousness, pain and grief can make a person pretty close to insane, and certainly extraordinarily unreasonable.

#### **Magnifying the difference**

An ancient circuit in the brain seems to gauge the importance or "stature" of a person by their height. That might in part tell us why a person in a wheelchair is ignored and dismissed so often. But people also seem to have a psychological need to magnify or maximize the difference. The phrase "people like you" is telling, for it separates "us" from "them." Perhaps we do this to reassure ourselves that "people like us" don't have to worry about ever being in a wheelchair. If so, it seems unlikely to offer real protection.

It does do real harm though, for, it defines me by my disability, by what I cannot do. It tells me I am a person who sits in wheelchairs, not one who has climbed cliffs. But a person with a disability tries very hard every day to *not* be defined by it. If an ill-considered comment

reaffirms and validates a characterization that I must steadfastly reject, then it certainly will not be well received.

Once, at the Mayo Clinic, an assistant offered to help in the cafeteria. Though he was with us for several minutes, he never spoke to me, but only to my wife Katya. Another time we went for a medical test, and the receptionist asked my wife (not me), "Can he sign?" Another headline looms: "CRAZED CRIPPLE CONKS CASHIER!" How could she imagine that, just because I'm in a wheelchair, I can neither talk nor sign my name? That is an extraordinary prejudice, a pre-judgment, a maximizing of the disability.

When expectations are so low, there is some danger that you will fall into them. So one tries to fight back and remain independent. An insurance representative absolutely insisted on pushing me around. I insisted he stop, finally telling him that if he didn't I would punch him. Another headline blares: "INSANELY EVIL INVALID INJURES INNOCENT INSURER!" He still didn't stop, and I didn't punch him, but he was a real jerk, and it was demeaning. He apparently thought my request was "invalid." For reasons such as this I even prefer the extravagantly egregious locution, "cripple."

### **Trivializing the difference**

It probably would be simpler to just have two categories, abled and disabled. Cases that fall in the middle ground make things more complex than people like. I have been accused of faking, for instance, when people see me get up and place the wheelchair in the car, and then walk to the driver's door. The *Inquirer* screams, "WHEELCHAIR WASTED: CURMUDGEON CAUGHT WALKING!" The person who made this accusation was trivializing or minimizing my problem. Well, I can walk, but it breaks my bones.

There is a golfer with this disease; like me he can stand enough to take his shots, but he cannot walk the course. As I understand it, the golf association won't make an exception and let him ride in a golf cart, although it has given such exceptions for people with more visible disabilities. I guess they see him stand and they think, it can't be that bad. Even doctors seem prone to this kind of error.

So while disability itself creates enough problems in terms of pain and grief, people's unreasonable actions seem to be an unnecessary addition. This additional pain of misunderstanding occurs with all kinds of disabilities, not just my own. As much as possible the best course of action is to let the facts of each case emerge, without allowing our preconceptions and prejudices to magnify or trivialize a disability.

### **Benefits**

It is odd to think, but there are positive aspects to being in a wheelchair. When I see how many people wish to be friendly and help, it restores my faith in the goodness of humanity. And all kinds of people with all kinds of problems now say hello to me and talk about them, maybe because they know I too have felt loss and stigmatization. Finally, I have come to see the truth of one aspect of Buddhist doctrine, namely, that everyone suffers, and that this is true whether they have a disability or not.

### **MAKING ROOM FOR ALL – Reverend Anderson**

We are all part of the human family. We are all beautifully, wonderfully human in a variety of ways. Our response to different abilities need not be and ought not be pity, it should simply be inclusion and empathy, for we all live from our abilities. We all live with our own talents, and our own barriers. We accomplish what is important to us because of who we are regardless of limitations or ability.

When we are in trouble or have difficulty or are in pain, we need understanding and caring people around us. And so we take the time to share what joys and sorrows are present with us during the week. We do this so that we might all be included, for THIS is life. This is the life we all share together. What special abilities or disabilities do YOU live with?