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Summer 2010

On Becoming Invisible

By

Edward F. Ansello, Ph.D.

One of my best friends in college used to say that I had “an amazing grasp of the obvious.” So it is, with an almost thudding sense of “Duh!”, that I realize that people do judge a book by its cover. Whether literally (why else do so many covers feature “beautiful” women, irrespective of the book’s content, in order to induce sales?) or figuratively (hence the relentless promotion of desirable appearances, fashions, and first impressions), we often respond to the superficial. But what about those whose “book covers” are something less than the current societal ideal? For many of us, the answer is some degree of invisibility. We can become less visible to the larger society because of age or impairment. We are less “attractive” in the literal sense, attracting less notice or attention.

It is sometimes amazing, as an older man, to walk through a crowd of strangers and realize that no one has looked at me. I may have been prepared to smile or greet others. Instead, I notice that passers-by look at other people but not at me. I don’t think that it’s their rudeness so much as my irrelevance. Age or impairment tends to render us less *germane* to the popular core values, less likely to be noticed. On an individual basis, growing older can be a Cheshire cat-like experience of gradually disappearing.

Physical appearance is the cover of our personal book. As our bodies age, we distance ourselves, or rather we are distanced, from the physical ideal. As our appearance changes with age, we elicit less notice by others. They are indifferent. Somewhat, this can be a blessing. There’s a certain freedom in it, not so great a pressure to compete for attention. When it comes to matters of need, however, not attracting attention can be a terrible impediment. If age or impairment may make us less visible or less relevant, age and impairment can combine to make us vanish.

Do we realize that there are tens of thousands of Virginians who are over age 60 and have survived to this point with lifelong disabilities such as cerebral palsy, autism, or Down syndrome? Moreover, the overwhelming majority have been living in the community all their lives. Have we noticed them? As a group or, more importantly, as individuals?

Acquiring a late-onset disability such as dementia creates another type of disappearing. Dr. Paul Raia, Vice President of the Alzheimer’s Association of Massachusetts and New Hampshire, spoke in June in Richmond at the annual conference of the Area Planning and Services Committee (APSC) on Aging with Lifelong Disabilities. In his keynote address, Paul, who is blind, emphasized *Honoring the Person Within*. In his quietly passionate delivery, without the current “essential” of Power Point slides, Paul related case after case of individuals who had developed dementia in later life, and their gradual disappearance from those who loved them. But he offered a way of seeing them.

Paul contrasted rehabilitation and habilitation as meaningful interventions in their lives. In his view, rehabilitation has as its core value an effort to restore, to take the person to the greatest degree of independence and productive citizenship, through external control of services to the person with a disability. Restoration is unlikely with a progressive disease like Alzheimer's. Habilitation, he countered, would work on restoring capacity only after assessing what the person needs to develop emotionally; habilitation doesn't make one's self-definition dependent on function but on who the person is, how the person feels about himself or herself. Explaining that one part of the brain left relatively untouched by Alzheimer's disease is the amygdala, where the person is able to hold and to recognize emotions, Paul related changes to the physical environment and to the ways we communicate with someone with dementia that foster positive emotions in that person. For example, someone with advanced dementia may not understand cognitively when a caregiver says "no," and this sets up an adversarial situation where the person with dementia picks up on the emotional cues. Agreeing with and then guiding the person to another activity are more likely to create a positive emotional climate. Paul explained that activities programming is the motor that drives habilitation, offering opportunities to experience the joy of learning, even if there is no chance that what's learned will be retained.

In his conclusion, Paul discussed reciprocity, noting that by readjusting how we see the person "we can learn to train our hearts and spirits to see that the person with the disease is giving us a gift, an opportunity to honor the person within."

A few days later I met a man in Cleveland at a conference on aging and lifelong disabilities. He has cerebral palsy, uses a motorized wheelchair, and wants to be a country singer. He calls himself Cowboy Tim and has been singing at small gigs here and there. For his day job, he works at an independent living center, getting up each day at 4 a.m. for all the necessary preparations so that he can be at his job by 7:30. He is articulate and has a nice singing voice. But to hear him, people have to look beyond appearances. At our table over lunch he asked me if I knew who Charley Pride is. I replied that he was one of my father's favorite singers. He then asked me if I knew one of Charley's songs called "*I'm Just Me.*" When I answered that I did not, Tim said that it was his favorite song and proceeded to sing a verse to me:

Oh I was just born to be
Exactly what you see
Nothing more or less
I'm not the worst or the best
I just try to be
Exactly what you see
Today and every day
I'm just me.

When he finished, we quietly sang it again together.