

The Lost Art of Manners

Revolutionary Common Sense by Kathie Snow, www.disabilityisnatural.com

What are manners? Years ago, I read a meaningful definition which described manners as “making another person comfortable.” Most of us probably try hard to have good manners, but many of us lose the art of manners when it comes to people with disabilities.

While I was presenting the “History of Disabilities” at Idaho Partners in Policymaking, Howard (who is fifty-something) said he wanted to share how individuals had been treated and talked about in the past, based on their disability diagnoses.

“I have two brothers,” Howard began. “All the time I was growing up, when my father introduced us, he said my brothers’ names and then he always said, ‘And this is our retarded son, Howard.’ Why did he do that, Kathie? *It always made me feel so bad.*” Then Howard broke into shoulder-heaving sobs, as the years and years of pain poured out. Several of us comforted him as best we could. Resuming my presentation, I noted that years ago, many people probably believed that it was appropriate to share this information with anyone (including strangers) and perhaps they also thought people with disabilities did not have the cognitive abilities to understand what was being said, so they didn’t think their words would hurt.

Howard’s pain was clear evidence that words—*especially the words used by parents and others who profess to care about you*—hurt very deeply and the pain is long-lasting. On that day, Howard’s decades-old pain felt as raw as it did every time Howard’s father described his young son as “retarded.” It seems things would have changed over the past thirty, forty, or fifty years, but...

Week in and week out, I meet parents who talk about their children (regardless of the child’s age) in the same way Howard’s father did! Sometimes the child is present, sometimes not, when parents say things like:

- My daughter is autistic.
- He’s sixteen, but he functions like a 5-year-old.
- She doesn’t have much “upstairs.”

Would we share private information about family members who *don’t* have disabilities, like:

—My teenager still sleeps with a night light.

—My husband takes Viagra.

—My wife has a big boil on her behind.

I don’t think so! Most of us—I hope—have better manners than to share personal information that is nobody’s business!

So how, in all good conscience, can we share private information about people who have disabilities? How can we talk about them, in front of them, as if they’re not there? And talking about them when they are *not* present isn’t much better—that’s a form of gossip, and the person isn’t there to defend himself!

Family members aren’t the only guilty parties, however. Many professionals have lost their manners, as well. After inviting me to present a seminar, some meeting planners have “helpfully” warned me, “Some of our ‘consumers’ will be there, and they’re more like children.” Would the meeting planner make this announcement *during* the seminar, when adults with disabilities are in the audience? Don’t think so. If a meeting planner feels it’s appropriate to warn me about people with disabilities, why isn’t she also motivated to warn me about others? As in, “Some of the parents and professionals who are coming to the meeting are real duds.” Many educators routinely use negative descriptors about their students, both in front of the students and behind their backs. Ditto for many therapists who shamelessly say things like, “The Down’s is coming in this afternoon.”

The loss of manners isn’t limited to our words. Our actions speak volumes.

“Janelle” recently introduced me to her 20-year-old daughter, “Micki,” a bright and lovely young lady who happens to have a disability. Micki shook my hand and greeted me. In the course of casual conversation, I asked Micki a couple of questions. She started to reply, but Janelle jumped in and answered! Micki could speak for herself, but her mother got in the way! Why did Janelle do this? Was she afraid I wouldn’t understand her daughter? Was she afraid I would judge Micki by her words or oral abilities? Did she think her daughter

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is incompetent? Or was she even *aware* she was doing this? Like all parents, Janelle probably spoke for her daughter when she was very young, and perhaps she hasn't realized Micki can now speak for herself. I can't imagine the frustration and anger Micki must feel.

What's frightening is that parents, professionals, educators, and service providers are supposed to be "on the same side" as the children and adults with disabilities they care about, serve, and/or teach. But with friends like these, who needs enemies?

Our poor manners are not only rude, but they also risk causing long-term and severe emotional pain in others. Furthermore, they reinforce the disability double standard: one set of rules for people *without* disabilities and another set for people *with* disabilities. And we wonder why inclusion, dignity, and respect for all continue to be out of our reach. Our words and actions set people up for exclusion.

How can we do better? First, using People First Language is crucial. (See the People First Language article at www.disabilityisnatural.com.) A person is not her disability, thus, she is not "retarded"—she "has a cognitive disability." A diagnosis represents a condition or a characteristic; it does not define a person. And consider that a family member of a person who has cancer does not say, "She's cancerous." So, why do we say, "He's disabled [or retarded, autistic, or whatever]."? Saying, "She has cancer," is more appropriate, as is, "He has a disability."

Second—and just as important—we need to be careful about sharing information with others. Howard's father might have shared that his son was "retarded" in order to "explain" his son's behavior, speech, or something else. But the outcome of his good intention was probably less than desirable: upon hearing "retarded," people most likely assumed the worst about Howard. (What terrible things we may inadvertently do in our efforts to "do good"!) Once that first impression was formed, there was probably very little Howard could do to change it. The same is true today when we focus on a person's disability as a "problem."

There are relatively few times when it's important to share a person's diagnosis with others: in special ed meetings, with medical personnel, and/or with others in the service system. Just as we wouldn't discuss the need for Viagra or the details about the boil on your bottom with anyone other than medical personnel, we do not need to share a person's disability diagnosis with anyone other than a few specific people in specific circumstances. (And even then, there are more respectful ways of sharing information with others, as described in "The Problem with 'Problem'" and other articles.)

Many people with disabilities are said to have "challenging behaviors." Perhaps we would do well to look at our own behavior before judging others. Is it possible these individuals may be reacting or responding to the vicious, verbal assaults they routinely experience when they hear others talking about them? Do we think people don't hear or understand what we're saying? How arrogant and uncaring can we be? Shouldn't we care about how others feel? How would you feel if others talked about you?

Third, we need to demonstrate our good manners by letting people with disabilities speak for themselves and be themselves. They are our equals! We have no right to speak for them, unless they have asked us to do so! In addition, to interrupt someone; to "explain" his behavior or actions; or to "apologize" for his drooling, his speech pattern, or anything else is to rob a person of his right to be who he is! How would you feel if your husband interrupted you and said to others, "My wife is quite the motor-mouth, isn't she?"

The personal lives of people with disabilities should not be part of the public domain. We have no right to speak for them, to reduce them to medical diagnoses, to share their personal information, or to talk about them (in front of them or behind their backs) in ways we would never talk about ourselves, and, in the process, strip them of every ounce of dignity. Have they ever given us permission to do any of these things?

Howard gave his permission to share his story. His experiences, as well as the experiences of countless others, are continuing lessons that help me stay on top of my manners. I hope they do the same for you.