What'd I Say?

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Think for a moment about how we talk about people we support. I've been listening to Ray Charles lately and just saw the movie *Ray*, so I couldn't help using a song of his as the title of this paper. But "What'd I say?" is more than a good song—it's a good question for us to ask ourselves. Our words are powerful. From what I've heard over many years in the service world, words spoken to or about people with disabilities are frequently limiting and not all that respectful. Usually, I think this happens without intending harm—I hope so anyway—but it happens.

There's a lot to this topic*; my hope is that this paper will start a discussion about the words we use, and the thoughts, beliefs, and feelings behind the words. We all know that direct support staff have important roles and close contact with the people they support; thus they—you—are key to the question of language.

There is no real list of language "do's and don'ts." This is not about what's politically correct – whatever that means these days. However, as we learn and evolve, attitudes change and the words we use change. Thankfully, words like "mongoloid" and "imbecile" and many others – words once widely considered acceptable descriptors of people with disabilities – have virtually disappeared from regular use. Hardly anyone would use them today in referring to someone with a disability. We are making progress—or are we?

Near the 2004 election, a radio host in Milwaukee used the word "wetbacks" while talking about illegal immigrants. There was a public outcry, because there is widespread agreement that you just don't do that. It's wrong. He was suspended, and after joking about apologizing, finally did apologize. A couple weeks later, a Madison radio host used derogatory terms about Condoleeza Rice and Colin Powell. A similar series of events followed. Andy Rooney, Howard Cosell, and numerous other public figures have found themselves in hot water over derogatory comments.

*There are a number of good resources on language and disabilities (see, for example, Kathie Snow's essay on people-first language www.disabilityisnatural.com, and Mayer Shevin's classic *The Language of Us and Them* at www.shevin.org/articles.)

What I'm wondering is, how do we gauge what's acceptable and respectful in the language we use in support work and about adults with disabilities? Teen entertainer Lindsay Lohan recently received a letter from the Arc-USA, one of the largest disability organizations in the country, gently scolding her for her frequent use of the word "retarded" as a synonym for stupid, as in "That is so *retarded!*" This use of the word occurs regularly on TV, in movies, and in popular music. (I heard it most recently on the

radio in the song *My Band* by D12 -- but some will be more offended by other lyrics in the unedited version of that song.)

But enough about famous people—back to us. Have you noticed that adults with disabilities are sometimes referred to as if they were children? I wonder if we agree that an adult is an adult, regardless of disability. One's life experience or intellectual development may be different or limited, but the person is an adult.

Yet I hear things like, "Mary is so spoiled." Whatever it is about Mary that would make her staff person say that, calling her spoiled is demeaning. What's underneath that? Doesn't Mary deserve better? Or, "I'm taking my girls to the zoo." Your girls? First, they're not yours, and second, they're not girls. A case manager (and speaking of language, think about those two words together...who is managing what?) says, "My people...."

Or this one: "Bill has the mental age of a one-year-old." Is that accurate and relevant? Does it matter? Who decided this, and how well do they know Bill? How does this opinion or medical diagnosis affect what people imagine as possible for Bill? I think the odds are pretty good that as this piece of "information" becomes part of the story told about Bill, following him around forever, Bill will be treated as a one-year-old his whole life.

I hear people use "high functioning" and "low functioning". I gotta say, I'm really tired of those terms. It seems to me that we *all* function differently, better in some ways than in others. Then there are words like profound, severe, moderate, and mild. I can accept that these classifications may serve a purpose, somewhere, to someone, but in twenty years I've never known them to matter much in real life. I think our words can create roadblocks to helping people make meaningful, real lives in the community. Would *you*, as a community member, be eager to get to know someone called "severe"?

"She's a Downs." I heard this not long ago when a staff person was talking about a woman with Down syndrome she supports. It was said in an effort to explain a certain behavior that the staff person believed was typical of people with Down syndrome. What do you think?

Here's a sentence taken from a newspaper story: "Wayne suffers from cerebral palsy." It was a story about a man who had been institutionalized for a long time who is now living in his own home. It was good news! He was beginning to live a full life and was apparently pretty happy about it. Nothing in his story was about suffering. But to the reporter, having cerebral palsy means Wayne must suffer. The reader has to wade through pity-evoking imagery to realize Wayne's life is good.

What the above examples have in common is that they tend to separate "them" from "us." They can take some of a person's humanity away. They sell people short.

To me, it's worth thinking and talking about the language and style of speaking we use with and about people we support. Let's listen to each other and ourselves. Let's pay attention to how respectful we are being. I think we owe it to people we support.

As we go through our day, it might be worthwhile to occasionally stop and ask ourselves, "What'd I say?"

These are some of my thoughts. What are yours?