



Complex Child E-Magazine

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Words Matter by Susan Agrawal

March 31, 2009, marked a great day for our children. It was the culmination of a campaign to end the use of the "R" word, which, as most of us know, means any variant of retard or retarded. The Spread the Word to End the Word campaign [<http://www.r-word.org/>], begun by youths with intellectual disabilities, aims to eliminate a word that can only be categorized as hateful and insulting to so many individuals.

This campaign also gives us the opportunity to talk to our family, friends, teachers, and neighbors about just why this word is so hurtful. I remember an amazing high school valedictorian speech given by Soeren Palumbo that illustrated this point in an incredibly poignant way. After describing a hateful incident in which racial minorities were stereotyped and called disparaging names, he turned the tables and posited a very simple idea: what if instead of being a racial situation, it was a kid calling a person with an intellectual disability a retard? Isn't that just as bad, if not worse, since in many cases the person with the disability cannot or will not defend himself?

I have a feeling that for the most part I am preaching to the choir on this one. Most of the families here have been stared out, called disparaging names, or otherwise received negative comments about their children with special needs. We know how painful and hateful it can be, whether the "R" word is used or not.

Many people have said that using terminology like "intellectually disabled," "user of a wheelchair," or "child with epilepsy" is just political correctness.

But words matter. They really do.

Let's take just one example: calling a child an epileptic. This terminology defines the child by her epilepsy. She is an epileptic, someone we then assume is constantly plagued by seizures. It reinforces stereotypes and images of disability that we have long been trying to break down. When I say epileptic, how many of you pictured a child writhing on the floor? Not only that, this terminology triggers the subconscious to focus on the illness or disability, dehumanizing children and adults. For those of you who pictured the writhing child, did she have a face? Was she a real person, or just a stereotype of a generalized seizure?

Using "child with epilepsy" instead places the emphasis on the fact that she is a child first, and, in addition to being a child, she happens to have epilepsy. This is commonly

called People First Language. In other words, you always define a person with a disability as a person, child, girl, boy, or other neutral term first. After that, you can tack on any extra features that that individual might have.

Child with cerebral palsy. Adult with mental health diagnosis. Girl who uses a walker. Boy with complex medical needs.

Most individuals go even further than this, also eliminating terminology that either places the person with a disability in the role of a powerless victim or evokes a sympathetic response. Examples of phrases that may be offensive include using "wheelchair-bound," "confined to bed," or saying a person with disabilities "struggles" or "suffers" with a given medical condition.

Using "has" instead of "is" is also important for People First Language. Instead of saying "John is autistic" or "Mary is blind," you would say "John has autism" and "Mary has a visual impairment." Certain loaded or archaic terms with negative connotations, such as retard, mongoloid, or midget, are also avoided. Some people even go so far as to eliminate terms like special needs, though others, including myself, feel comfortable with that particular terminology.

Yes, this language can be a bit cumbersome, but it is definitely worth it to try to incorporate it into your written and spoken language. It is what we attempt to use exclusively in our articles on Complex Child.

I am the first to admit that I slip up plenty of times, especially when I am typing quick replies on message boards. But I am going to make more of an effort to always use People First Language, and I hope you will too.