

People-First and Competence-Oriented Language

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*Some stories enhance life;
Others degrade it.
So we must be careful
About the stories we tell,
About the ways we define
Ourselves and other people.*

--Burton Blatt (1987, p.142)

A plethora of political volleyball regarding the use of specific derogatory terms (e.g., *the retarded*) recently made headlines throughout the United States. Often movies are made without concern for their portrayal of persons with disabilities using stereotypes and stigma supporting language in the script. Many of us in special education, as well as individuals with disabilities, are dismayed at the lack of sensitivity surrounding the use of such terminology and might be wondering whatever happened to the *people-first language* movement. Although the movement may have had a positive effect on a generation of individuals associated with persons with disabilities, it appears as if our work is not yet done.

This paper reviews people-first language, its beginnings, its current status, and how we can promote it and the use of competence oriented language. This article provides guidelines to promote the effective use of people-first and competence-oriented language. Our hope is to educate others so they use language that empowers students with disabilities.

Competence-oriented based language is aligned to the people-first language movement. Smith, Salend, and Ryan (2001) defined competence-oriented language and interactions as "...positive language that shows acceptance of students with disabilities and provides a classroom environment where they can flourish" (p. 21). Competence-oriented language and interactions promote the use of language that focuses on the abilities and skills of a person instead of his or her disability or deficits. It is having positive interactions with, or about, persons with disabilities instead of negative ones.

Background on the use of People-First and Competence-Oriented Language

People-first language is the philosophy and practice of referring to an individual *first* rather than referring to a disability and then the person (e.g., the disabled or autistic person) when writing and speaking in order to minimize bias or stereotypes (Snow, 2005). Individuals are endowed with multiple characteristics, but too often people with disabilities are labeled as or referred to by their disability (Dinerstein, 2007; Michailakis, 2003). Hodgson, Hughes and Lambert (2005) conducted an exploratory study of 32 individuals with disabling genetic conditions and their advocates in Melbourne, Australia. Participants responded to a questionnaire regarding the terms they felt were "offensive or unsuitable" when referring to persons with disabilities (pp. 416-417). The following terms were reported as most offensive by respondents: retarded (94%), mental retardation (81%), handicapped person (69%), followed by disabled person (38%), intellectual disabilities (13%), and person with a disability (0%). Through the questionnaire, respondents revealed a preference for terms that aligned with *people-first language*.

Heatherton, Kleck, Hebl and Hull (2003) identified the devaluation of those perceived as "different" and noted the profound repercussions both for individuals and for society. Old, outdated labels, phrases, and names can hurt; they perpetuate myths about people and portray them in demeaning and derogatory ways (Hadley & Brodwin, 1988; Lynch, Thuli, &

Groombridge, 1994). Shapiro, Margolis, and Anderson (1989-1990) wrote that “Disabilities are often used to make odious comparisons, further perpetuating negative images of persons with disabilities” (p. 89). Stereotypes influence how people think about, feel about, and act/react to others (Heatherton et al., 2003). A person with a disability may also internalize negative stereotypes and labels (Sartre, 1946, 1965), resulting in a diminished self-esteem or belief in competence.

The use of labels such as *retarded* can be viewed as a form of bullying. Bullying includes using derogatory words directed towards a person with a disability. A study of bullying identified prevalence rates that indicated 24.5% of elementary school and 34.1% of middle school students with disabilities were victims of bullying (Blake, Lund, Zhou, Kwok, & Benz, 2012). These findings are 1 to 1.5 times higher than the national average for students without a disability. Further, elementary and middle school students diagnosed with an autism spectrum disorder and high school students with orthopedic impairments experienced the greatest risk for repeated victimization. The people-first language movement aligns with and complements recent anti-bullying campaigns and related curricula.

The media plays an important role in shaping public opinion and attitudes towards people with disabilities. The choice of words, images, and messages can influence perceptions, attitudes and behaviors. A handful of influential articles in the 1990s focused on the newspaper coverage of persons with disabilities (Keller, Hallahan, McShane, Crowley, & Blandford, 1990; Yoshida, Wasilewski, & Friedman, 1990). In 1987, Keller et al. collected a stratified random sampling of daily newspapers across the United States to gauge how disability was being portrayed. While 51% of the articles were neutral as to the impact of disability on the person's life, 48% showed the disability as having a negative impact, and only 1% portrayed the impact as positive (Keller et al., 1990). Within the negative impact references, 78% used terminology like "victim of" or "suffers from" (Keller et al., 1990). The Internet is quickly replacing newspapers as a preferred news source. Social networking is a powerful medium for developing public opinion about issues. Stereotypes are presumed to develop with repeated exposure to stimuli that portrays people in a certain way (Yoshida et al., 1990). The media is a powerful influencer and use of written and spoken language can perpetuate stereotypes particularly in an era where electronic media, especially social networking, is constantly available. Thus, the use of people-first language requires a concerted effort to influence how popular media portrays people with disabilities.

Over time substantial changes occurred in language usage when referring to or describing individuals with disabilities. Pejorative words used in the past to describe persons with intellectual disability are currently being used in a derogatory context. Words such as *feble-minded*, *idiot*, *moron*, *imbecile*, and, most recently, *mentally retarded*, *retarded*, or *retard* often are used in an offensive manner, thus, demonstrating disrespect or mocking individuals with or without a disability. The word *retard* is not only used to insult individuals in schools and communities, but it is ubiquitous in the popular media (e.g., movies, comedy and talk shows, and reality programs). In the past four years, the word *retard* became a worldwide topic of public outcry. Media policies and campaigns such as *The “R” Word Campaign-Spread the Word* (<http://www.r-word.org/>), and protesters of the movie *Tropic Thunder* (see Ulaby, 2009) garnered attention. Many disability advocates objected to the film's repeated and excessive use of the word "retard." Entertainers and other individuals highlighted in the media often defend their use (or others' use) of words that offend people in the name of humor or satire. “However, irrespective of the context, hearing the words *retard* or *retarded* used as slang invectives is demeaning to those who have intellectual disabilities as well as to their families, friends, and

advocates” (Stephens as cited by Siperstein, Pociask, & Collins, 2010, pp. 126-127). In an interview of E. Duff Wrobbel, Neda Ulaby (2009) described how activists against the use of the word *retard* feel, “To them, it’s not a hilarious put-down; it’s hate speech” (p. 1). Siperstein and colleagues (2010) discussed how *The “R” Word Campaign-Spread the Word* is only a beginning in helping individuals to change their perceptions and attitudes towards people with intellectual disability. They state:

...instead of simply replacing or eliminating terms, we believe that the focus should be on alleviating the stigma associated with intellectual disabilities, for until we do so, it will only be a matter of time until a new word emerges to replace the r-word (p. 131).

Bouck (2010) devoted her Division on Autism and Developmental Disabilities President’s Message in support of *The “R” Word Campaign-Spread the Word*. She advised:

I think spreading the word to end the word is something we can do as part of our daily lives – to monitor our own language and to educate others about the power of language, especially, use of language that has the power to hurt and stigmatize. ...It starts with talking to our students, our families, our friends, strangers we meet... It won’t be easy, but doing what is right rarely is (p. 2).

In recognizing that we cannot create language that will be immune from misuse, we seek to raise awareness on the importance of language choice. Use of people-first language and a focus on persons’ strengths (i.e., abilities, skills and interests) can help reduce bias against those with disabilities and its use reflects a shift in attitude toward respect and dignity (Snow, 2005). Since 1988, disability rights organizations in the United States have advocated for the use of people-first language. Although people-first language is coming into common usage, many people struggle with its use while others choose to simply ignore it.

Historical Overview of Special Education and Its Impact on Language Usage

Special education has a long history in the United States. Several historical events moved the field forward towards a more inclusive society. For example, Elizabeth Farrell established the field of special education in the United States and pioneered the notion of special classes, not special schools, with the goal of returning the children to regular classes. A second, prominent individual was Helen Keller, an American educator who was blind and deaf and became one of the 20th century’s leading humanitarians, as well as co-founder of the American Civil Liberties Union (ACLU).

Unfortunately, in contrast to the positive events were several events that were gross violations of human rights. The United States became a leader in the eugenics movement in the early 1900s. State institutions that separated people deemed “undesirable” from the general population were commonly used as a method to “clean” the gene pool. Sterilization of persons with disabilities without their consent was legal and a common practice in state institutions.

Specialized instruction for children who were blind or deaf was prevalent at the turn of the 20th century. During that era, institutional programs for children with intellectual disability began as schools and safe havens for a vulnerable population. By the end of World War II, the

number of classes in public schools for children who were “educable mentally retarded” (the term used at that time) increased greatly. Programs for children labeled with minimal brain dysfunction and emotional problems started to appear at universities and in some medical sites (Yell, Rogers & Rogers, 1998).

Use of people-first language was borne out of the civil rights movement and through subsequent laws regarding the education of individuals with disabilities. In that time span (1964 to 1990), various researchers, writers, and practitioners whose focus was on the rehabilitation of individuals with disabilities (Dooley & Gliner, 1989; Hadley & Brodwin, 1988; Kaile, 1985; Richardson, Ronald & Kleck, 1974) began to advocate for a change in attitude and for specific language in describing and supporting people with disabilities. The Americans with Disabilities Act (ADA) passed into law in 1990, spurred a renewed effort to change the language. Use of people-first language was widely adopted by federal and state governments as well as professional organizations that work with people with disabilities. The disability field entered the civil rights movement of the 1960s with President John Kennedy leading the movement (Oppenheimer, 1994). He used his sister, Rosemary, as an example and advocated for more open programs for children with intellectual disability. Rosemary, the family claimed, was born with an intellectual disability and underwent a prefrontal lobotomy at the age of 23. Following this surgery, Rosemary lived in an institution. President Kennedy’s influence helped to support disability advocates in their movement to expand public school programs and close institutions. The culmination of this movement was the passing of the federal Education for All Handicapped Children Act (P. L. 94-142) in 1975. In the 1990s, federal laws such as the ADA and the Individuals with Disabilities Education Act (IDEA) incorporated people-first language into the law for the first time (Russell, 2008). In 1992, the Office of Civil Rights in the U. S. Department of Education issued a statement that supported and encouraged the use of people-first language (Bickford, 2004). Textbooks increasingly required the use of people-first language and journals required submissions written following people-first guidelines (Russell, 2008). In 2010, Rosa’s Law was enacted which required any references in federal law to *mental retardation* or to *mentally retarded individuals* be changed to intellectual disability or individuals with intellectual disability, respectively.

During this period (1960-1990s), a focus on individuals and their need to be included in society as valued members emerged. In the fall of 1965, United States Senator Robert Kennedy toured a number of institutions that housed people with an intellectual disability and revealed the deplorable conditions he saw during his visits. Administrators and public officials were furious with Senator Kennedy’s account (Blatt & Kaplan, 1966). More fuel was added to the fire when Burton Blatt and Fred Kaplan soon thereafter visited five institutions and co-authored, *Christmas in Purgatory: A Photographic Essay on Mental Retardation* (1966). They called these institutions an inferno, shocking the world with their horrific visual and written accounts of the degradation of persons with an intellectual disability living there (Blatt & Kaplan, 1966). In time, their exposé led to a fairer treatment of individuals with an intellectual disability living in institutions and to the deinstitutionalization movement. A few years later, Wolfensberger brought Nirje’s (1969) normalization principle to the forefront in the United States. Normalization calls for providing all the opportunities to all persons with disabilities which are available to persons without disabilities in society. There were misconceptions of what this principle meant and how it could be applied (Wolfensberger, 1980). In 1983, Wolfensberger reconceptualized the normalization principle and renamed it social role valorization (SRV). Based on the normalization principle, SRV helped service providers and others to focus on positive changes in the environment and social context of the individual with a disability

(Osburn, 2006). The result was to help others view the individual with a disability in a more socially valued way, based on the demonstration of personal competencies. Ultimately, the focus of SRV was to move others from viewing the person with a disability as having deficits to having competencies and from being devalued to being valued within our society (Osburn, 2006).

Two major movements in the lives of individuals with disabilities have been the concepts of normalization and inclusion. Normalization and inclusion are guiding philosophies that have the same end in common and reflect some shared values and attitudes, but seem to have different ideas about how to reach that end. Culham and Nind (2003) identify “the values and attitudes that can be regarded as a legacy of normalization/SRV and as a foundation for inclusion are: attitudes towards difference, attitudes regarding normality, attitudes about who is responsible for the social acceptance of people with an intellectual disability and attitudes about their rights” (p.71). Culham (2000) identifies that both claim to have the interests of people with disabilities at heart, yet they have very different value bases and aims that may threaten their compatibility. Culham and Nind suggest, “There is indeed a shared desire to see people with an intellectual disability as valued members of the community. There is a key difference, however, in that in normalization or SRV, at least, this community presence and value are earned through denial of difference, whereas in inclusion the person’s difference is welcome and valued” (2003, p.74). This distinction is important to the consideration of whether inclusion has grown out of the normalization/SRV movement. Inclusion seems to emerge more strongly from criticisms of normalization/SRV than from the movement itself. Despite the criticisms of normalization/SRV and how it relates to inclusion, the achievements seen in the application of the movement include improved services for people with disabilities (Tyne, 1992).

Person-centered planning also evolved during this time period and focused on valuing individuals with a disability. This planning process is used to describe individuals with a disability based on his or her strength, skills and needs using language that is competence-oriented as opposed to deficit-oriented (see Lyle O’Brien & O’Brien, 2002 for a complete description of the origins of person-centered planning). Person-centered planning was developed to improve the quality of life of individuals with disabilities, specifically to help individuals be valued by others, to have a voice in making decisions, and be included in activities and environments with individuals without disabilities (e.g., classes, schools and community). This planning process changed the way service providers and others perceived individuals with disabilities and how they used language to discuss individuals with disabilities (Lyle O’Brien & O’Brien, 2002).

Contrasting Views of People-First Language

Despite the general belief in the field of people-first language, it is not without some differences of opinion. Some individuals with disabilities and their disability communities do not follow the principle of people-first language. Disability culture advocates and disability studies scholars have challenged the sole use of people-first language (e.g., Brueggemann, 2013; Davis, 2013; Goodley, 2011; Longmore, 2003; Shapiro, 1994). These advocates and scholars recommend also using identity-first language (i.e., “disabled person”) to characterize disability and to refer to people with disabilities. For example, disability researchers and activists, particularly in the United Kingdom, refer to themselves as “disabled” as a point of pride in their disability (Ballan, 2008, p. 194). Brueggemann (2013) suggests that this approach allows the individual or group to claim the disability and reframe it from a point of pride. Gabel (2001)

discussed the use of disability-first language by researchers and activists to show pride in their disability by symbolizing “the oppressive or discriminatory social conditions facing disabled people” (p. 32). “Some people with physical disabilities and their advocates prefer the phrase disabled people to emphasize that it is society that is limiting or disabling the individual, and not some inherent characteristic of the person” (Dinerstein, 2007, p. 41).

In another example, many individuals who are deaf use deafness to define themselves, their culture, and their language – American Sign Language. This community uses the capital “D” in Deaf when referring to Deaf individuals and to denote the Deaf culture or Deaf community (Tyler, 1993). Also, in 1993, the National Federation of the Blind formally rejected people-first language because they believed that their blindness was nothing of which to be ashamed and indeed, it was/is respectable to be blind (Bickford, 2004). They expressed that the use of people-first language presumed there was something about blindness for which to apologize (Bickford, 2004) and, when separated from the individual, the disability was something bad and troublesome (Titchkosky, 2001).

More recently, some individuals diagnosed with an autism spectrum disorder argued against the use of people-first language because they see autism not as a disability but rather an integral part of their personalities (Tennant, 2008). Sarrett (2012) offers a proposal for “autistic human rights” and suggests that the growing language of neurodiversity is promoting a new lexicon for discussing the traits and personalities developed on the autism spectrum. Sarrett acknowledges that disability and autism advocates either use person-first language or use the term “autistic person” to show that they value and embrace autism as a “critical and life forming aspect of themselves and their personalities.” In 1999, Jim Sinclair eloquently stated autism is not terrible and that he is autistic and accepts and values himself. As admirable and healthy as Mr. Sinclair’s viewpoint is, other individuals with disabilities believe using people-first language help others to see them as more than their disability (Murphy, 2003).

People with disabilities will vary in their use of people-first or identify-first language and educators should have a working knowledge of this perspective. A recommendation from the American Psychological Association Publication Manual (APA, 2010) is to, whenever possible, ask people how they wish to be referred to. Individuals with intellectual disability and their advocates commonly prefer people-first language (Dinerstein, 2007).

Promoting the Use of People-First and Competence-Oriented Language

It is important to educate others so they understand what it means to have a disability and to accept differences in others. Educators should model an acceptance of others as their interactions and behavior can help to educate students and adults about disabilities and acceptance (Smith et al., 2001). As scholars who are also educators, it is our responsibility to model the use of people-first language and respect individuals with disabilities who choose not to use people-first language such as Deaf individuals. Snow (2006-2013) stated “People first language was created by individuals who said, ‘We are *not* our disabilities; we are people first.’ It’s not ‘political correctness,’ but good manners and respect” (p. 4). In 2010, Siperstein and his colleagues found that teachers use a variety of methods to educate students about disabilities including “direct education about differences, structured contact with peers (e.g., peer buddy or peer tutoring programs), and participation in cooperative learning activities” (p. 131). Teachers are in a pivotal position to influence perceptions and supports for students with disabilities. How teachers use language in inclusive settings can facilitate student success (Smith et al., 2001). Smith, Salend and Ryan (2001) identify that an educators language and interactions with students

can affect their students' learning, acceptance, socialization, and independence. Negative or “deficit-oriented language” can contribute to the devaluing and rejection of students with disabilities. Instead, educators can use positive or “competence-oriented” language in describing and interacting with their students. Smith and colleagues (2001) created a list of deficit-oriented and competence-oriented language and interactions between educators and students. The authors’ deficit-oriented language and interaction list was modified to suggest examples of positive or competence-oriented language and interactions between educators and students:

- Defining student’s performance in terms of strengths including academic and social achievements.
- Describing student’s strengths and achievements in the presence of the student and others.
- Commenting positively on behaviors that are unique to the student’s disability and explaining them when necessary.
- Referring to students using their names rather than their disability or other labels.
- Using language and talking about topics that are age appropriate.
- Providing opportunities for student participation during instructional activities.
- Including students with disabilities with the rest of the class.
- Creating independence from adults.
- Providing opportunities for and encouraging social interactions with peers.
- Speaking directly to students rather than to another adult or student. (Adapted from Smith et al., 2001, pp. 19-22)

The use of people-first language includes speaking or writing of the individual *first* rather than his or her particular disability and avoids the use of an adjective as a noun (e.g., the blind, deaf, or autistic). Murphy (2003) proposed avoiding sensational descriptors such as *suffering from*, *a victim of*, or *afflicted with* that elicit unwarranted and unwanted sympathy or pity toward individuals with disabilities. A list of suggested terminology when referring to individuals with disabilities appears in Table 1. Educators must also be mindful of the media they use to ensure it does not contain offensive or demeaning depictions of individuals with disabilities.

Educators must be careful not only of the words they use, but also the content or context in which statements are made and how the individual may be portrayed. Parents, teachers, students and administrators may perceive an individual negatively based on remarks made about a student within the school setting (e.g., hallway, teachers’ lounge, playground, at an individual education plan meeting). Comments about students with and without disabilities, even those not meant to be pejorative, have negative and sometimes hurtful impact on the student. Further, peers may be influenced by the remarks or interactions. Words can be very powerful and can be used to portray individuals in positive or negative ways. Words show respect or disrespect. We all should model appropriate language and positive communications for others. As Brown (2010) stated, “The words we use influence the words used by those with whom we interact, as well as their perceptions and attitudes” (para 5). Joan Blaska, as cited by Blaska (1993), aptly stated:

Table 1***Suggested Competence-Based Terminology***

Competence-Based Language	Non Competence-Based Language
person who uses a wheelchair	confined or restricted to a wheelchair; wheelchair
person with an intellectual disability	retarded, mentally disabled
he has a physical disability	he is a quadriplegic, crippled
person with a mental health condition	crazy, psycho, lunatic
brain injury	brain damaged
people with disabilities	the handicapped or disabled
she receives special education services	she's in special ed.... is a special ed. student
person on the spectrum	an autistic
individual who has autism	autistic person

(Adapted from Kailes, 1985; Snow, 2010)

Professionals who work with individuals with disabilities should ask themselves: How do I refer to the children or students with whom I work? When I speak to parents, how do I refer to their child and his or her disability? When I speak to colleagues, how do I refer to the children? When I write, what order do I place my words when referring to a person with a disability? (p. 31)

Professionals should ask if the words they use in describing their students show respect, value the individuals, and acknowledges abilities. “We have a choice to continue to send negative messages which will be harmful to persons with and without disabilities or we can accept the challenge and CHANGE OUR LANGUAGE which has the potential to positively impact society” (Blaska, 1993, p. 31).

Conclusion

Since 1990, changing the paradigm of labeling from disability-first to people-first language was relatively successful in the federal, state, and local educational and research communities. Referring to individuals as *people* first without regard to their specific challenges

allows others to look beyond the single diagnostic characteristic and to see them as diverse and unique. People who work with individuals with disabilities are usually careful and aware of the language they use, but sometimes we become lax or indifferent. Now is the time for each of us to renew our commitment to promote the dignity and respect of people with disabilities. Educators and advocates always should be respectful, thoughtful, and supportive of people-first and use competence-oriented language when referring to individuals with disabilities. As agents of change, it is up to us to model and use appropriate language when talking with and about students in our schools and communities. It is our responsibility to teach others through modeling and, when necessary, respectfully advocating within and beyond the education community about the importance of using communication that fosters respect and dignity. We recommend that people-first language be used and promoted by members of our schools and communities unless the individual expresses a different preference. We also recommend competence-oriented language be used when describing and working with individuals with disabilities.

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