

# Put People First! - Words Matter



Guidelines for thinking about the impact of language

Using respectful language is an essential piece of treating people with intellectual disabilities with dignity and recognizing their many abilities. The words we use to talk about people should emphasize their capacity for self-determination and communicate respect, dignity, empowerment, and a supportive environment. People should not be defined by their medical or clinical diagnoses, but by their many accomplishments and contributions to our shared communities.

The use of outdated or inaccurate descriptors can perpetrate negative stereotypes and make it difficult to build trust and craft individualized person-centered supports. There are many traditional phrases used in everyday language that are very offensive to the people we support. As Thelma Greene, member of the Developmental Disability Administration's Community Advisory Board (DDA CAB), says, "Think about how you want someone to talk to you. Treat people the way you want to be treated. Talk to people just like they are your friend or co-worker."

#### End the Use of the R Word

We should all do our part to end the use of the term "mentally retarded." People with intellectual disabilities want to be seen and talked about as people just like everyone else. As Project ACTION! board members Thomas Mangrum and Ricardo Thornton recently wrote in a letter to the Washington Post, the term "mentally retarded" is experienced as rude and hurtful by the people who are labeled with this term. As they explain: "The term takes us back to a time when people with developmental disabilities were often excluded from the community, schools and jobs and denied many rights and opportunities."

Across the nation, momentum is shifting to eliminate the label "mentally retarded." The federal government, along with many state governments and the District of Columbia<sup>ii</sup>, have passed legislation to remove this offensive language from laws and regulations, so that as a country we will stop labeling and defining people by their medical diagnosis. As President Obama said when he signed Rosa's Law,<sup>iii</sup> amending the language in all federal health, education and labor laws to replace the phrase "mentally retarded" with "intellectual disability": "Too many Americans with disabilities are still measured by what folks think they can't do, instead of what we know they can do."

## People With Intellectual Disabilities Are People First and Foremost

As Thomas and Ricardo point out, people with intellectual disabilities are people first. When we talk about them, we should use their names or call them "people" or "person," just as we refer to everyone else. In the District, we often hear people with intellectual disabilities referred to as "individuals." The concept behind this is a good one –

recognizing that everyone is different and has unique abilities, preferences, goals, and needs. Yet, the term has become synonymous with "person who receives services and supports from DDA" or "person with an intellectual disability" – and therefore, has become a label.

The term individual only works well when we can apply it equally to any person and have it mean the same thing. According to Bernard Crawford, also a member of the DDA CAB, we "should be using the word person or people, not individual." Thelma also reminds us that when we are talking about a person, we should not automatically refer to the person as a client, i.e. "My client needs help with transportation." Instead, we should use the person's name and say "Ms. Smith is the person with whom I work, and she needs assistance with transportation."

#### **Avoid Use of Labels**

Many of the terms that have been used as references for people with intellectual disabilities are common terms that describe different social roles. Words like clients, consumers or patients are used in everyday language to describe specific relationships between people. For example, if you get services from an attorney, you are typically described as a client. When you go shopping, you are described as a consumer. And, when you go to your doctor, you are described as her patient.

Each of these terms used in context and applied based on activity and relationship is acceptable language. The problem for people with disabilities arises when these terms are applied to them without connection to what they are doing or as a general description. Instead of a description of activity or relationship – the terms are being used to describe who people are, and it marks (or labels) them as being different than other people. No one else in the community is a "consumer" 24 hours a day! As Thelma explained, "It's fine to have a title, but they are forgetting people's names."

### **COMMONLY MISUSED TERMS:**

individuals, clients, consumers, customers, patients, residents, recipients, and beneficiaries.

REMEMBER... Any term can become a LABEL if it is over-used or used incorrectly.

#### **Put People First**

We should always talk about people first – and not their disability, the support they need, or the provider that supports them. Sometimes it is relevant to mention someone's disability, but not always. Think before you describe someone: Is it necessary to bring up his or her disability in this conversation? Would you want to always be described by *your* medical condition? Compare "Andrew is autistic," with

"Andrew has autism," or even better, "Andrew likes to stay by himself. He'll let you know when he is ready to talk."

#### **Advocates are Advocates**

We often hear people with disabilities who are engaged in reform efforts described as "self-advocates." Yet, this term is used only to apply to people with intellectual disabilities. Have you ever heard Dr. Martin Luther King, Jr. described as a self-advocate? Rather than using this special term, we recommend simply calling people "advocates" or "advocates with disabilities."

### **Assistive Technology is Simply a Tool**

When we talk about what kind of support a person uses, our language should recognize the device is just a tool to help the person, not a symbol of who he or she is. Compare: "Ms. Smith uses a wheelchair for assistance" with "Ms. Smith is wheelchair-bound."

#### **Providers Support People**

People are supported by providers, but they do not belong to providers. Terms like "my people" denote ownership and property, rather than valued community members. So, for example, you should say "The three people (use names if possible) supported by Provider X need overnight staffing," rather than "Our people" or "'Our three clients' need overnight staffing."

### People Have a "Support Team" not an "Interdisciplinary Team"

The concept of an interdisciplinary team (IDT) originated at a time when people with intellectual disabilities lived in institutions. It was believed that people required many clinicians and professionals to help them. Our thinking on this has evolved over time and we now customize support to each person's needs and preferences.

We now recommend using the term "support team," which better describes the role and recognizes that there are a wide range of people – not just paid professionals – who provide support, including family, friends, and community members.

### **People Live in Houses and Apartments**

Just like us, people with disabilities live by themselves, with their friends, or with their families in an apartment or a house. Using the term "natural home" to mean a house that is not funded through DDA indicates that some people's homes are not natural. Thelma explains that she has always had her own apartment, but now that she receives waiver services, people refer to her place as her "natural home." Likewise, waiver is a description of a funding source, not a type of housing. So Bernard, like Thelma, lives in an apartment, not a waiver apartment. Finally, people live in apartments and houses, not "at a provider".

### Focus on People's Achievements and Individuality

Remember to focus on the positives – what people *can* do, instead of their limitations. For example, say that "Ms. Smith communicates with her eyes and with facial gestures," rather than "Ms. Smith is non-verbal." Or, "John can get in the bathtub and start the water, but needs assistance with washing himself and toweling dry," instead of "John cannot bathe himself without staff supervision."

Talk about the parts of a task a person can complete rather than saying they cannot do the whole thing. For example, say "Ms. Smith can pick up a pencil and copy letters, but has not yet mastered writing independently;" instead of saying "Ms. Smith cannot write." These small changes reflect an acknowledgement that people have meaningful skills – and do not shift undue focus on what people cannot do without support.

#### In Summary

Using person first language means applying the same social rules of language that we use with everyone else when we are talking with and about people with disabilities. It is not polite or "acceptable" social behavior to focus on the limitations of the people around us. We all prefer that others hone in on and talk about our positive attributes – such as our sunny disposition, helpfulness to others, or skill as a hostess. By challenging ourselves to use these same traditional patterns in our everyday interactions, we will naturally become more respectful and supportive of people with disabilities.

#### Questions?

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<sup>&</sup>lt;sup>i</sup> Thomas Mangrum Jr. and Ricardo Thornton, Letter to the Editor, *Hurtful Use of the 'R' Word*, Washington Post, June 3, 2011, available at: <a href="http://www.washingtonpost.com/opinions/hurtful-use-of-the-r-word/2012/06/01/gJQAobCDCV\_story.html">http://www.washingtonpost.com/opinions/hurtful-use-of-the-r-word/2012/06/01/gJQAobCDCV\_story.html</a> (last visited July 9, 2012).

<sup>&</sup>lt;sup>ii</sup> B. No. 19-189, Council Period 19 (D.C. 2012) (enacted) (People First Respectful Language Modernization Amendment Act of 2012)

<sup>&</sup>lt;sup>iii</sup> S. 2781, 111th Cong. (2011) (enacted).

<sup>&</sup>lt;sup>IV</sup> U.S. President Barack Obama, "Remarks by the President at the Signing of the 21st Century Communications and Video Accessibility Act of 2010" (October 8, 2010), *available at* <a href="http://www.whitehouse.gov/the-press-office/2010/10/08/remarks-president-signing-21st-century-communications-and-video-accessib">http://www.whitehouse.gov/the-press-office/2010/10/08/remarks-president-signing-21st-century-communications-and-video-accessib</a> (last visited July 9, 2012) (including Presidential remarks on "Rosa's Law").