Person First Language

This module seeks to assist service providers in using inclusive and respectful language that values people with disabilities.

Key Points

- Person first language places the focus on the person, not the disability. For example, "an
 individual with epilepsy" is a person-focused phrase, while "an epileptic person" is disabilityfocused. This shift in language eliminates labeling and instead helps us view individuals with
 disabilities with respect.
- Avoid using negative terms that stereotype, devalue or discriminate against persons with disabilities, such as "handicapped," "disabled," "special needs," etc. Use positive language that is not outdated or offensive.
- Person first language that is acceptable to individuals with disabilities can change over time.
 Also, some persons with disabilities may prefer terminology that is not person first language,
 while others find that person first language makes speaking and writing complicated. For
 these reasons, simply asking the person what terms they prefer is often the best course of
 action when speaking or referring to individuals with disabilities.
- You may have co-workers who don't use person first language. Some ways to encourage
 person first language would be to model appropriate terminology and to share this module
 with them. You can also encourage victims to speak up if they are uncomfortable with the
 language being used and feel it needs to be addressed.¹

C2. Person First Language

Purpose

This module seeks to assist service providers in using inclusive and respectful language that values people with disabilities. The term "person first language" means communication that recognizes the person first, then the disability. Person first language is "an objective way of acknowledging, communicating and reporting about disabilities. It eliminates generalizations, assumptions and stereotypes."²

Objectives

After completing this module, participants will be able to:

- Describe how the words used to refer to persons with disabilities often focus on the disability rather than the individual;
- Discuss how outdated and offensive language perpetuates negative stereotypes of persons with disabilities and reinforces the attitudinal barriers they face; and
- Replace stereotypical and devaluing language related to individuals with disabilities with respectful and positive language.

Part 1: CORE KNOWLEDGE

Why person first language?

There are many social barriers to full community inclusion for people with disabilities. One of the greatest barriers is language. It is common in Western society to either refer to a person with a disability as a "disabled person" or to use all inclusive categories such as "the disabled" or "the handicapped." A person might also be described by their medical diagnosis (e.g., an epileptic). Not only can this language reflect a negative view of persons with disabilities, it can have a direct impact on how persons with disabilities perceive themselves and their worth in society. The term "handicapped" implies that someone is at a disadvantage. Service providers who view persons with disabilities as less able or less skilled may not encourage self-sufficiency with their clients who have disabilities or may unnecessarily modify their goals. Limited expectations can rob clients of their individuality and imply that they are their disability rather than what they really are—persons with disabilities.

Person first language places the focus on the person, not the disability. For example, "an individual with epilepsy" is a person-focused phrase, while "an epileptic person" is disability-focused. This shift in language helps us reject labeling and view individuals with disabilities as deserving of respect.³ It recognizes that people are not defined by their disability anymore than they should be characterized solely by their hair color, race, gender, nationality, etc.^{4,5}

FYI—When interacting with persons with disabilities, ask yourself if the disability is even relevant to your conversation or needs to be mentioned when referring to them.⁶

What terms are inappropriate?

It is important to avoid using negative terms that stereotype, devalue or discriminate against persons with disabilities.⁷ Here are a few examples:⁸

- "Handicapped" is an outdated term that can create negative images. The word originates from an Old English game in which the losers were left with their "hands in their caps" and considered to be at a disadvantage. It also is thought to refer to war veterans who held their caps in their hands as they begged for money. In reality, a handicap is often a disadvantage that occurs as the result of a disability and environmental and/or attitudinal factors. For example, a person with a disability who uses a wheelchair is handicapped when he faces a set of stairs and there is no ramp for equal access. The stairs create the disadvantage, not the disability.
- "Disabled" is often used to describe something that is broken or injured. For example, a
 broken-down car may be described as a "disabled vehicle." People with disabilities,
 however, are not broken nor do they need to be fixed.
- Words soliciting empathy such as "suffers with" or "afflicted with" have been used when
 describing people with disabilities.¹³ People with disabilities are sometimes depicted as
 "heroes" for doing everyday activities. It also may be said that people with disabilities have
 to "fight to overcome their challenges," but more often the real fight is to be treated as equal
 to everyone else.
- The term "special needs" can generate pity. However, it is not the disability that makes a person special, but characteristics (e.g., talents, skills and individuality). 14

• The words "normal," "healthy" or "whole" might be used when speaking about people without disabilities as compared to those with disabilities. These terms imply that people with disabilities are not normal, healthy or whole.¹⁵ Another way to convey a similar message of inferiority compared to a person without a disability is saying someone is "mentally challenged," "physically challenged," or "cognitively challenged."

FYI — Some legal terms used in state sex offense laws to describe persons with disabilities—for example, "incapacitated," "mentally defective" and "a person suffering from mental disease or defect"—clearly do not represent person first terminology. But, while these terms would not be our choice of language, they currently are in many laws. Although we must use these terms in this and other modules to explain state laws and their application, first responders are urged to avoid use of offensive legal terms in their interactions with victims. (See *Sexual Violence 101. West Virginia Laws on Sexual Assault and Abuse.*)

What are examples of person first language?

The following chart provides examples of currently accepted person first language for specific disabilities and medical conditions, as well as very brief explanations of why the old descriptors are inappropriate. It is by no means a comprehensive chart of terms; you are encouraged to consider additional examples or determine whether the currently accepted terms listed are still the most appropriate to use.

Outdated or Offensive Terms	Reasons	Currently Accepted Terms
Deaf and dumb Dumb	 Implies mental incapacitation Simply because someone is deaf does not mean that they cannot speak 	 Deaf person Non-verbal Hard of hearing Person who does not speak Unable to speak Uses synthetic speech
Hearing impairedHearing disabilitySuffers a hearing loss	Negative connotation of "impaired" and "suffers"	Deaf Hard of hearing
Slurred speech Unintelligible speech	Stigmatizing	Person with a communication disabilityPerson with slow speech
Confined to a wheelchair Wheelchair-bound	Wheelchairs don't confine; they make people mobile	Uses a wheelchairWheelchair userPerson who uses a wheelchair
Cripple Crippled	Old English, meaning "to creep"Also used to mean "inferior"Dehumanizing	 Has a disability Physical disability

DeformedFreak	Implies repulsiveness, oddnessDehumanizing	Multiple disabilitiesSevere disabilities
CrazyInsanePsychoManiacNut Case	StigmatizingConsidered offensiveReinforces negative stereotypes	 Behavioral disorder Emotional disability Person with a mental illness Person with a psychiatric disability
RetardedMentally defectiveSlow or simpleMoron or Idiot	StigmatizingImplies a person cannot learn	 Cognitive disability Developmental disability (use "mental retardation" sparingly)
Mongoloid	Considered offensive	Person with Down syndrome
Stricken/Afflicted by MS	 Negative connotation of "afflicted" and "stricken" 	Person who has multiple sclerosis
• CP victim	Cerebral palsy does not make a person a "victim"	Person with cerebral palsy
• Epileptic	Stigmatizing	Person with epilepsyPerson with seizure disorder
• Fit	Reinforces negative stereotypes	Seizure
Birth defect	Implies there was something wrong with the birth	Congenital disability
Deinstitutionalized	StigmatizingGroups people into one categoryNot focused on individual	 Person who used to live in an institution
• Midget	Outdated term Considered offensive	Person of short stature Person with dwarfism

Are there exceptions to person first language "rules?"

Yes. Some groups of persons with disabilities have been vocal about choosing terms to describe themselves that are not person first terminology. For example, the community of Deaf people prefers to use deaf with a capital D to denote the Deaf culture and the Deaf community, not the hearing loss. ¹⁷ In some communities of the blind, "he's blind" or "person without sight" is preferred over he has "blindness." ¹⁸ Also, some persons with autism prefer "autistic person" rather than "person with autism." ¹⁹ People with disabilities who reject person first terminology may see it "as devaluing an important part of their identity and falsely suggesting that there is, somewhere in them, a person distinct from their condition." ²⁰ Rather than viewing their condition (e.g., deafness, autism and blindness) as a disability, they may view it as a trait. ²¹

In addition, some who write or speak about disabilities may reject person first terminology because they think it can make sentences long, repetitive and unwieldy.²² They also may

question if the use of this terminology changes attitudes and if, in fact, it draws more negative attention to the disability.²³

While acknowledging these exceptions and criticisms, it is important to remember that the promotion of person first language in recent decades has facilitated a healthy debate. It has stimulated conversations about what terminology best represents persons with disabilities as valuable members of our communities with equal status to persons without disabilities. For service providers, familiarity with person first language can help them strive to use language when speaking or referring to clients with disabilities that will lead to positive client outcomes (e.g., greater satisfaction with services provided, more rapid healing from trauma, increased self-esteem, more job productivity, etc.).

According to Tim Harrington, in *The Ten Commandments of Communicating with People with Disabilities*,²⁴ terms for disabilities have changed over the years and probably will continue to do so. "That's why the best and usually most appreciated course of action is to ask the person what terms they prefer." In addition, Harrington said to keep it simple—the most common way we all prefer to be acknowledged is by our name.

Another recommendation is to listen to the language used by a person with a disability and take your cues from what is said.²⁵

Questions to consider:

1. Think about examples of outdated or offensive terminology you have heard used in your work setting to describe people with disabilities. Did or could use of these terms impact service providers' interactions with, or their perceptions of, persons with disabilities? In what ways?

Here are two examples:

- a. A rape crisis center volunteer advocate tells her supervisor that she received a crisis hotline call from a "mental patient" at an inpatient psychiatric program. While the victim may, in fact, be dealing with a mental illness, the label of "mental patient" may limit the advocate's recognition of the many facets of the victim beyond her mental state: the trauma she has faced, the connection of her mental health with her experience of sexual assault, and her capacity to heal from the sexual assault.²⁶ Rather than criticizing the advocate for her terminology, the supervisor can point out why the term "mental patient" might be offensive, acknowledge that the advocate in no way meant to be offensive, and then discuss more acceptable terminology. (See Disabilities 101. Working with Victims with Mental Illnesses.)
- b. A service provider receives a call from a nurse at the hospital saying he is needed to assist a "downs victim" of sexual assault. In the past, individuals with Down syndrome were referred to as "downs people" or "downs kids." By labeling a person a "downs victim," the service provider and the nurse might make several assumptions about the victim. For instance, they might assume that someone with Down syndrome will have significant cognitive limitations and lack the capacity to make his/her own decisions. However, because Down syndrome affects everyone differently, cognitive limitations could be significant to minimal. They might also assume that the difficulty the victim has in communicating is due to the Down syndrome, when in fact, it could be the victim's response to the trauma. Both of these assumptions could lead to a misunderstanding about

the circumstances and needs of the victim, inappropriate service provision, and subsequently minimize the victim's autonomy in making decisions about his healing. (See Disabilities 101. Self-Advocacy and Persons with Disabilities.)

- 2. When interacting with a sexual assault victim with a disability, what could you do to minimize the likelihood that your language will alienate the victim? Some suggestions are offered below. (See Sexual Violence 101. Crisis Intervention.)
- Refer to victims with disabilities by their names.
- Ask victims with disabilities open-ended questions about the assault and their circumstances/needs so that they can guide you in providing appropriate services and/or in making referrals. Ask them to tell you the best way to facilitate communication with them (e.g., they may use equipment such as word boards or speech synthesizers, need an interpreter or prefer to communicate through an intermediary who is familiar with their pattern of speech). If you are having difficulty understanding the person, don't pretend you understand or assume you understand when you do not. Instead, listen patiently, paraphrase back what you think you heard and allow the person to confirm your understanding or to restate what she said.
- Listen carefully to what victims with disabilities say to learn what terminology is acceptable to them and evaluate if the disability is relevant to your conversation or needs to be mentioned when referring to them. For example, a victim who uses a wheelchair recounts to the service provider how the offender repeatedly took advantage of her limited mobility. She experienced the feelings of powerlessness and vulnerability because she was not able to defend herself. In this case, the victim's disability is relevant to the conversation. Also, the fact that she uses a wheelchair may impact which services she utilizes (e.g., she may prefer telephone rather than face-to-face support).
- Avoid terminology that is not person first. For example, don't refer to a person with a severe stutter as a "stutterer" or "stuttering person." Don't say her speech is unintelligible.
- Limit referencing a person's medical diagnosis as it can divert attention from her need for victim services. For example, don't refer to a victim who uses a wheelchair as a "quadriplegic" or a "quad."
- 3. Based on what you have learned in this module, what changes will you make in your terminology related to persons with disabilities?

Test Your Knowledge

Refer to the pages in this module as indicated to find the answer to each question.

- 1. What is the purpose of using person first language when talking with or referring to people with disabilities? What are some examples of how person first language is different from disability-focused language? See page C2.2.
- 2. What terms should service providers avoid if they are using person first language to speak with or refer to persons with disabilities? Why? What are acceptable alternatives? See pages C2.3–C2.4.

- 3. What are some examples of exceptions to person first language "rules?" See pages C2.4-C2.5.
- 4. What is the best course of action when speaking with individual clients with disabilities to ensure that they are comfortable with the language used to refer to them? See page C2.5.

Part 2: DISCUSSION

Projected Time for Discussion

1.25 hours

Purpose and Outcomes

This discussion is designed to help participants apply the information presented in *Part 1: Core Knowledge* of this module to their collaborative work with sexual violence victims with disabilities. The discussion could be incorporated into forums such as agency staff meetings, orientations and continuing education programs, as well as multi-agency meetings or trainings. Anticipated discussion outcomes include an increased understanding of barriers and challenges experienced by victims with disabilities; enhanced ways to create a welcoming environment through appropriately worded agency policies, procedures and materials; increased awareness of how the spoken and written language can promote respect for and understanding of persons with disabilities; and greater comfort and competency in interacting with and assisting victims who have disabilities.

Refer to the learning objectives at the beginning of this module for specific outcomes.

Preparation

- Ensure that the meeting is held at an accessible location. Ask participants prior to the meeting if they need any accommodations—if so, work with them to secure accommodations.
- Select the facilitator. The facilitator should be familiar with issues facing persons with disabilities in general and knowledgeable about person first language and its application.
- Participants and the facilitator should review *Part 1: Core Knowledge* of this module before the discussion.
- Request that participants bring in copies of written materials from their respective agencies
 that refer to clients with disabilities (e.g., policies and procedures, training and informational
 materials and public awareness materials).
- Bring the following supplies and materials to the meeting: flipcharts and colored markers, sufficient copies of participant materials, office supplies (tape, pens, paper, etc.) and a clock/watch to monitor time. Optional items include name badges and table tents.

Suggested Activities and Questions

The words we use to describe persons with disabilities are often indicative of our attitudes towards them and can significantly influence our interactions with them. This discussion focuses on using person first language with individuals with disabilities who use our services to facilitate positive outcomes for them (e.g., rapid healing from trauma, increased self-esteem,

West Virginia S.A.F.E. Training and Collaboration Toolkit—Serving Sexual Violence Victims with Disabilities more job productivity, etc.).

- 1. Invite participants to identify/review the discussion ground rules to promote open communication. Utilize the following principles: (10 minutes)
- An environment of mutual respect and trust is optimal. Everyone should feel comfortable expressing their opinions and feelings about the various topics.
- Avoid personalized comments that are negative as they can lead to defensiveness and confrontation among the participants and ultimately may shut down dialogue.
- Be clear about what information discussed during this meeting is confidential and what the expectations are for confidentiality in the context of this partnership.
- 2. In a large group setting, ask each participant to briefly discuss the extent to which person first language is used in their agency's materials. (5 minutes)
- 3. **Ask participants to pair off and talk about examples** of when, in their interactions with clients with disabilities, a person's disability might be relevant to the conversation or needs to be mentioned when referring to them. Are there situations where their disability is not relevant? (5 minutes)

Follow with a large group discussion on this topic. (5 minutes)

4. Ask participants to individually review the following scenario and then break into three small groups to discuss the subsequent questions. (10 minutes)

In the course of the preliminary investigation of a sexual assault case occurring at a place of employment (both the victim and offender participate in a vocational training program at the local thrift store), the police investigator spoke with the 25-year old victim, her mother, the victim advocate, the nurse examiner who conducted the forensic medical examination, a representative from Adult Protective Services (APS), and a case manager with the vocational program. During those conversations, the investigator referred repeatedly to both the victim and offender as "retarded," "mentally defective" and "simpleminded."

Questions:

- a. What reaction do you think each person would have to the investigator's choice of words? What stereotypes do these words perpetuate? Why do you think the investigator used these particular terms? What impact do you think the use of these terms might have on the progression of the case and on the victim's recovery? What other terms could the investigator have used that would have been more acceptable?
- b. What could the participating providers do to (1) minimize the damage done by the investigator's use of terminology; and (2) prevent this scenario from reoccurring? What could they do if a colleague uses inappropriate language?
- c. The police investigator was the "bad guy" in this scenario. But recognize that any one of your community partners may find themselves in the position of the investigator and make inappropriate language choices. Also, your agency's policies may use outdated/offensive terminology. In what ways might community partners collaborate to encourage the use of positive and respectful language with persons with disabilities? How could local persons

with disabilities be involved in this collaboration? (For example, they might help review agency publications to ensure person first terminology is used, or help develop training materials.)

- 5. Facilitate a large group discussion, with each group reporting back its comments on the above questions. For timing purposes, consider having the first group report back on (a), the second group on (b), and the third group on (c). (30 minutes)
- 6. **Closing.** Ask each participant to write down how the information gained from this module discussion will:
- · Change the way they interact with individual clients;
- · Change the way they partner with other agencies to assist clients; and
- Promote change in their agency's policies, practices or training programs.

Then facilitate a large group discussion on this topic. (10 minutes)

Project partners welcome the non-commercial use of this module to increase knowledge about serving sexual violence victims with disabilities in any community, and adaptation for use in other states and communities as needed, without the need for permission. We do request that any material used from this module be credited to the West Virginia Sexual Assault Free Environment (WV S.A.F.E.) project, a partnership of the West Virginia Foundation for Rape Information and Services, the Northern West Virginia Center for Independent Living and the West Virginia Department of Health and Human Resources (2010). Questions about the project should be directed to the West Virginia Foundation for Rape Information and Services at www.fris.org.

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¹Partnering agencies refer to the persons they serve as "clients," "consumers" and "victims." For convenience, "victims" and "clients" are primarily used in this module. Also note that the terms "sexual violence" and "sexual assault" are generally used in this module to encompass sexual assault, sexual abuse and other forms of sexual violence.

²United Cerebral Palsy, *People first language*, through http://www.ucp.org. This and other online documents referenced in this module were available at the links provided at the time the module was written. It is suggested you check the sites for any updates or changes. If you experience difficulty accessing the documents via the links, another option for locating documents is doing a web search using titles.

³A. Logsdon, *Person first language –Focus on the person first is good etiquette*, through http://www.about.com/. ⁴K.S. Lawrence, *Guidelines for reporting and writing about people with disabilities* (Schiefelbush Institute, 1996). As cited E. Bass, *Speaking and writing about people with disabilities: Disability, handicap or challenge? What to call it and how to say it*, http://www.cloudnet.com/~edrbsass/edpeoplefirst.htm.

⁵There may be instances where a person with disability does view her/his disability as a defining trait. The key, however, is that only that person has the right to make this decision for her/himself.

⁶United Cerebral Palsy.

⁷United Cerebral Palsy.

- ⁸These bullets, with the exception of the last one, were drawn in part from K. Snow, *To ensure inclusion, freedom, respect for all, It's time to embrace people first language* (revised 2008), 2, through http://www.acdd.org/pfl.pdf.

 ⁹Drawn from Snow.
- ¹⁰Miriam Webster Online Dictionary, through http://www.merriam-webster.com/; and Snow.
- ¹¹Drawn from Snow.
- ¹²Bullet from Snow.
- ¹³Drawn from Snow.
- ¹⁴Bullet from Snow.
- ¹⁵This bullet was drawn from National Center on Workforce and Disability, Institute for Community Inclusion, *Watch your language* (Boston, MA: University of Massachusetts), through
- http://www.onestops.info/subcategory.php?subcat_id=402. This article was originally adapted from material developed by Mid-Hudson Library System, Outreach Services Department, 103 Market Street, Poughkeepsie, NY 12601.
- ¹⁶The chart was excerpted/minimally adapted from the National Center on Workforce and Disability, Institute for Community Inclusion.
- ¹⁷J. Folkins, *Resource on person-first language, the language used to describe individuals with disabilities* (American Speech Language, Hearing Association, 1992), through http://www.asha.org/default.htm. ¹⁸Logsdon.
- ¹⁹See *Person-first language and autism, Neurodiversity and the prejudice of politically correct terminology,* through http://autismaspergerssyndrome.suite101.com/.
- ²⁰Excerpted/adapted from Wikipedia, *People first language*, http://en.wikipedia.org/wiki/People-first_language. ²¹Excerpted/adapted from Wikipedia.
- ²²C. Edwin Vaughan, *People-first language: An unholy crusade* (National Federation of the Blind, 1997), http://www.blind.net/. Also referenced in Wikipedia.
- ²³Vaughn, in *People-first language: An unholy crusade*, noted that the awkwardness of the person first language called attention to a person as having some type of "marred identity" He drew the concept of "marred identity" from E. Goffman, Stigma: Notes on the management of spoiled identity (Englewood Cliffs, New Jersey: Prentice Hall, 1963).
- ²⁴I. Ward & Associates, *The ten commandments of communicating with people with disabilities* (1994). ²⁵Logsdon.
- ²⁶In addition, although males and females are both victimized by sexual violence, most reported and unreported cases are females (see endnote in the *Toolkit User's Guide* for a full citation). Therefore, in this module, victims are often referred to as female.