

# Support Plan Development, Part 1: Recording Person-Centered Information

## Supplemental Resources

## ***Table of Contents***

---

This document contains the forms, tables, lists, and websites that were either displayed or referred to in the Support Plan Development - Part 1 Pre-Service training. This document also contains additional resources to aide new WSCs in gaining the skills necessary to effectively coordinate the supports and services for individuals on their caseload.

Overview of the Support Plan Template .....	3
Support Plan Template Sample .....	4
Avoiding Errors in Recording Person-Centered Information.....	11
Guidelines: How to Write and Report About People with Disabilities .....	13

# Support Plan Development, Part 1: Recording Person-Centered Information

## ***Overview of the Person-Centered Support Plan Template***

The support plan can be divided into four major types of information:

**Identifying Information and Demographics**, including who is currently involved in supporting the individual and any funding sources for each paid service.

**Person-Centered Information** that creates a complete picture of the individual's daily life from their perspective, including their strengths and capacities, preferences, and daily routines.

**Significant Needs and Risks**, which include information taken from the most current QSI assessment and medical history documentation. Based on identified needs and risks, the support plan identifies strategies, specific plans, and follow up steps that will be taken to address these needs and who is responsible.

**Past Accomplishments and Future Goals**, describing what the person worked on last year and any progress toward reaching those goals, what the individual wants to accomplish in the next five years, and the goals he or she wants to focus on during the upcoming year.

**Below is a copy of the Person-Centered Support Plan Template that is filled out through the APD iConnect System.**



## Person-Centered Support Plan

Support Plan Effective Date: \_\_\_\_\_

Date of Support Plan Update: \_\_\_\_\_

### About Me

Last Name \_\_\_\_\_ First Name \_\_\_\_\_ Nickname \_\_\_\_\_ Date of Birth \_\_\_\_\_  
 Medicaid ID \_\_\_\_\_ iConnect ID \_\_\_\_\_ Legal Status \_\_\_\_\_  
 Living Setting \_\_\_\_\_ Spoken Language \_\_\_\_\_ Alternate Communication \_\_\_\_\_

### Where I Live

Street Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
 Email Address \_\_\_\_\_ Cell/Home Phone \_\_\_\_\_ Work Phone \_\_\_\_\_ Region \_\_\_\_\_  
 Deliver my mail to \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
 Best way to contact me \_\_\_\_\_

### My Legal Representative(s)

#1

Last Name \_\_\_\_\_ First Name \_\_\_\_\_ Guardian/Legal Representative Type \_\_\_\_\_  
 Relationship \_\_\_\_\_ Other \_\_\_\_\_  
 Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
 Day Phone \_\_\_\_\_ Night Phone \_\_\_\_\_ Cell Phone \_\_\_\_\_  
 Email Address \_\_\_\_\_

### My Waiver Support Coordinator

Name	Agency (if applicable)	Email	Phone Number(s)

### My Family, Friends, and Support System

Name	Relationship	Email	Phone

### Other People Who Support Me or Work for Me (Teachers, Providers, Doctors, CDC+ Representative)

Name	Relationship	Email	Phone

### Other Funding Sources for Supports (Vocational Rehab/Job Coach, Division of Blind Services, MSP Behavior Therapy)

Support Need	Funding Source

### People Who Can Provide Information for My Support Plan (Doctor, Service Providers, Family, Friends)

Last Name	First Name	Relationship	Phone	Invite to Support Plan Meeting Y/N?
-----------	------------	--------------	-------	-------------------------------------

### My Life

**My current day-to-day life:** (This is a "day in the life" description of me: where I live, if alone or with others, my daily routines, Services received during the day and/or night. List the housing information I was provided and where I choose to live in the future)

**How I get around in my community:**

**My interests, talents, abilities, strengths, preferences, and skills:**

**Things I would like to change:**

**Things I want to stay the same:**

**Important aspects from my personal history:** (Medical, Social, Behavioral history)

**How I communicate and make choices and decisions:**

### Employment

Job I Have	Job I want (for those who choose to not work, state N/A):	Supports needed to reach my employment goals:
------------	---	---

<b>I tried to access services from Vocational Rehabilitation</b>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<b>The outcome of my VR referral</b>		

### Other Services Needed for Health and Safety

This Information is captured in the QSI. Identify: <b>A)</b> Areas of critical needs/potential risk to the health/safety of myself or others <b>B)</b> The specific issue, how it is addressed or where to find this information <b>C)</b> The service/support to address need <b>D)</b> The source of funding			
Identified Need/Risk Area	Specific issue and measures in place to address/minimize risk	Service/Support	Source of Support
<b>Functional (Choose all that apply)</b>			
Vision			
Hearing			
Eating			
Ambulation			
Transfers			
Toileting			
Hygiene			
Dressing			
Communications			
Self-protection			
Ability to Evacuate (Home)			
<b>Behavioral (Choose all that apply)</b>			
Hurtful to Self/Self-injurious			
Aggressive/Hurtful to Others			
Destructive to Property			
Inappropriate Sexual Behavior			
Running Away			
Other Behaviors that May Result in Separation from Others. List "Other" behaviors:			
<b>Physical (Choose all that apply)</b>			
Injury to Person Caused by Self-injurious Behavior			
Injury to the Person Caused by Aggression to Others or Property			
Use of Mechanical Restraints or Protective			

## Person-Centered Support Plan

Equipment for Maladaptive Behavior			
<b>Identified Need/Risk Area</b>	<b>Specific issue and measures in place to address/minimize risk</b>	<b>Service/Support</b>	<b>Source of Support</b>
Use of Emergency Chemical Restraints			
Use of Psychotropic Medications			
Gastrointestinal Conditions (includes vomiting, reflux, heartburn, or ulcer)			
Seizures			
Antiepileptic Medication Use			
Skin Breakdown			
Bowel Function			
Nutrition			
Treatments			
Assistance in Meeting Chronic Health Care Needs			

**Back-up Plans for My Critical Needs/Risks**(in case my primary supports are not available)

Service/Support	Back-up Plan	Specific Strategies (as needed)

**What I Accomplished Last Year**

<b>My accomplishments last year:</b>

Goals I worked on last year	Progress on each goal

**My Personal and Future Plans**

<b>What I Want in the Next Few Years:</b> (Supports, accomplishments, dreams, desires, interests, or activities I want in my life in the next few years)

**Personal Goals**

<b>The most important things I want to achieve this coming year. Identify goals/desired outcomes and be as specific as possible.</b>	<b>What service will help me?</b>	<b>Paid or Non-Paid. If non-paid, provide name and relationship.</b>

**Personal Rights: (not related to guardianship)**

Signatures on the last page indicate that the individual or their Legal Representative are aware of the individual's personal rights and the Bill of Rights for Persons with Developmental Disabilities.

Is there a right in which I would like to learn more?      Yes  No

Do I have restrictions on my rights? This might include limited restrictions such as not being able to lock my bedroom door with a key,

restricted visitation, inflexible schedule, limited food or environmental access, etc.      Yes  No  If yes, complete the table.

Right Limited	Reason (the assessed need for the restriction and what less intrusive methods were tried but did not work out)	What is being done to help me obtain my full rights?	When will it be reviewed to determine ongoing effectiveness, or to terminate restriction?

WSC, initial as assurance that the interventions and supports cited above will not be harmful

Safety Plan Required and Attached (if applicable)      Yes  No

**My Health**

<b>Important health history about me:</b>			
Hospitalizations in the past year	Yes	<input type="checkbox"/>	No <input type="checkbox"/>
<b>If yes, why I was hospitalized?</b>			

**My medication information (Current as of support plan meeting date)**

Medications	Dosage/Frequency	Purpose of Medication	Side Effects/Problems Experienced

Allergies: (Including any reactions to any medications, substances, chemicals, etc.)

My critical health follow-up areas and preventative health plan: (How will I maintain my Health and Health Stability?)

**My Health Care Contact Information:** Include all doctors you see, any therapists, and anyone you have designated to act as your decision maker in health-related issues (health care surrogate)

Name	Date of Last Visit	Findings	Follow Up Activities

Health Care Decision Maker Name	Role	Follow Up Activities

**Equipment and Supplies**

Do I use any adaptive equipment, special equipment, glasses, hearing aids or need any adaptations made to my home? Yes <input type="checkbox"/> No <input type="checkbox"/> If yes, please list below.

Do I need any consumable supplies? Yes <input type="checkbox"/> No <input type="checkbox"/> If yes, please list below.

**Personal Disaster Plan**

I have a Personal Disaster Plan Yes  No

Date Personal Disaster Plan Completed or Updated \_\_\_\_\_

**Signature Page**

I have participated in the development of this plan. I have been informed of my due process rights under Florida Statutes 120 and acknowledge that I may appeal any portion of this plan. I understand that if my needs change, an update to this plan may be needed. I also understand that I may request to change something in my plan throughout the support plan year. Supports should be identified according to my needs or the needs of my family, regardless of the availability of funding. Supports and services needed to meet my needs will be sought from my personal resources, community resources, and government resources. When government resources are necessary, they shall be provided based on the availability of funds. My Support Coordinator reviewed the Bill of Rights for Persons with Developmental Disabilities with me and I understand my personal rights.

Date Sent to Individual \_\_\_\_\_ Date Sent to APD \_\_\_\_\_

Consumer Signature \_\_\_\_\_ Date \_\_\_\_\_  
 Witness Signature (if needed) \_\_\_\_\_ Date \_\_\_\_\_  
 Legal Representative Signature \_\_\_\_\_ Date \_\_\_\_\_  
 Waiver Support Coordinator Signature \_\_\_\_\_ Date \_\_\_\_\_

Signature of Support Plan Meeting Participants:

Relationship	Signature	Signature Date	Date Copy Sent

## ***Avoiding Errors in Recording Person-Centered Information***

The following are some common mistakes in recording information on the support plan:

- Writing in a subjective way, based on your own personal biases.
- Not describing specifically what is important to the person.
- Using professional lingo and acronyms
- Using slang or disrespectful terms

### **Writing in a subjective way.**

What is written must be from the person's or their legal guardian's perspective. The support plan must never include your own subjective opinions, assumptions, or biases about the person. Instead, the information should be written based on objective facts, observations, and information taken from other sources.

#### **For example:**

- Gloria had the opportunity to volunteer at a garden store. I think she'll love it there.
- John is really scary when upset. I don't think this group home is going to work out for him.
- Everyone knows Sharon is lazy in the morning and would do best with a job at night.

These sentences are written from the WSC's **personal opinion**. The WSC cannot assume that Gloria will love volunteering at the garden store, or that the group home will not work out for John. In addition, labels such as "scary" or "lazy" are subjective and not respectful of the individual.

### **Not enough information**

In an effort to develop a support quickly and concisely, you may be tempted to cut out important details and write in short, vague sentences. Resist this urge!

This error is often why a support plan is neither meaningful or motivating for the individual and their supports to carry out. Without enough details, information can be misinterpreted by anyone that does not fully know the individual.

#### **Examples of this are:**

- "Gloria likes music." - What kind of music? Does she want to listen to music or play an instrument?

- “Jonathan want to remain safe.” - How is he potentially not safe? What is the specific risk?
- From this sentence, we would not know that Jonathan has had two major incidents of eloping from home and almost got injured. Safety for Jonathan includes keeping him engaged in activities and intervening when he is getting agitated so that he does not leave the house.
- “Michael likes to go out in the community.” – Where in the community and what types of activities?

## **Using professional lingo and acronyms**

Professionals often write using terms specific to their field and WSCs are no different. When lingo or acronyms are used, it is difficult for anyone outside of the profession to understand what is written and to gain meaning from it.

### **Examples of hard to understand sentences are:**

- “It is important for John that his medical protocol be followed any time he displays symptoms of anaphylaxis.”
- “Michael’s PCP stated that his SLC should f/u with recommendations to purchase a pulse ox to address his URI.”
- “Gloria’s BIP was signed off by the LRC this week.”

## **Using slang or disrespectful language**

Be aware of terms that are not professional, such as overly casual and slang words, derogatory terms, and terms of endearment, especially if the individual or their family has not requested to be addressed that way or if the term is not age appropriate. A couple examples include:

- “Gloria’s behaviors have been off the hook lately.”
- “Louise is a real sweetie. She is usually a very happy girl.” (Louise is 55 years old)

When in doubt, consider how a family member or another provider will read and interpret what you wrote!

**Below is a helpful resource on how to record person-centered information on the support plan.**

*Guidelines:*  
**How to Write  
and Report About  
People with Disabilities**



Based on a national survey  
of disability organizations

*8th Edition*

*The difference between the right word and the almost right word is the difference between lightning and the lightning bug.*

- Mark Twain

## Your Words, Our Image

Writers, editors, reporters and other communicators strive to use the most accurate terminology about people with disabilities. However, inaccurate, archaic and offensive expressions are still commonly used, perpetuating negative stereotypes and beliefs about people with disabilities.

For example, a person *who uses a wheelchair* – an objective fact – is often described as *wheelchair-bound*, a subjective description that implies victimhood.

As one wheelchair user puts it, “I personally am not ‘bound’ by my wheelchair. It is a very liberating device that allows me to work, play, maintain a household, connect with family and friends, and ‘have a life.’”

### Who Says?

Since the first edition was published in 1984, we have consulted with hundreds of disability groups and individuals who have disabilities to produce *Guidelines: How to Write and Report About People with Disabilities*. The eighth edition presents the latest terminology preferred by people with disabilities.

*The Associated Press Stylebook*, the *Publication Manual of the American Psychological Association* (6th edition) and the American Association for the Advancement of Science have all adopted some of the recommendations from previous editions of the *Guidelines*.

The first edition of the *Guidelines* was produced with funding from the National Institute on Disability and Rehabilitation Research. Since then, more than one million copies have been distributed, and the electronic version is now used by people around the world.

Please use the *Guidelines* when you write or report about people with disabilities. We also offer a poster that presents a short list of disability writing style dos and don'ts.

© 2013 EIGHTH EDITION. No part of this booklet may be printed without prior written permission of the RTC/IL.

## Portrayal Issues

The Americans with Disabilities Act (ADA) defines disability as a physical or mental impairment that substantially limits one or more major life activities.

That said, people with disabilities are like every other human being – they have strengths and weaknesses, successes and failures, hopes and dreams. Like other minority groups, they don't want to be stereotyped when their stories are told. By following these guidelines, you can portray people with disabilities in an accurate and objective manner.

**Put the person first**, not his or her disability. Use *person with a disability*, *woman with multiple sclerosis* or *a child who has an intellectual disability*. This “person-first language” puts the focus on individuals, not their functional limitations. Labeling a person (for example, *an autistic*) dehumanizes him and equates a person with a condition. Think people first, too, for indicating disability groups, such as *people who have cerebral palsy*.

**Emphasize abilities**, not limitations. For example, *uses a wheelchair* or *uses a communication device* rather than *confined to a wheelchair* or *unable to speak*. In reality, wheelchairs and other assistive devices represent independence for their users, not a burden. To emphasize capabilities, avoid negative words that portray the person as passive or suggest a lack of something, such as *victim*, *invalid* or *defective*. While the term *disability* itself implies a negative, it is the most objective term we have in English.

**Do not focus on a disability** unless it is essential to a story. Avoid tear-jerking human interest stories about incurable diseases, congenital disabilities or severe injury. Focus instead on issues that affect the quality of life for those same individuals, such as accessible housing and transportation, affordable health care, employment opportunities and discrimination. Focus on personal characteristics that aren't related to disability, such as artist, professional, mother, etc.

**Bypass condescending euphemisms.** Terms such as *special*, *handicapable*, *differently abled* and *challenged* reinforce the idea that people cannot deal honestly with their disabilities. While *special* is used in the names of some educational programs and organizations, the use of *special needs* is offensive to many adults with disabilities, who want to be treated like everyone else in their community. *Special* also implies a paternalistic need to be taken care of, which is frequently not true. Just say *children with disabilities*.

**Do not portray successful people with disabilities as heroic overachievers or long-suffering saints.** Every human faces challenges in life. Even though the public may find such portrayals inspirational, these stereotypes raise false expectations for people with disabilities.

**Avoid sensationalizing and negative labeling.** Saying *afflicted with*, *crippled with*, *victim of* or *suffers from* portrays individuals with disabilities as helpless objects of pity and charity. State the facts in neutral terms, saying *a person who has AIDS*. Avoid emotional descriptors such as *unfortunate* or *pitiful*.

**Do not equate disability with illness.** People with disabilities can be healthy, though they may have chronic diseases such as arthritis, heart disease and diabetes. People who had polio and experienced after-effects have *post-polio syndrome*; they are not currently experiencing the active phase of the virus. Also, do not imply disease if a person's disability resulted from anatomical or physiological damage (for example, *a person with spina bifida*). Finally, do not refer to people with disabilities as *patients* unless their relationship with their doctor is under discussion, or if they are referenced in the context of a clinical setting.

**Respect the person.** Do not use offensive words such as *retard*, *freak*, *lame*, *subnormal*, *vegetable* and *imbecile*. If you maintain the dignity and integrity of each individual, there is no need to panic about being politically correct. When appropriate, you may ask a person how she prefers you to describe her disability. While some common phrases can be hurtful, such as *blind as a bat*, it's fine to use everyday expressions like *See you later*.

## Person-First Language: A Partial Glossary of Disability Terms

We know that language shapes perceptions, so a small word choice can make a big difference in communicating attitudes towards people with disabilities and assumptions about the quality of their lives.

Person-first language literally puts the person first instead of his or her disability. By referring to an individual as *a person with a disability* instead of a *disabled person*, you are providing an objective description instead of a label. While opinions differ on some words, this partial list offers preferred terms for many visible and invisible disabilities, illustrated with person-first language.

**AD/HD** (Attention Deficit/Hyperactivity Disorder) is the clinical diagnosis for a genetic neurobehavioral condition that is characterized by symptoms in three categories: inattention, excessive activity and impulsive behavior. While the medical community includes **ADD** (Attention Deficit Disorder) as a subset of this condition, disability advocates consider the two conditions as distinctly different. A person who has ADD has difficulty focusing attention and a high level of distractibility, but does not experience hyperactivity or impulsive behavior. Say *person with ADHD* or *student with ADD*. Do not use *hyper* or *lazy*.

**Autism spectrum disorders (ASD)** refers to a group of complex disorders of brain development that may cause difficulty with social interactions, problems with verbal and nonverbal communication and repetitive behaviors. In terms of symptoms, **Asperger's syndrome** is on the milder end of the spectrum. People with an ASD can have severe limitations in one area with no limitations in others. Use *child with autism* or *Asperger's syndrome* or *person on the spectrum*. Do not say *autistic*. (See also "A Few Exceptions" on page 11.)

**Blind** describes a condition in which a person has loss of sight for ordinary life purposes. A person is *legally blind* when vision with best correction is no better than 20/200. *Low vision* and *vision loss* are generic terms for

vision loss caused by macular degeneration and other conditions. *Low vision* usually denotes someone who is legally blind, but can still see large print, bright colors, light and shadow, and large shapes, while *vision loss* refers to those who have lost vision after birth. Say *boy who is blind*, *girl who has low vision* or *man who is legally blind*. (You may ask which term best suits the person.) Some blind people consider themselves visual thinkers so they regard *visually impaired* and *visually challenged* as negative terms.

**Brain injury or traumatic brain injury (TBI)** describes a condition where there is temporary or long-term disruption in brain function resulting from injury to the brain. Difficulties with cognitive (thinking remembering, learning), physical, emotional and/or social functioning may occur. Use *person with a brain injury* or *employee with a traumatic brain injury*. Do not say *brain damaged*.

**Chemical and/or electrical sensitivities** describe chronic medical conditions characterized by neurological impairment, muscle pain and weakness, respiratory problems and gastrointestinal complaints. Reactions for those with chemical sensitivities are triggered by low-level exposure to everyday substances and products including pesticides, solvents, cleaning agents, new carpeting and adhesives, fragrances and scented products. Electrical sensitivities are triggered by electromagnetic fields from electrical devices and frequencies. These conditions are also called *environmental illness*, *toxicant-induced loss of tolerance* or *sick building syndrome*. Use *person with chemical intolerance* or *people with environmental illness*. People with this condition should not be called *chemophobic* or described with the term *idiopathic environmental intolerance*.

**Chronic fatigue syndrome** refers to a chronic condition in which individuals experience six or more months of fatigue accompanied by physical and cognitive symptoms. *Chronic fatigue*, *immune dysfunction syndrome* and *myalgic encephalomyelitis* are currently preferred. Do not say *Yuppie Flu*. Also, don't confuse this syndrome with overlapping or similar conditions such as *Epstein-Barr virus syndrome* and *fibromyalgia*.

**Cleft palate or lip** describes a specific congenital disability involving the lip and gum. Say *person who has a cleft palate*. The term *hare lip* is anatomically incorrect and stigmatizing.

**Congenital disability** describes a disability that has existed since birth but is not necessarily hereditary. Use *person with a congenital disability or disability since birth*. Do not say *birth defect or deformity*.

**Deaf** refers to a profound degree of hearing loss that prevents understanding speech through the ear. *Hearing impaired or hearing loss* are generic terms used by some individuals to indicate any degree of hearing loss, from mild to profound, although some dislike the negative term *impaired*. *Hard of hearing* refers to a mild to moderate hearing loss that may or may not be corrected with amplification. A person who has hearing difficulties may have speech difficulties, too, but deafness does not affect mental abilities. Say *woman who is deaf* or *boy who is hard of hearing*. People who have some degree of both hearing and vision loss prefer the term *deaf-blind*. Also acceptable is *person with combined vision and hearing loss* or *dual sensory loss*. Never use *deaf and dumb*. (See also "A Few Exceptions" on page 11.)

**Developmental disability** is a broad term that describes any physical and/or mental disability that starts before the age of 22. Examples include cerebral palsy, autism spectrum disorders and sensory impairments. People with developmental disabilities have a wide range of functioning levels and disabilities. Although the term *intellectual disability* is often used in conjunction with developmental disability, many people with a developmental disability do not have an intellectual disability. Say *she has cerebral palsy, he has autism* or *he has a developmental disability*. Do not say *she is mentally retarded*.

**Disability** is a general term used for an attribute or a functional limitation that interferes with a person's ability, for example, to walk, lift or learn. It may refer to a physical, sensory or mental condition such as Lyme disease, depression, irritable bowel syndrome, post-

traumatic stress syndrome, diabetes, multiple sclerosis and other conditions that restrict the activities of daily living. Do not use the term *handicapped* because many people with disabilities consider it offensive.

We recognize the need for succinctness, but when possible, avoid using *the disabled* as a generic label. It describes a condition, not people, and has connotations of "non-functioning" (as in *a disabled car*). It also implies a homogenous group separate from the rest of society. Instead use *people with disabilities* or *the disability community*.

**Disfigurement** refers to physical changes caused by burns, trauma, disease or congenital conditions. Do not say *burn victim*. Say *burn survivor*.

**Down syndrome** describes a chromosomal disorder that causes a delay in physical, intellectual and language development. Say *person with Down syndrome*. Do not use *Mongol, mongoloid* or *Down person*.

**HIV/AIDS** is a disease of the immune system. Over time, HIV (human immunodeficiency virus) can weaken the immune system to a point where the body becomes susceptible to certain illnesses that healthy immune systems resist. People with HIV are diagnosed with AIDS (acquired immunodeficiency syndrome) when one or more specific conditions are met. Use *person living with HIV* or *people who have AIDS*. Do not use *AIDS victim*.

**Intellectual disability** refers to limitations in intellectual functioning and adaptive behaviors that require environmental or personal supports for the individual to live independently. Though *mental retardation* was previously accepted as a clinical term, many consider it an insult, so people who have this condition, their families and related organizations have campaigned to end its use. (See "Rosa's Law and the Language of Bullying" on page 8.) Say *people with intellectual disabilities*. Do not use *mentally retarded* or *subnormal*.

**Learning disability** describes a neurologically based condition that may manifest itself as difficulty learning and using skills in reading (called dyslexia), writing (dysgraphia), mathematics (dyscalculia) and other cognitive processes due to differences in how the brain processes information. Individuals with learning disabilities have average or above average intelligence, and the term does not include a learning problem that is primarily the result of another cause, such as intellectual disabilities or lack of educational opportunity. Say *person with a learning disability*. Do not use *slow learner* or *retarded*.

## Rosa's Law and the Language of Bullying

Signed into U.S. law in 2010, Rosa's Law replaces the term *mental retardation* with the phrase *intellectual disability* in federal health, education and labor statutes. The law was named for nine-year-old



Rosa Marcellino, whose brother Nick explained the change this way: "What you call people is how you treat them. If we change the words, maybe it will be the start of a new attitude towards people with disabilities."\*

Most states have also changed their laws to use more respectful language in statutes and the names of state agencies.

The disability community supports a national campaign called "Spread the word to end the word," which raises the public's awareness about ending use of "the R word." This movement is also part of the battle against bullying, which often begins with demeaning and destructive words.

\*From "Remarks by the President at the Signing of the 21st Century Communications and Video Accessibility Act of 2010," <http://www.whitehouse.gov/the-press-office/2010/10/08/remarks-president-signing-21st-century-communications-and-video-accessib>, accessed 12/7/12.

8

**Nondisabled** is the preferred term when the context calls for a comparison between people with and without disabilities. Use *nondisabled* or *people without disabilities* instead of *healthy*, *able-bodied*, *normal* or *whole*.

**Post-polio syndrome** is a condition that affects some persons who have had poliomyelitis (polio) long after recovery from the disease. It is characterized by new muscle weakness, joint and muscle pain and fatigue. Say *person with post-polio syndrome*. Do not use *polio victim*.

**Psychiatric disability** refers to a variety of psychological conditions. Say *person with a psychiatric disability* or *mental illness*. In a clinical context or for medical or legal accuracy, use *schizophrenic*, *psychotic* and other diagnostic terms. Note, too, that *bipolar disorder* has replaced *manic depression*. Words such as *crazy*, *maniac*, *lunatic*, *schizo* and *psycho* are offensive and should never be applied to people with mental health conditions.

**Seizure** describes an involuntary muscle contraction, a brief impairment or loss of consciousness resulting from a neurological condition such as epilepsy or from an acquired brain injury. Say *girl with epilepsy* or *teen with a seizure disorder*. The word *convulsion* should be used only for seizures involving contraction of the entire body. Do not use *epileptic*, *fit*, *spastic* or *attacks*.

**Service animal** or **service dog** describes a dog that has been individually trained to do work or perform tasks for people with disabilities. In addition to guiding people who are blind, they may alert people who are deaf, pull wheelchairs, alert and protect a person who is having a seizure, remind a person with mental illness to take prescribed medications, or calm a person with post-traumatic stress disorder during an anxiety attack. Miniature horses are also considered service animals under the Americans with Disabilities Act (ADA), though monkeys no longer are. Do not use *seeing eye dog*.

9

**Short stature** describes a variety of genetic conditions causing people to grow to less than 4'10" tall. Say *person of short stature*, although some groups prefer *little people*. *Dwarfism* is an accepted medical term, but should not be used as general terminology. Do not refer to these individuals as *midgets* because of its circus sideshow connotations.

**Speech disability** is a condition in which a person has limited or impaired speech patterns. Use *child who has a speech disability*. For a person without verbal speech capability, say *person without speech*. Do not use *mute* or *dumb*.

**Spinal cord injury** describes a condition in which there has been permanent damage to the spinal cord, resulting in some degree of paralysis. *Quadriplegia* denotes loss of function in all four extremities, while *paraplegia* refers to loss of function in the lower part of the body only; in both cases the individual might have some function in the affected limbs. While people with spinal cord injuries often refer to themselves as a *para* or a *quad*, communicators should use *man with paraplegia*, *woman who is paralyzed* or *person with a spinal cord injury*. Don't say *cripple* or *handicapped*.

**Substance dependence** refers to patterns of substance use that result in significant impairment in at least three life areas (family, employment, health, etc.) over any 12-month period. Although such terms as *alcoholic* and *addict* are medically acceptable, they may be derogatory to some individuals. Acceptable terms are *people who are substance dependent* or *person who is alcohol dependent*. Individuals who have a history of dependence on alcohol and/or drugs and are no longer using alcohol or drugs may identify themselves as *recovering* or as a *person in recovery*.

**Survivor** is used by people to affirm their recovery from or conquest of an adverse health condition such as *cancer survivor*, *burn survivor*, *brain injury survivor* or *stroke survivor*. Avoid calling them *victims*.



## A Few Exceptions

Language is continually evolving, and no rule is absolute. Here are a few notable exceptions to person-first language.

**Deaf/deaf.** As a group, this population typically refers to itself as *the Deaf* or *Deaf community* (with a capital D) rather than *people who are deaf*. They identify with a specific community made up of those who share a common language, American Sign Language, and culture.

**Disability humor.** Some people with physical disabilities who embrace the culture of disability refer to themselves with the same offensive terms that we urge you to avoid. This familiarity is a form of disability humor and should not be adopted by those outside of the group.

**Identity language.** Some people prefer "identity language" to person-first language as a way to signal their disability pride. Thus, a person who values her autism as an inseparable and important part of who she is might proudly say, "I am autistic," in the same way she describes herself as an American. Similarly, many regard a *blind man* as a neutral descriptor (the same as a *tall man*), and *amputee* is more often used than a *person with an amputation*.

Still, the guiding principle remains: Accord people with disabilities the dignity that all people want. By using person-first language, you will maintain objectivity and convey respect.

## Key Concepts in the Disability Community



These terms and concepts may be helpful when writing about people with disabilities.

**Accessible** describes the nature of accommodations for people who have a disability. Say an *accessible parking space* rather than *handicapped parking* or *disabled restroom*. *Accessible*

also describes products and services for people with vision or hearing disabilities, such as when a hospital provides patient education materials in large print or a university adds captions to a recruitment video. *Handicapped* has negative connotations because it suggests that obstacles to participation are in the person rather than in the environment.

**Advocacy** is an active process designed to make institutions and social and political systems more responsive to the civil rights, needs and choices of individuals. Through individual and group advocacy, people with disabilities can assert their rights under various civil rights laws and participate in decision-making that affects them.

**Consumer** is the term used by many in the disability community to refer to someone with a disability. The civil rights movement in the U.S. inspired the independent living movement of the 1970s, which maintained that people with disabilities are *consumers* of assistive services and have a responsibility to evaluate and control those services. On a similar note, some people prefer to be described by what they use, such as *wheelchair user*, *ventilator user* or *mental health service user*.

**Independent living (IL)** refers to the philosophy that people with disabilities should be able to make decisions that affect their own lives. IL also refers to a civil rights movement that advocates for equal participation in community life and a service system

made up of centers for independent living. These nonresidential resource centers are run by and for people with disabilities, as well as for the benefit of the entire community. Their core services include advocacy, information and referral, independent living skills training, peer counseling and, most recently, de-institutionalization of people with disabilities.

**Inclusion** is perhaps best known for its role in public school programs, though the concept has a wider significance. It means that people with disabilities are considered full citizens, with equal opportunity to participate in community life. As the largest minority in the U.S., people with disabilities should also be included in conversations about diversity.

**The medical model** is an attitude and practice that regards disability as a defect or sickness that must be cured or normalized through medical intervention. People in the disability community prefer the **social or independent living model**, which regards disability as a neutral difference between people – and acknowledges that people with disabilities can be healthy. In the social model, problems related to disability are caused by the interaction between the individual and the environment rather than the individual's disability itself. These problems can be remedied by changing social attitudes, physical environments, public policies and other barriers to full participation.

**On the cover:** Jeff Gordon, Ranita Wilks, Rachel Magario and Magario's service dog, Nettie, on the University of Kansas campus. Photo by Diane Guthrie.

The University of Kansas prohibits discrimination on the basis of race, color, ethnicity, religion, sex, national origin, age, ancestry, disability, status as a veteran, sexual orientation, marital status, parental status, gender identity, gender expression and genetic information in the University's programs and activities. The following person has been designated to handle inquiries regarding the non-discrimination policies: Director of the Office of Institutional Opportunity and Access, IOA@ku.edu, 1246 W. Campus Road, Room 153A, Lawrence, KS, 66045, (785)864-6414, 711 TTY.



Permission to reprint is granted by the Research and Training Center on Independent Living, The University of Kansas. Please reference as: Research and Training Center on Independent Living. (2013). *Guidelines: How to write and report about people with disabilities, 8<sup>th</sup> edition*. Lawrence, KS: The University of Kansas, Life Span Institute.