Using Person-Centered Language

The language health plans and providers choose when communicating with and about people matters. Language is a powerful tool that reflects our attitudes and beliefs; while some words may make a person feel uplifted or supported, others may make them feel disrespected, stigmatized, or harmed. And while providers must sometimes use diagnostic labels and clinical language for clear communication, overreliance on such language can unintentionally but negatively impact relationships. Thoughtful language choices support meaningful partnerships with individuals and ultimately bolster their success in meeting their own health and wellness goals.

Person-centered language acknowledges the person first and foremost and places any diagnosis, condition, or disability in the context of the whole person. It is an essential component of a person-centered model of care *(see The Medical Model versus Person-Centered Model callout box)*. Plans and providers serving beneficiaries dually eligible for Medicare and Medicaid may have particular interest in person-centered models, as dually eligible individuals have high rates of chronic conditions and disability, use multiple types of services (i.e., medical and non-medical), and account for a disproportionately large share of Medicare and Medicaid expenditures.[3]

The Medical Model versus Person-Centered Model

The traditional **medical model** of health care focuses mainly on diagnosis and treatment of disease. Individuals receiving care are typically expected to take a passive role in this model. In a **person-centered model**, people are empowered to participate as active partners in discussions and decisions about their care. The model considers diagnosis, condition, and disability in the context of the whole person. The person-centered model focuses on supporting and communicating with people by emphasizing their strengths, capabilities, and opportunities to reach their chosen goals.[1,2]

This tip sheet provides practical and meaningful tips on the use of person-centered language. Health plan staff and providers can incorporate person-centered language in all communication with individuals, families, and caregivers; and in marketing materials, internal meetings, care planning, and documentation.

Person-Centered Language

By using words that respect and acknowledge an individual as a whole person, person-centered language emphasizes that people are experts in their own lives, health, and needs.[4] Plans and providers seeking to employ person-centered language should consider these guidelines:

- **Use "person-first" language.** Person-first language means focusing on the individual as a whole human being first, not their disability, condition, or diagnosis.[5] Using person-first language avoids the assumption that a person's disability or condition is a characteristic of their personal identity, placing these as secondary to who the person is. Examples of person-first language include "people with disability," "person with multiple sclerosis," "person with chronic pain," or "people who have epilepsy."

- **Ask individuals for their language preferences.**[7] While person-first language is a good starting point, it is still important to ask a person about their preferences. Some people prefer "identity-first" language, such as "autistic person" rather than "a person with autism," or "blind person" rather than "person who is blind." Some people may prefer "Deaf" (with a capital D) instead of "person who is deaf," because they identify with a community of people (the Deaf Community) with a common culture and language (i.e., American Sign Language).[8] Similarly, asking for a person's preferred gender pronouns, rather than making assumptions about how they identify, is another example of using preferred and respectful language.

An exception to "person-first language" is "identity-first language," which means that some people prefer to identify with their disability or condition first because they value their disability as a vital part of who they are.[6]

Language Matters: Mental Illness

A 2016 study asked a sample of adults, including professional counselors, about their perceptions of mental illness. Study participants who were asked about "people with mental illness" demonstrated more acceptance than participants asked about "mentally ill people." The findings of this study suggest the power that simple changes in words can have on encouraging positive attitudes toward people with mental illness.[9]

- **Describe "who" the person is.** When describing the individuals your organization works with or serves, it is important to consider the person holistically. Only include a person's condition or disability if it is required or essential to the description. Where appropriate, you can also make a description more person-centered by including information on what people like to do, how they spend their time (e.g., hobbies, occupation, or favorite activities), what is important to them, and their goals for the future. For example, "Kayla is a grandmother and retired bus driver who loves cats. She volunteers for a local animal shelter two days a week" or "Omar likes to spend time with friends, and tries to attend every home game for the local professional hockey team and wants to continue to be able to do that in the future."

- **Use strength-based language.** Strength-based language emphasizes people's strengths, abilities, and opportunities, instead of their challenges, conditions, or perceived deficiencies. For example, "Maria uses a communication device" rather than "Maria is non-verbal." Another example of strength-based language is to use "Malik hires staff to do tasks around the house that he cannot do as a result of his stroke," rather than say "Malik requires total assistance with housework."

- **Avoid language that labels or perpetuates stereotypes.**[10] Instead of labels, use words or terms to communicate what a person has instead of what a person is. For example, "Amal has type 2 diabetes" rather than "Amal is a diabetic." Avoid language that perpetuates negative stereotypes about individuals with psychiatric or behavioral health conditions. For example, say "Jerry has a diagnosis of bipolar disorder" instead of "Jerry is bipolar," or "a person with schizophrenia" instead of "a schizophrenic." As noted above, only include information that is pertinent to the particular context and avoid oversharing irrelevant information.

Small Change, Big Impact

One health plan attributed improvements in their Consumer Assessment of Healthcare Providers and Systems (CAHPS) scores to training customer service representatives to ask members' names when they first call in. Greeting members by name before asking for additional information, such as identification numbers, helps create a positive relationship between customer service staff and members.

Person-Centered Language at a Glance

Simple changes in word choice, such as the examples highlighted in the table below, can make the language that plans and providers use on a regular basis more person-centered, while accounting for individual preference.

Use….	Instead of….
Person/people with disability	Disabled
Person/people without disability	Able-bodied, healthy, normal
Person, individual, member, consumer	Patient (*outside of a healthcare encounter*)
At risk for falls	A falls risk
Person with a substance use disorder, person in recovery	Addict
Person with an alcohol use disorder, person in recovery	Alcoholic
Person with, who has	Afflicted with, suffers from
Has barriers, experiences challenges, "often chooses not to do… because"	Non-adherent, non-compliant
Prefers not to, chooses not to	Resistant, refuses
Uses a wheelchair	Confined to a wheelchair/ wheelchair-bound
Accessible *[entrance, restroom]*	Handicapped [*entrance, restroom*]
Survivor	Victim, vulnerable

Person-Centered Language in Action

The following passages illustrate how plans and providers serving dually eligible beneficiaries can incorporate person-centered language into success stories or descriptions of how they have made a difference in people's lives. The passage on the left uses language consistent with a traditional medical model, whereas the passage on the right demonstrates person-centered language, emphasizing who the individual is and their goals and preferences, and reframing the person's "difficulties" as challenges, barriers, and opportunities.

Dorothy's Story	
Before	**After**
African American female, age 72. Member suffers from Parkinson's disease, high blood pressure, chronic obstructive pulmonary disease (COPD) and depression. Member also is a falls risk and initially refused support services due to a lack of understanding of the importance of the interventions to keep her safe. Member's primary care physician (PCP) reported a lack of medication compliance.	Dorothy is a retired professor who lives with her husband of over 40 years. Remaining at home is a key goal for Dorothy, as she is very active in her community and enjoys having her grandchildren visit her home. Until recently Dorothy and her husband traveled frequently, and being able to continue traveling is a priority for Dorothy. Dorothy's current diagnoses include Parkinson's disease, high blood pressure, and COPD. Her health has declined over the last six months and she and her husband have had to cancel many of their travel plans. Her health challenges have impacted her mood and her PCP diagnosed her with depression. During conversations with her care manager and husband, Dorothy said she sometimes struggled with managing her medications and might like some help; however, she was reluctant to have someone she did not know deliver paid supports and services in her home.
The care manager informed the member of the importance of medication compliance to have better control over her chronic medical conditions. The care manager arranged for the member to receive personal care services at home, which made her adhere to the treatment plan. She is now medication-compliant and reports that she feels better.	Dorothy and her care manager discussed her concerns and Dorothy now feels more comfortable receiving supports at home because she understands how services, such as gait training with a physical therapist, can help her reach her goals. With support from her care manager, Dorothy also obtained personal care services that support her ability to self-manage her medications as well as remain in her home with her husband. Her health improved and she says that she feels much better.

Mr. Park's Story	
Before	**After**
The member lives alone and is primarily wheelchair-bound due to severe pain and mobility limitations from rheumatoid arthritis and uncontrolled diabetes that resulted in amputation of two toes on his	Mr. Park is an electrician who has been living independently in his home for the past two years since his wife died. His daughter, her husband, and two children live 20 miles away. Recently, he has struggled with managing his blood glucose, resulting in two toes being amputated

left foot. Member has had multiple hospitalizations over the last three months due to a lack of adherence to his treatment plan, which caused cellulitis and skin ulcers on his feet. Member frequently misses medical appointments due to transportation issues. He is at risk for additional amputations.	and cellulitis and skin ulcers on his feet. As a result, Mr. Park began using a wheelchair and was admitted to the hospital multiple times in recent months. He also reports severe pain and mobility limitations from rheumatoid arthritis. During team meetings, Mr. Park shared that he previously participated with his family in social activities before his wife passed away. Now, he stays at home more often and because he does not drive, has missed many medical appointments, putting him at risk for additional amputations.
The care manager arranged for transportation for medical appointments, which allowed him to attend physical therapy consistently. The care manager reports he is able to increase his mobility and has started to get out of the house more often. He has biweekly sessions with a dietician and has lost 10 pounds.	Mr. Park's goals include spending more time with his family, using his wheelchair less often, controlling his pain, and losing weight. Occasionally, Mr. Park asks his daughter to take him to medical appointments, but feels this may be a burden to her. He discussed options for accessing transportation with his care manager and is now consistently able to attend physical therapy and other medical appointments. He reports he has lost 10 pounds, is feeling better, has less pain, and is using his wheelchair less often. He attended his granddaughter's birthday party recently and is eager to continue working on his goals.

Additional Person-Centered Resources

Making language more person-centered is an important starting point to further an organization's efforts to become more person-centered overall. The following resources provide additional information for plans and providers interested in enhancing person-centered practices within their organizations and systems.

Resources on Person-Centered Language

Resource	Description
Guidelines for Writing about People with Disabilities	This resource from the ADA National Network provides guidelines for how to describe people with disability in a respectful way.
Guidelines: How to Write and Report About People with Disabilities (8th Edition)	This brochure from the Kansas University Research & Training Center on Independent Living provides guidance from people with disability for preferred spoken and written language.
Using Person-First Language across the Continuum of Care for Substance Use Disorders & other Addictions: Words Matter to Reduce Stigma	This paper from the Ohio Language First Team describes person-first language in the context of addiction and substance use disorders. The lists of words and phrases to avoid and preferred terminology on pages 7 through 9 may be particularly useful.
Identity-First Language	This article from the Autistic Self Advocacy Network describes the identity-first language that many autistic individuals prefer, and the power that language has in shaping attitudes.

Person- Centred Language Guidelines	This resource from the Alzheimer Society of Canada provides detailed examples of person-centered terminology to use in the context of caring for and serving individuals with dementia. While created in the Canadian context, the majority of guidelines apply for language used in the United States.
The Language of Culture Change	This resource from the Pioneer Network provides examples of respectful and accurate language to use to replace outdated words and terms in a long-term care setting.

Resources on Person-Centered Care and Systems

Resource	Description
National Center on Advancing Person-Centered Practices and Systems (NCAPPS)	NCAPPS is a new initiative from the Administration for Community Living (ACL) and the Centers for Medicare & Medicaid Services (CMS) focused on person-centered thinking, planning, and practice in systems for people with disabilities and older adults with long-term services and supports needs. Topics include working across systems and programs to integrate rules, regulations, and policies to promote person-centered practices; engaging service users and families to create high expectations for services and supports; and measuring person-centered processes and outcomes to evaluate impacts.
Person-Centered vs System-Centered Models	This short video highlights the differences between a medical or system-centered model and a person-centered model.
Achieving Person-Centered Care: The Five Pillars of System Transformation	This brief from The SCAN Foundation describes systems-level changes supporting person-centered care models, including administrative reorganization, global budgeting, universal assessment, integrated information systems, and quality measurement and monitoring.
Person-Centered Thinking, Planning, and Practice: A National Environmental Scan of Definitions and Principles	This NCAPPS environmental scan describes criteria for and definitions of person-centered thinking, planning, and practice across a variety of settings. The resources include population-specific information for older adults, individuals with intellectual and developmental disability (IDD), and mental health conditions.
Person-Centered Thinking, Planning, and Practice: A National Environmental Scan of Foundational Resources and Approaches	This NCAPPS environmental scan includes resources and approaches for person-centered thinking, planning, and practice that may be helpful for organizations and systems seeking to make broader changes to become more person-centered. The scan includes early foundational resources as well as population-specific resources.
Guidance for Implementing Principles of Section 2402(a) of the Affordable Care Act: Standards for Person-Centered Planning and Self-Direction in Home and Community-Based Services Programs	This U.S. Department of Health & Human Services (HHS) guidance describes standards on person-centered planning and self-direction of home and community-based services (HCBS) that should be incorporated into all HCBS programs funded by HHS.

National Quality Forum: Person-Centered Planning and Practice	This website contains information about the National Quality Forum's 18-month project addressing person-centered planning and practice within long-term services and supports systems through a multi-stakeholder committee.

The Medicare-Medicaid Coordination Office (MMCO) in the Centers for Medicare & Medicaid Services (CMS) seeks to help beneficiaries dually eligible for Medicare and Medicaid have access to seamless, high-quality health care that includes the full range of covered services in both programs. This tip sheet is intended to support health plans and providers in integrating and coordinating care for dually eligible beneficiaries. It does not convey current or anticipated health plan or provider requirements. For additional information, please go to *https://www.resourcesforintegratedcare.com/*. Please submit feedback to *RIC@lewin.com*.

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[1] Kumar, R. & Chattu, V. K. (2018). What is in the name? Understanding terminologies of patient-centered, person-centered, and patient-directed care! *Journal of Family Medicine and Primary Care, 7*(3), 487-488. https://dx.doi.org/10.4103%2Fjfmpc.jfmpc_61_18.

[2] Resources for Integrated Care. (2014). *Integrating Behavioral Health Competency within Disability-Competent Teams* [PowerPoint Slides]. Retrieved from https://resourcesforintegratedcare.com/sites/default/files/Presentation%20-%20Integrating%20BH%20Comtetency%20within%20DCC%20Teams%20-%20Disability-Competent%20Care.pdf.

[3] Medicare-Medicaid Coordination Office. (2018). *Report to Congress*. Retrieved from https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Downloads/FY-2018-Report-to-Congress.pdf

[4] ADA National Network. (2018). Guidelines for Writing About People with Disabilities. Retrieved from https://adata.org/factsheet/ADANN-writing

[5] The University of Kansas Research and Training Center on Independent Living. (2013). Guidelines: How to Write and Report About People with Disabilities (8th Edition). Retrieved from http://rtcil.org/products/media/guidelines

[6] ADA National Network. (2018).

[7] Ibid.

[8] The University of Kansas Research and Training Center on Independent Living. (2013).

[9] Grabmeier, J. (2016, January 26). Why you should never use the term "the mentally ill." *Ohio State News*. Retrieved from https://news.osu.edu/why-you-should-never-use-the-term-the-mentally-ill/

[10] ADA National Network. (2018).