The influence of disability models on person-centeredness in Home and Community-Based Services

Lindsay DuBois, PhD and Tonie Sadler, PhD

Summary

State departments of health and human services work with human service provider organizations to deliver supports and services that enable people with disabilities to reside in the community rather than an institution. These services are typically paid for using Medicaid funding. The Home and Community Based Services (HCBS) Settings Final Rule by the Centers for Medicare and Medicaid in 2014 emphasizes the importance of person-centeredness in defining how services should be delivered.[1] Although models of disability have created a framework for conceptualizing person-centeredness, little attention has been given to the connection between societal perceptions of disability, as influenced by these disability models, and the subsequent realization of person-centered policies, services, and practices. This issue brief examines frameworks of disability (i.e., medical, social, and biopsychosocial models of disability), evolving concepts of person-centeredness, and implications for providers and others who deliver HCBS in order to achieve improvements in person-centered supports.

Introduction to HCBS

Home and community-based services (HCBS) refer to health-related and social supports and services (e.g., job coaching and employment supports, transportation assistance, home health, etc.) designed to assist people with disabilities and older adults to live in their own home or the community, rather than an institutional setting. HCBS are most often covered by Medicaid, either as part of state plan benefits or as part of waivers designed to target certain segments of the population. According to the Kaiser Family Foundation, there were more than 2.5 million people receiving services through Medicaid waivers in 2018, which amounted to $62.5B in spending. Most states use 1915(c) waivers and 1115 demonstration waivers to cover HCBS for different populations.[2,3] In 2018, states used 1915(c) waivers to provide HCBS services to 785,800 people with intellectual and developmental disabilities (IDD), 795,200 adults with physical disabilities, 17,100 medically fragile or technology dependent children, 25,100 people with mental health disabilities, 17,500 people with spinal cord injuries or traumatic brain injuries, 162,500 older adults, and 3,600 people with HIV/AIDS.[4]

In 2014, the Centers for Medicare & Medicaid Services (CMS) released the HCBS Settings Final Rule, which stipulates the requirements to be eligible for HCBS reimbursement.[1] The Final Rule emphasizes, among other criteria, the use of person-centered approaches to enhance

community integration, thereby improving quality of services and outcomes for people with disabilities. Experts looking to strengthen the HCBS system have focused on the measurement tools that are used to evaluate HCBS and participant outcomes across populations, service plans, and states.[5] Many have also emphasized the need to develop a more skilled workforce that can deliver person-centered services and supports. However, less importance has been placed on the models of disability, how these models shape societal perceptions of people with disabilities, and how they impact person-centered policies and services.

Models of disability

Before the 21st century, disability was typically conceptualized using a medical model, which describes disability as the result of a medical condition or impairment that was considered a deficit.[6] In contrast, the social model of disability emphasizes that although people may have medical conditions or impairments, a disability results from the society's limitations in making adaptions or accommodations to allow people to participate equitably in their community.[4] Table 1 below, originally described by Haegele and Hodge (2016) summarizes several key distinctions between these models.

Table 1. Distinctions between the Medical and Social Models of Disability[7]

Topic	Medical Model	Social Model
What is disability?	A medical condition or impairment	A social construct from a lack of inclusive societies
Goal of intervention	Fixing people with disabilities	Social or political change to promote inclusion
Outcome of intervention	Normalized or typical functioning	Self-advocacy and inclusion
Authority on disability	Scientists and doctors	Academics and advocates with disabilities
Agent of change	Medical professionals	Individuals or advocates who promote attitudinal change
Effect of change	Society remains the same	Society is more inclusive
Perception of disability	Being disabled is a bad thing	Being disabled is neither bad nor good

Critiques of the medical model focus on the "labels and categorizations based largely on the individuals' bodily function," as well as the emphasis on "disability in a deficit model orientation" (pg. 196).[5] Likewise, critiques of the social model center on the separation of impairment and disability, which can result in the lived experience of people with disability not being fully taken into consideration; further, while the social model emphasizes the role of society to make accommodations, the reality is that disability intersects with other attributes of individuals as

well as institutions at large, and there is a need to explore how these are related.[5] The World Health Organization (WHO) defines disability through yet another model, the biopsychosocial model. This conceptualization blends aspects of the medical and social models, defining disability as a condition that results from the interaction of personal and environmental factors, resulting in body function and structure impairments, participation restrictions, and activity limitations, as illustrated in figure 1.[8]

Figure 1. The Biopsychosocial Model of Disability
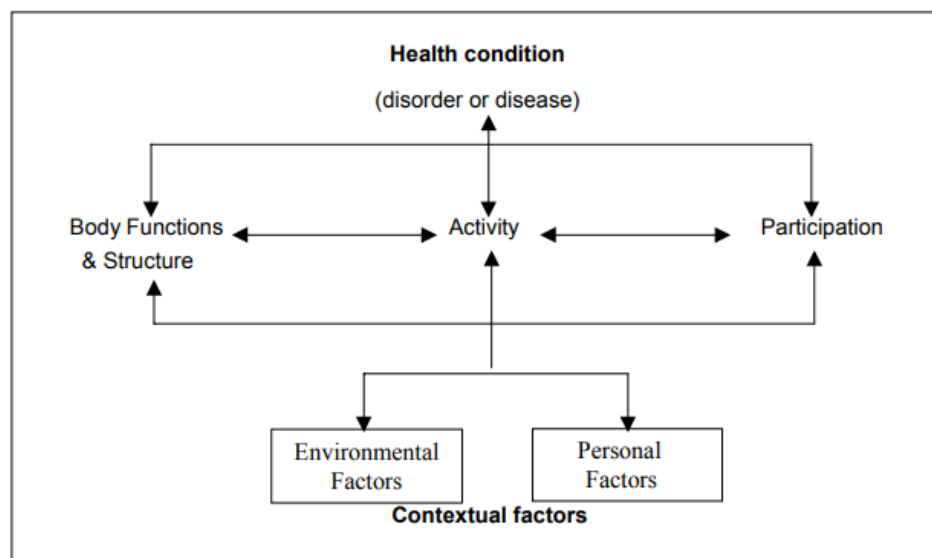
Despite the variety of conceptual paradigms, the legacy of the medical model is pervasive across health polices and organizations in the U.S. For example, some health professional education programs (e.g., medical and dental training programs,) have not yet adopted these more modern definitions of disability, and still rely heavily on the medical model and trying to "fix" people who have disabilities.[9] Adopting a medical model of disability without integrating social and psychological aspects of disability does not explicitly recognize how health and functioning are strongly influenced by social determinants of health and limited accessibility in social environments. The medical model contributes to the perception that people with disabilities are inherently "unhealthy."

Moving from a medical-only definition of disability to social or biopsychosocial models is complex. Outdated definitions and connotations about disability can lead to societal misconceptions about what people with disabilities are capable of doing. For example, a recent study examining a nationally representative sample of the general population found that less than 50% of respondents thought people with intellectual disabilities were capable of voting in elections, playing sports on a team with people without intellectual disabilities, making their own decisions, and being a community leader.[10] Another research study investigated implicit attitudes of healthcare providers and found that 83% held negative, unconscious attitudes toward people with a variety of disabilities.[11] These conscious and unconscious perceptions of people with

disabilities may contribute to paternalistic assumptions that people with disabilities don't understand what they need and that professionals and others without disabilities know their needs better.

Legislative landscape and models of disability

Several laws and policies have improved access to home and community-based services and other social safety-net programs. These laws and policies can be examined more closely according to their use of medical, social, or biopsychosocial models of disability to provide a better understanding of their impacts.

Profound policy shifts, starting in the 1940's and 1950's, such as the expansion of social insurance and Medicaid and Medicare, began to improve the safety net for Americans with disabilities.[12] These expanded policies improved access to health care as well as access to cash benefits for people with disabilities, but they did not reflect a social or biopsychosocial philosophy of disability given the eligibility requirements for a medical diagnosis for these programs.

During the 1960's and 1970's, deinstitutionalization movements led to a significant transition toward community-based services, which reflected a philosophy of community integration and social accommodation, aligning more with the social model of disability than the medical model. Salmi et al. (2010) coined the period between 1988 and 2008 as the "generation of community living" due to the "greater net increases in community residential services and accompanying decreases in institutional service than any other 20-year period in U.S. history" (p. 168).[13] Institution closures progressed alongside the creation of Medicaid in 1965, "establishing a state-federal government entitlement program, which provides a legal right to services to those who meet eligibility criteria." Medicaid HCBS was created in 1981 "to address both the rising cost of skilled nursing care and the institutional bias of Medicaid" by offering community-based services.[14]

A transition toward community-based services ensued, and this movement was later strengthened by the 1990 Americans with Disabilities Act, or ADA, and the *Olmstead v. L.C. 527 U.S. 581* decision in June 1999. Both the ADA and the Olmstead decision had a significant influence on the movement toward integrated community-based services for people with disabilities.[15] The ADA focuses on equal employment opportunities and the right to reasonable accommodations, prohibits exclusion from state and local government services on the basis of disability, and improves telecommunications accessibility; these changes reflect a "[s]ocial or political change to promote inclusion," a crucial tenant of the social model of disability (Table1). The Olmstead decision states that "public entities are required to provide community-based services to persons with disabilities when (a) such services are appropriate; (b) the affected persons do not oppose community-based treatment; and (c) community-based services can be reasonably accommodated, taking into account the resources available to the entity"[1] In short,

the ADA and the Olmstead decision delineate the right to community-based integrated services for people with disabilities.

While the ADA and Olmstead decision have advanced the rights of people with disabilities in the U.S., there is still the need to improve disability-based policies and services. For example, despite the emphasis on community living and inclusion, the ADA does not explicitly adopt a social or biopsychosocial model of disability. Rather, it follows the medical model and focuses on the physiological condition of disability. This can lead to a "Goldilocks dilemma whereby … [the] limited definition of disability finds disabled Americans either "'too disabled' or 'not disabled enough' to qualify for the protections of the ADA" (pg. 309).[16]

In contrast, the Convention on the Rights of People with Disabilities (CRPD) adopted by the United Nations in 2006 explicitly uses the biopsychosocial model of disability from a human rights perspective in its treaty.[14] Similar to the ADA, this human rights treaty emphasizes the rights of people with disability and in particular their right to access education, health, rehabilitation, employment, recreation, and adequate standards of living to name a few. The UN CRPD has been ratified by 177 countries; however, the U.S. has not signed or ratified the treaty. The decision by the U.S. Congress is partly due to the ADA, which, as U.S. law, supersedes any international treaty; nevertheless, the decision not to sign a treaty that endorses more social and biopsychosocial models of disability raises questions about the importance of these models in U.S. policy. Unlike the ADA or Olmstead decision, the CRPD focuses less on defining disability and more on actions that society ought to take in order to ensure equity for people with disabilities. An equity-oriented approach to services centers on understanding the supports individuals need to be independent and achieve their goals. Thus, legislation reflecting the biopsychosocial model of disability promotes developing and implementing person-centered approaches to services. While U.S. disability policies do not explicitly adopt the biopsychosocial model of disability, the HCBS Settings Final Rule focused on person-centered supports is a step toward these models.

Person-centeredness: definitions and considerations

There are a variety of terms used in health and human services to describe approaches that focus on the needs of individuals; some examples include:

- Person-centered
- Patient-centered
- Person-directed
- Consumer-directed
- Shared Decision Making
- Supported Decision Making

Several of the terms, such as person-centered and patient-centered, sound similar and are sometimes used interchangeably; however, it is important to understand their similarities and their differences.

According to [Tanya Richmond and Bob Sattler from Support Development Associates](#), the movement towards person-centered supports started in the 1960s with Carl Rogers' development of patient-centered therapy. Over the next 60 years, a number of other thought leaders promoted concepts of person-centeredness in different settings, including supporting people with physical and age-related disabilities, people with intellectual and/or developmental disabilities, and people with mental health needs. Although the perspectives of what it means to be person-centered evolved somewhat independently for different populations, the intent was to move people out of institutional settings and into more integrated community settings.

Presently, the National Center on Advancing Person-Centered Practices and Systems (NCAPPS), a federally-funded program with the goal of promoting systems changes that make person-centered principles a reality across the lifespan, defines three elements of person-centered supports:

- Person-centered thinking: focuses language, values, and actions toward respecting the views of the person and their loved ones. It emphasizes quality of life, well-being, and informed choice
- Person-centered planning: is directed by the person with helpers they choose. It is a way to learn about the choices and interests that make up a good life and identify the supports (paid and unpaid) needed to achieve it
- Person-centered practices: are present when people have the full benefit of community living and supports are designed to assist people as they work toward their desired life goals

In contrast to definitions of person-centered supports, the National Academy of Medicine defines patient-centered care as: "care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions."[17] An analysis of literature on person-centered care in comparison to patient-centered care found that although there is significant overlap with regard to empathy, respect, engagement, communication, coordinated care, and even shared decision-making, the goal of the process is different.[18] The authors found that articles citing person-centered care often focused on goals of living a *meaningful* life, while patient-centered care often focused on goals of living a *functional* life. Living a meaningful life, as it relates to person-centered supports, is likely derived from the social model of disability. Conversely, functional status, as it relates to patient-centered care, more closely reflects the tenets of the medical model of disability.

Similarly, a special commentary examining characteristics of patient-centered, person-centered, and person-directed care found that person-centered and person-directed models place greater emphasis on the social determinants of health and their impact on decision making. Person-directed care, however, is unique in the emphasis on education and empowerment of the person receiving care and coordination of services between acute, post-acute, and long-term care

settings.[19] The authors concluded that terminology has a tremendous influence on attitudes and behaviors of providers, which may impact patient and participant outcomes.

As noted, HCBS developed from a social movement to establish the rights of people with disabilities to live in community settings. This movement based in the social model of disability involved an important shift away from support of institutionalization, which is based on the medical model of disability. Nevertheless, remnants of language and policies influenced by the medical model of disability are present in federal health-related policies (e.g., CMS or LTSS guidance) and state policies that inform HCBS. This history has placed priority on measuring health outcomes of HCBS, which are often medical in nature and not always person-centered. However, non-medical outcomes that reflect the desires of the people who receive services are gaining traction, evidenced by the HCBS Settings Final Rule.

Although person-centered concepts are aligned with social and biopsychosocial models of disability, there is still opportunity to improve terminology to ensure that people with disabilities are making decisions about their lives. As Lines, Lepore, and Weiner point out, "person-centered" terminology may be too low a threshold; rather they argue for person-directed supports as the next step forward. When it comes to HCBS, there is a long history of examining person-directed supports in self-direction programs. According to *Applied Self-Direction*, "when a person self-directs, they decide *how*, *when*, and *from whom* their services and supports will be delivered." Although most states allow for self-direction in some HCBS waivers, these programs are limited in terms of who qualifies and how many people can enroll. Whether or not a person is enrolled in self-direction prgorams, it is important that people receiving HCBS are guiding service decision making rather than simply being centered in conversations about them.

Implications for providers, policy makers, and others in the general public

There are several federal rules or programs with the Department of Health and Human Services that specify person-centered requirements, and many states also have legislative policies or codes about person-centeredness. To satisfy these requirements, a wide array of resources exist on training people in person-centered thinking, planning, and practices. However, there is not yet widespread implementation of this training, and HCBS participants, by and large, are not receiving truly person-centered supports. Further, these trainings often do not cover models of disability and how these influence person-centered thinking, planning, and practices. The barriers are multifaceted, but to achieve an HCBS system that meets the needs of HCBS participants, we must adopt more person-centered or person-directed approaches by improving: 1) policies and regulations, 2) attitudes, and 3) training to the HCBS workforce.

First, we need to explore the terminology and impact of HCBS policies and regulations to ensure that they promote the social and biopsychosocial models of disability and uphold the equal rights of people with disabilities. This needs to include an examination of how HCBS policies and regulations can improve and embrace person-centered philosophy. For example, we recently

released a [podcast episode](#) that examined how to meet the needs of HCBS participants; in it, we interviewed a man named Kenny who shared stories about safety-related regulations his provider agency was required to follow and how these often interfered with what Kenny wanted for his daily life. Some service-related regulations may be remnants of the medical model of disability, where people with disabilities are not presumed competent to understand risks and providers make decisions about what they can and cannot do. In instances where the policies are counter to what a person wants, providers should ask: "Why do we have this rule and what exceptions can we make?"

During the COVID-19 pandemic, many of these regulations were relaxed, to allow flexibility to provide supports to people in ways that promote their autonomy and safety. When the pandemic ends, we should examine whether and how this flexibility improves outcomes for HCBS participants, and if this agility can be maintained. Ultimately, people who receive HCBS need to be part of the design of policies so that those who are responsible for creating guidance and regulations have input on how these policies impact the lives of people who receive them.

Second, if we intend to address attitudes and, in particular, the perceptions resulting from the medical model that people with disabilities are less capable than people without disabilities, we must again start with policies and ensure that they promote equity and opportunities for meaningful involvement of people with disabilities. For example, laws that allow for sub-minimum wages for people with disabilities, which were based on the idea that people with disabilities are less productive than those without disabilities, should be phased out; these laws propagate the perception that people with disabilities are not equal to peers without disabilities and hence should be paid less for the same jobs or should work in sheltered settings. In fact, the federal agency, the Committee for Purchase from People Who Are Blind or Severely Disabled, recently solicited public comments about proposed rule changes to subminimum wages.[20] Instead, person-centered approaches would offer reasonable accommodations so that people with disabilities can work in the same jobs and same environments for the same pay as people without disabilities.

Although changing attitudes will be a tall order, intentionally seeking out the guidance of people with disabilities is imperative. It is important to adopt the disability advocacy framework of "nothing about us, without us" by ensuring that people with disabilities have leadership roles in disability education, advocacy, policy development, and research.[21] For example, people with disabilities should have meaningful roles (e.g., leadership roles such as Chair or Co-Chair) on boards of directors for HCBS provider organizations, federal work groups and task forces related to disability policy development, and advisory boards of research projects that focus on disability. Organizations involved in the delivery of HCBS, whether directly providing services or managed care organizations who pay for services, could collaborate with disability advocacy groups, including developmental disability councils, councils on aging, and independent-living centers, to ensure that services are truly person-centered. By including people with disabilities in positions of authority, those who may have low expectations about the capabilities of people with

disabilities will be able to see first-hand what the reality is, and be able to recognize and change their biases.

Finally, training of the HCBS workforce is an essential element of achieving person-centered approaches to supports. Although many organizations, such as [Support Development Associates](), the [Council on Quality and Leadership](), and federally funded centers such as [the National Center on Advancing Person-Centered Practices and Systems]() have created training and resources to promote person-centered supports, training on person-centered thinking, planning, and practice needs to be interdisciplinary to promote an organizational culture of person-centeredness; HCBS provider organizations should train all staff members, from their custodial staff to their executive leadership and board of directors in person-centered thinking, planning, and practices. In addition to training on person-centered supports, training should emphasize models of disability and how they influence our perceptions of the capabilities of people with disabilities; disability rights and identity; and [cultural and linguistic competence](). To be effective, people with disabilities should facilitate or co-facilitate training. And, we must evaluate the effectiveness of training on intermediate and long-term outcomes of HCBS participants. State-level data, such as [National Core Indicators](), are important measures of system performance; however, individual-level measures that allow continuous quality monitoring of person-centered supports are needed, and HCBS providers should receive training in how to administer these measures and use the resulting data to promote a culture of quality improvement. While these suggestions may not fix all aspects of the HCBS system, they hold promise for making significant inroads towards promoting more biopsychosocial models of disability and the ultimate attainment of person-centered supports.

[1] Department of Health and Human Services (2014). Home and Community-Based Settings Final Rule: 42 CFR Parts 430, 431, 435, 436, 440, Section II. https://www.govinfo.gov/content/pkg/FR-2014-01-16/pdf/2014-00487.pdf

[2] Centers for Medicare & Medicaid Services (2020). 1915(c) Waivers by State. https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/1915-c-waivers-by-state#:~:text=Review%20State%20Medicaid%20Policies%20for,state%20waivers%20on%20Medicaid.gov.

[3] National Conference of State Legislatures (2019). Medicaid 1115 Waivers by State. https://www.ncsl.org/research/health/medicaid-1115-waivers-by-state.aspx#:~:text=State%20demonstrations%20promote%20Medicaid%20program,least%20one%20Section%201115%20waiver.

[4] Watts, M. O., Musumeci, M & Chidambaram, P (2020). Medicaid Home and Community-Based Services Enrollment and Spending. *Kaiser Family Foundation Issue Briefs*. https://www.kff.org/report-section/medicaid-home-and-community-based-services-enrollment-and-spending-issue-brief/

[5] Lipson, D. (2019) Assessment and Care Planning Measures. *Mathematica* https://www.medicaid.gov/medicaid/quality-of-care/downloads/hcbs-quality-measures-brief-1-assessment-care-planning.pdf.

[6] Marks, D. (1997) Models of Disability, *Disability and Rehabilitation,* 19:3, 85-91, DOI: 10.3109/09638289709166831

[7] Haegele J.A. & Hodge, S. (2016) Disability Discourse: Overview and Critiques of the Medical and Social Models, Quest, 68:2, 193-206, DOI: 10.1080/00336297.2016.1143849

[8] *ICF Beginners Guide - Who | World Health Organization*. https://www.who.int/classifications/icf/ icfbeginnersguide.pdf.

[9] VanPuymbrouck, L. & Friedman, C. (2019). Relationships between occupational therapy students' understandings of disability and disability attitudes. *Scandinavian Journal of Occupational Therapy*, 27:2, 122-132. https://doi.org/10.1080/11038128.2019.1596310

[10] McConkey, R., Slater, P., Smith, A., DuBois, L. & Shellard, A. (2020). Public attitudes to the rights and community inclusion of people with intellectual disabilities: A transnational study. *Research in Developmental Disability*. doi: 10.1016/j.ridd.2020.103754.

[11] VanPuymbrouck, L., Friedman, C., & Feldner, H. (2020). Explicit and implicit disability attitudes of healthcare providers. *Rehabilitation Psychology,* 65:2, 101–112. https://doi.org/10.1037/rep0000317

[12] Pollack, H. (2011) Health policy and the community safety net for individuals with intellectual disability. *Developmental Disability Research Review*, 17, 44–51.

[13] Salmi, P., Scott, N., Webster, A., Larson, S.A. & Lakin, K.C. (2010) Residential Services for People with Intellectual or Developmental Disabilities at the 20th Anniversary of the Americans With Disabilities Act, the 10th Anniversary of Olmstead, and in the Year of Community Living. *Intellectual and Developmental Disabilities,* 48:2, 168–71. https://doi.org/10.1352/1934-9556-48.2.168.

[14] Burke, M.M., Lulinski, A., Jones, J. & Gallus, K. (2018) A Review of Supports and Services for Adults With Intellectual and Developmental Disabilities (IDD) and Their Families in the United States. *International Review of Research in Developmental Disabilities*, 54, 137–76. https://doi.org/10.1016/bs.irrdd.2018.07.005.

[15] U.S. Department of Justice, Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C., 1990*.

[16] Areheart, B.A. (2008) "When Disability Isn't "Just Right": The Entrenchment of the Medical Model of Disability and the Goldilocks Dilemma," Indiana Law Journal: Vol. 83: Iss. 1 , Article 5.

[17] Institute of Medicine. (2001). Crossing the Quality Chasm. Washington: National Academies Press.

[18] Håkansson Eklund J et al. (2019) "Same same or different?" A review of reviews of person-centered and patient-centered care. *Patient Education and Counseling*, 102:1, 3-11. doi: 10.1016/j.pec.2018.08.029.

[19] Lines, L.M., Lepore, M., Wiener, J.M. (2015) Patient-centered, Person-centered, and Person-directed Care: They are Not the Same. *Medical Care*, 53:7, 561-3. doi: 10.1097/MLR.0000000000000387.

[20] https://www.federalregister.gov/documents/2021/10/12/2021-22118/prohibition-on-the-payment-of-subminimum-wages-under-14c-certificates-as-a-qualification-for

[21] Charlton, James I. *Nothing about Us without Us: Disability Oppression and Empowerment*. 3. Dr. Berkeley, Calif.: Univ. of California Press, 2004.