The influence of disability models on person-centeredness in home and community-based services (Easy Read Version)

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For the full policy brief, please go to:
https://www.sralab.org/research/labs/cror/projects/influence-disability-models-person-centeredness-home-and-community-based-services

This resource is about models of disability and how they influence home and community-based services (HCBS) and supports that people get. After a brief introduction, we will talk about five main topics:

1. How disability is defined

2. How disability definitions affect policies and laws

3. What are person-centered supports

4. How definitions of disability affect person-centered supports

5. How to improve person-centered supports

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Words to Know

Term	Definition
Home and community-based services (HCBS)	These services allow people with disabilities and older adults to live in their own homes or in a community setting, instead of an institution. Services refer to the paid supports that people use.
HCBS Providers	People who have a job to deliver services to people with disabilities.
Institutions	Institutions are places where people with disabilities live apart from their families and communities.
Medicaid	Medicaid is a public health insurance program. Our taxes pay for it.
Centers for Medicare and Medicaid Services (CMS)	The Centers for Medicare & Medicaid Services makes the rules and provides money for the Medicaid program.
HCBS Final Settings Rule	This rule says that people with disabilities have the right to live in the community that they want. The rule also says services should help people do that.
Person-centered planning	Person-centered planning involves the person with a disability: • Sharing information about the things they like • Describing the things they want to do, or their goals • Identifying what help or support they need to reach their goals
Medical model of disability	The medical model defines disability as something that is wrong with someone. Disability is a medical condition to be fixed.
Social model of disability	The social model defines disability as coming from a lack of accommodations. Without accommodations, people may not be able to participate in their communities the way they want.
Accommodations	Accommodations help make places more accessible for everyone.

| Biopsychosocial model of disability	This model thinks about disability as the relationship between: • Individual impairments, or differences in the way a person's body or brain works • Personal factors, like age or gender • Environmental factors, or the physical or social aspects of places that people live. This includes stigma.
Americans with Disabilities Act (ADA)	This act made it illegal to deny people with disabilities access to employment, education, transportation and other places that are open to the public.
Stigma	Negative attitudes about people with disabilities.
Olmstead Decision	A Supreme Court decision in 1997 that said people with disabilities have a right to live in the communities of their choice.
United Nations Convention on the Rights of People with Disabilities (CRPD)	The United Nations in 2006 highlighted actions that improve how people with disabilities are treated in different areas of life. The United Nations used an equity approach to improving outcomes for people with disabilities.
Equity	Equity means that people need different amounts and types of supports to have the same outcomes. This is different than equality, where everyone gets the same support.
National Center on Advancing Person-Centered Practices and Systems (NCAPPS)	This program is funded by the federal government to help states, tribes and territories be more person-centered when they help people.
Person-centered practices	Person-centered practices are present when: • People can live in their communities • People have the supports they need • People are able to work on life goals that are important to them
Patient-centered care	Providing care that respects the preferences, needs, and values of patients.

| Policies	Policies are guidelines or laws created by governments and organizations.
COVID-19	COVID-19 is a disease that is caused by a virus. It very easy to catch, spread and can result in Illness and/or death. The disease spread quickly around the world, starting in 2019.
Attitudes	Thoughts, feelings and beliefs someone may have toward objects, people, things or events.

Introduction to HCBS

This section focuses on home and community-based services (HCBS). You will learn:

- *What HCBS are*
- *Who uses HCBS*
- *They ways that people are trying to make HCBS better so people live the lives that they want*
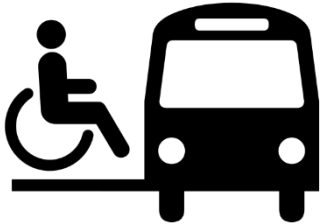
HCBS are services and supports that people with disabilities and older adults may receive. Medicaid pays for them. People with disabilities sometimes need support with:

- Transportation
- Health
- Daily activities
- Employment
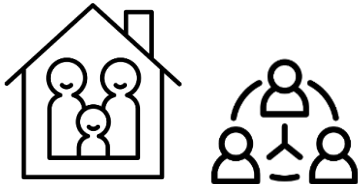
These supports are provided by HCBS providers. HCBS providers are people who deliver services to people with disabilities. Years ago, people with disabilities who needed support were often moved into institutions. This means that they would have lived apart from people without disabilities. HCBS helps people with disabilities get support in their homes or in their communities.

Medicaid is a public health insurance program. This means that it is a type of health insurance that the Federal government helps pay for with taxes. Medicaid pays for most HCBS.

The Centers for Medicare and Medicaid (CMS) makes the rules about and provides money for the Medicaid program. In 2014, they made a rule called the **Final Settings Rule.** This rule says:
- People with disabilities have the right to live in the community that they want.
- HCBS providers should help people do that.
- People using HCBS should participate in "person-centered planning."

Person-centered planning is a process where a person can share information about the things they like and want to do. This is sometimes called goal planning. People can also use person-centered planning to share what help or support they need to reach their goals.

Many people think that person-centered planning will improve HCBS. Different people have different ideas about other things that could make HCBS better. Some people think we should do a better job of asking about what matters to people. Others think we need to do a better job of training HCBS providers.

Models of disability affect how we think about disability and people with disabilities. All of this can affect person-centered policies and services.
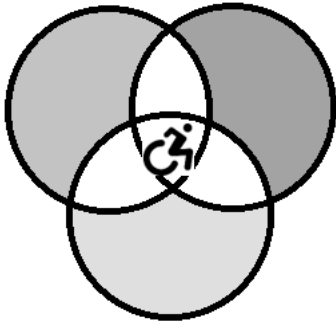
Models of disability

This section focuses on various models of disability. You will learn about the:

- *Medical model of disability*
- *Social model of disability*
- *Biopsychosocial model of disability*

You will also learn about the pros and cons of each model

For many years, people used the **medical model of disability.** In this model, disability is defined as something that is wrong with someone. In this model, people think of disability as a medical condition to be fixed.

More recently, people have started to think about disability in other ways. One of these ways is called the **social model of disability**. In this model, disability comes from a lack of accommodations. **Accommodations** are tools used to make something more accessible for everyone. As a result of accommodations, changes can be made to:

- a job
- the work environment
- the physical environment
- other settings

Without accommodations, people with disabilities are not always able to participate in their communities the way they want. For example, a wheelchair user may not be able to get around their community if there are no ramps. In the social model of disability, the wheelchair user is disabled because their environment is not accessible.

Some people do not like the medical model of disability. They do not like how it focuses so much on disability as a bad thing. Other people do not like the social model of disability. They feel like it does not do a good job of thinking about how personal factors of people, like their age or gender, affect disability.
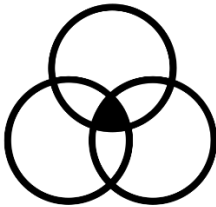
A third model is called the biopsychosocial model of disability. This model thinks about disability as the relationship between:
• Individual impairments, or differences in the way a person's body or brain works
• Personal factors
• Environmental factors, or the physical or social aspects of places that people live. This includes things like stigma, or negative attitudes about people with disabilities

In the biopsychosocial model, the focus is how disability can make it hard for people to take part in many things. For example, a person with depression might need accommodations in the workplace. They might need a flexible work schedule and work-from-home options. In this model, disability can occur if:
• Their employer does not give accommodations
• Their employer gives accommodations, but coworkers have stigma about working with a person with depression

Legislative landscape and models of disability
This section focuses on:
- *Laws and policies that improve access to HCBS*
- *How these laws and policies were shaped by the different models of disability*

In the 1940s and 1950s, the United States government began to provide health insurance to Americans with disabilities. Sometimes this meant people with disabilities needed to live in institutions to receive services. Then, in the 1960s and 1970s, disability activists fought to shut down institutions. These activists wanted people with disabilities to get services in the community. Congress created Medicaid in 1965. People with disabilities are eligible for Medicaid because of having a disability. In 1985, Medicaid started to pay for certain types of HCBS.

In 1990, President Bush signed the **Americans with Disabilities Act** (ADA). This act made it illegal to deny people with disabilities access to:
- Employment
- Education
- Transportation
- Other places that are open to the public

In 1997, there was a lawsuit called *Olmstead v L.C.* The Supreme Court decided that people with disabilities have a right to live in the communities of their choice. The ADA and the Olmstead decision gave people with disabilities a legal right to get services in their communities.

Even with the legal right to community living, there is still work to do. Many people with disabilities in America do not get the services they need. Sometimes, there are not enough services available. Other times, this is because their disability does not meet the definition in the ADA or Olmstead decision of a "disability." For example, the ADA uses the medical model of disability to determine which conditions are a "disability."

There are other policies that use the social or biopsychosocial model of disability. For example, the United Nations adopted the **Convention on the Rights of People with Disabilities** (CRPD) in 2006. The CRPD uses the biopsychosocial model of disability. The CRPD focuses on actions that can help improve how people with disabilities are treated in different areas of life.
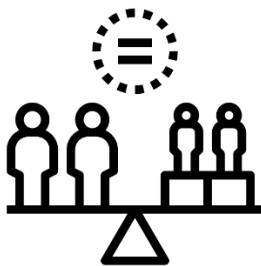
The CRPD uses an equity approach to improving outcomes for people with disabilities. **Equity** means that people need different amounts and types supports to have the same outcomes. This is different than equality, where everyone would get the same support. Focusing on equity is important for person-centered services.

The HCBS Final Settings Rule is a big step toward making services more person-centered. This can make services better.

Person-centeredness: definitions and considerations
This section focuses on what person-centered supports are. You will learn about:

- *Terms such as "person-centered and "patient-centered"*
- *How these terms are used in different contexts*
- *How these terms affect the way that people view disability and supports for people with disability*
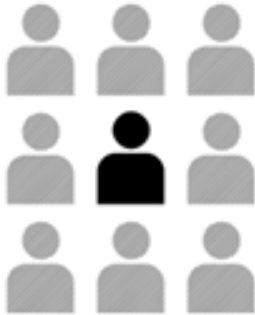
The National Center on Advancing Person-Centered Practices and Systems (NCAPPS) defines **person-centered practices** as present when:
- People can live in their communities
- People have the supports they need
- People can work on life goals that are important to them

Different people use different terms to talk about this idea of person-centered practices. For example, the terms "person-centered" and "patient-centered" are sometimes used to talk about the same thing. While these terms have some things in common, they have other things that are different.

Patient-centered practices mean providing care that respects the preferences, needs, and values of patients (Institute of Medicine). Person-centered care and patient-centered care are similar because they try to include service users in making decisions about their care. But, they have different goals. Researchers found that person-centered care was about providing services so people live a meaningful life (Häkansson Eklund et al). Patient-centered care was about providing services so people have a functional life. In other words, in patient-centered care, providers are often trying to "fix what is wrong." In this way, the goal of patient-centered care is more like the medical model of disability.

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While these differences may seem small, the words we use to talk about things can affect the way people act. It is important that people who receive HCBS get to guide their services to meet their goals.

Implications for providers, policy makers, and others in the general public
This section focuses on how to better meet the needs of people who use HCBS. You will learn about some examples of how to improve person-centered supports:
- *Policies and regulations,*
- *Attitudes, and*
- *Training*

There are lots of different ways to improve person-centered supports. A few examples we can look at are policies, attitudes, and training.

Policies
Policies are rules or guidelines that are created by individuals, organizations or governments. There are many policies in the United States that focus on HCBS. However, HCBS policies do not always lead to person-centered supports.

For example, some HCBS policies are about making sure people who use services are safe. This means that sometimes, HCBS providers decide how they think they should keep a person safe. But, this decision may not be what the person wants for their life. When this happens, providers should ask:
- Why do we have this policy?
- If I do what the person I support wants, does this mean I'm not following this policy?

- Are there any times when the policy does not have to be followed?

Many HCBS providers were flexible with some of the rules during **COVID-19**. Because of this, HCBS users might have had better experience with their services. We should look at if we can keep being flexible with some rules. If we can be flexible, we need to look at how this affects person-centered supports.

We should also think about how the words used in HCBS rules reflect the medical model of disability. For example, some policies use the medical model of disability. This can lead to wording that suggests people with disabilities do not understand risks. This can lead to wording that suggests that people with disabilities should not make decisions for themselves. These policies can be harmful to people with disabilities. When the medical model is used, we should think about if we should change the words used to be the same as the social and biopsychosocial model. This might help make sure we encourage the rights and abilities of people with disabilities.
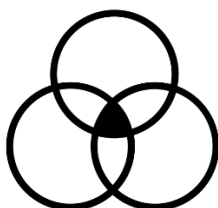
Most importantly, the opinions and ideas of people who use HCBS should be included when policies are created. Doing so assures that the policies reflect the wishes of people with disabilities.

Attitudes
Another important thing we should think about is how to improve attitudes. This includes attitudes of HCBS providers about people with disabilities. It also includes attitudes of community members,

such as employers. For example, in many states, employers can pay people with disabilities less than people without disabilities. The law lets this happen because of stigma about people with disabilities and what they can do. It is not fair to pay a person with a disability less money to do the same job. Instead, Employers should offer accommodations so people with disabilities can work in the same jobs for fair pay. This would be one way to make sure that we have person-centered supports. If we can improve attitudes towards people with disabilities, we can improve use of person-centered supports.
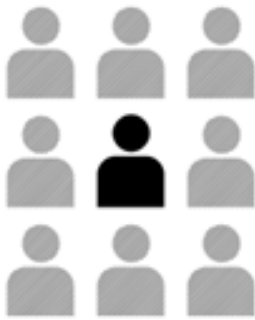
It's also important to make sure that we follow the principle of "nothing about us, without us." This means that we need to make sure that people with disabilities are helping to lead work related to:
• educating providers,
• developing policies, and
• designing research

Training
There are many great examples of training on person-centered supports. HCBS organizations employ providers and other staff to offer services and supports. HCBS organizations should continue training all staff in person-centered supports. These trainings should also include information about:
• the models of disability,
• disability rights, and
• disability identity
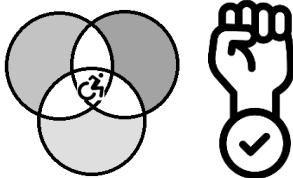
In addition, providers should understand different cultures. A person's culture can affect what support they want. Cultures affect how they want

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to be supported. People with disabilities should help create and lead these trainings.

Lastly, we need to make sure that we understand how well training improves HCBS. This means looking to see whether the training helps people who use HCBS users have the outcomes that they want. It is important that we have good ways to measure how well services are working for people. We need to know this so we can make services better. Providers should be trained to collect data on how to make services better.

While these ideas may not fix everything, they might help make progress.

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