

Plain Language:
**Medicaid Services for People with Intellectual
or Developmental Disabilities – Evolution of
Addressing Service Needs and Preferences**

Report to:

The Medicaid and CHIP Payment and Access
Commission

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Introduction

This is a plain language version of a report about Medicaid services for people with intellectual or developmental disabilities called, 'Medicaid Services for People with Intellectual and Developmental Disabilities – Evolution of Addressing Service Needs and Preferences'. It includes lots of information about different types of Medicaid services and how people with intellectual or developmental disabilities use these services. The report shares what Medicaid services are working well for people with disabilities, and what could be better.

When you read this plain language version of the report, it might be helpful to know about who wrote it and why. This section will help to explain that.



Who is MACPAC?

The Medicaid and CHIP Payment and Access Commission (MACPAC) is a part of the [federal government](#) of the United States. It gives information and recommends improvements about Medicaid and the Children's Health Insurance Program (CHIP) to members of Congress, to the Secretary of the U.S. Department of Health and Human Services, and to [state governments](#).



Who is HMA?

Health Management Associates (HMA) is a group of people who work on projects to try to make the health care system work better for everyone. When they think about health care working for all people, they want to make sure that means it works for people who are poor or have trouble getting what they need for other reasons, including people with disabilities.



Who is AUCD?

The Association of University Centers on Disabilities (AUCD) wrote this accessible version of the report. AUCD is an organization that works to make the world better for and with individuals with developmental and other disabilities, their families, and communities. The team that worked on this plain language version includes people with disabilities.

Why did MACPAC ask HMA to write this report?

The goal of this report is to give information about people with intellectual and developmental disabilities (ID/DD) and how Medicaid policies are impacting their lives. This report can help people make good decisions for future changes to programs.



Where did the information in the report come from?

HMA, the report's author, looked at what had already been written about Medicaid and people with ID/DD, interviewed people with ID/DD and other experts, and wrote a report about what they learned.

Why is it important for people with ID/DD to understand this report?

People with ID/DD need to know about and be involved in decisions that affect their lives. This report talks about changes to Medicaid that could affect people with ID/DD and how they live, work, make decisions, get healthcare and participate in the community.



What are the definitions of intellectual disabilities (ID) and developmental disabilities (DD) for Medicaid programs?

Developmental disability (DD) is defined in a federal law called the Developmental Disabilities Assistance and Bill of Rights Act. That law says that DD is a disability that starts before a person turns 22 years old and that impacts how the person does daily life activities in at least three ways. A person with a DD will need some support in their daily life.

Intellectual disability (ID) is a disability that impacts both thinking and behavior, and that may impact skills needed for daily life. This disability starts before a person turns 18 years old.

It is important to know that each state gets to make its own definition of who has an Intellectual Disability or Developmental Disability that is used for government programs. How a state defines disabilities is a part of how the state decides who can get help and supports.

Findings

This section of the plain language version shares what the report’s authors learned during their research and interviews with people with intellectual and developmental disabilities (ID/DD), and interviews with other people who know about people with ID/DD and their services. The report’s authors first looked at what researchers have already learned about people with ID/DD who use Medicaid services. Then they interviewed 37 people about Medicaid services, including people with ID/DD, family members, state Medicaid workers, a federal government Medicaid worker, people who work for organizations that provide Medicaid services, and people who work for organizations that protect the rights of people with ID/DD. This section shares “findings,” or information the authors learned, from the research and interviews.



Every person with ID/DD is different.

Like all people, people with ID/DD have their own personalities, life stories, interests, and daily lives. People with ID/DD have different strengths and support needs that can be based on where they live, their families and friends, housing, health, and jobs. Here are some examples:

- Most people with ID/DD live on their own or with family. But some live in a place with care all of the time like a [group home](#), [institution](#), or nursing home.
- Many people with ID/DD rely on the support of other people, technology, or services in their daily lives. But the kind of support and amount of support is different for every person.
- Many people with ID/DD have a hard time finding good medical care to stay healthy. But the kind of healthcare needed is different for every person.



Figure 1. The one white house represents the 1 out of every 4 people with ID/DD who live in a group home or institution. The three black houses represent the 3 out of every 4 people with ID/DD who live on their own or with family.

For more information and sources, see pages 11-12 of ‘Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences’.



People with ID/DD from different backgrounds have different experiences and needs.

Like all people, people with ID/DD have backgrounds that affect their daily lives. A person's background can include many things that are important to them, such as [race](#), [ethnicity](#), religion, [culture](#), language, social groups, gender, or family values. The different parts of a person's background can affect what food they eat, holidays they celebrate, traditions, what clothes they wear, and more.

The background of a person with ID/DD can also affect things like how much money they make, how others treat them, what supports they get, and how good their healthcare is. Government systems like Medicaid do not work the same for people of every background because they are not always set up to consider things like [race](#), [culture](#), and language.

For example, in California, researchers found that people from [races](#) and [ethnicities](#) that are not white were not getting as many Medicaid services as people who are white. This means that people who are Black, Asian/Pacific Islander, or Hispanic were not getting all of the services they needed. One reason could be that people who are from different [races](#) or [ethnicities](#) did not have enough information, time, money, or energy to ask the state for the services they needed. Another reason could be that people who are not white did not trust the services from the [state government](#).

Many of the people interviewed for this report think that state agencies, healthcare providers, and others need to do a better job at making sure that big systems like Medicaid work for people with ID/DD who come from different backgrounds, [cultures](#), and speak different languages.

For more information and sources, see pages 12-14 of 'Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences'.



Each state makes different decisions about Medicaid services and supports for people with ID/DD.

Each state in the United States decides how to provide Medicaid services and supports for people with ID/DD in that state. The federal government makes basic rules that all states must follow, but then state governments make decisions about how to follow those rules and can make their own rules, too. This means that Medicaid services can look different in each state.

Overall, states are spending more Medicaid money on [HCBS](#) than on [institutions](#). States can help more people by spending Medicaid money on [HCBS](#) than institutions because it costs less to support each individual in the community. Less than 1 out of 10 people with ID/DD who get services through Medicaid now live in [institutions](#).

But how each state provides Medicaid services and supports in [HCBS](#) to people with ID/DD is different. Some states provide services through their own state organizations. Other states pay ‘[managed care](#) organizations’ to provide the services and supports. Sometimes [managed care](#) organizations might not understand how to best support people with ID/DD.

For more information and sources, see pages 14-17 of ‘Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences’.



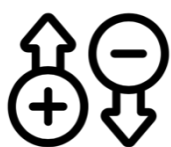
Many states have waitlists for people with ID/DD who want home- and community-based services.

Some people with ID/DD might have to wait for [HCBS](#) in the community on a waitlist before they can start the services. This can happen when more people want [HCBS](#) services than the state can afford to pay for.

Each state decides if it wants to have a waitlist and how to organize the waitlist. The state must make decisions about who can go on the waitlist, who gets served first, if the state will provide any services for people while they’re on a waitlist, and how the state will work to get people off the waitlist. Many of these decisions are based on how much money the state can afford to spend on [HCBS](#).

Some of the people on the waitlists already have services but are waiting for different ones to become available. For example, an adult with ID/DD might be getting some support services while living with their family, but are waiting for services to support living in their own home.

For more information and sources, see pages 17-18 of ‘Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences’.



Each state has a different amount of Medicaid services and supports available for people with ID/DD.

Each state makes its own decisions about funding and resources for Medicaid services and supports for people with ID/DD. These decisions can change the amount and types of services available.

Many states do not have enough money to give lots of services to all the people with ID/DD in their state. These states must choose between giving more services to less people, or less services to more people. Many states choose to give less services to more people. For example, in Indiana, many adults with ID/DD can get in-home, employment, family, and other part-time supports quickly. But adults with ID/DD who need full-time support in a [group home](#) may have to wait on the state waitlist.

There is no perfect way for states to meet the different needs of everyone with ID/DD because they do not have enough money and resources. They try to match supports and services to people's needs. People with higher support needs usually get more services.

For more information and sources, see page 18 of 'Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences'.



Case managers and [person-centered](#) planning are important in supporting people with ID/DD.

Case managers help people with ID/DD find and use supports and services, and to solve any problems with these services. This includes helping with Medicaid, school, health, employment and other services.

Many case managers also help people with ID/DD advocate for the supports they need and for their rights.

Case managers can also be very helpful during times of change in a person's life. For example, many case managers use a tool called 'Charting the [Life Course](#)' that can help people with ID/DD and their families make decisions and plans.

Many people with ID/DD and their families trust case managers to help them get the services they need. Sometimes case managers do not have enough time and resources to meet every need of every person and family.

Many case managers mostly focus on [HCBS](#) for people with ID/DD. They think about how to get services that will best support the wants and needs of people with ID/DD. Case managers think about every part of life important to a person with ID/DD – their home, employment, family, health and more. Even though case managers are supposed to focus on both health care and [HCBS](#), in many states, case managers do not spend as much time on medical issues. This makes it harder for people with ID/DD to make sure all of their different needs are met.

[Case management](#) is different in every state, but all case managers must use [person-centered](#) planning. This means that case managers must focus on the wants and needs of the person with ID/DD that they are helping. Case managers help people set goals for the life they want and help them find ways to meet those goals. States and case managers have different ways to do [person-centered](#) planning.

For more information and sources, see pages 19-20 of 'Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences'.



Long-term services and supports for people with ID/DD are now more in the community and more individualized than before.

Most people with ID/DD live in the community in their own homes or with their families. Many people with ID/DD want to receive supports and services where they live their daily lives like in their homes, schools, workplaces, or other places in the community. Most people with ID/DD do not want services in separate places only for people with ID/DD like [group homes](#), day centers, or sheltered workshops.

People interviewed for this report said that many [group homes](#) feel like [institutions](#), not homes. The Centers for Medicare and Medicaid Services has made a rule to try to fix this. The rule says that states must provide [HCBS](#) in ways that help people with ID/DD be part of the broader community, and that also protects their rights and freedom to make their own choices. States are working hard to follow this rule but there are still more changes needed.

Sometimes people end up living in group homes because it can be hard for people with ID/DD to find housing in the community. Many options are too expensive or are not accessible. Some states are working on ways to help people with ID/DD find houses or apartments that are not run by provider agencies. This gives people with ID/DD more choices about who they live with and who provides services, instead of just focusing on the place. For example, [Shared Living](#) or [Supported Living](#).

[Shared Living](#) means that a person with ID/DD lives with a family who supports them in daily activities and treats them like a family member. Another type of [HCBS](#) is [Supported Living](#). [Supported Living](#) means that a person with ID/DD receives [HCBS](#) in their own home, sometimes with the provider living in the person's home. There is a need for more of these options.

[HCBS](#) also support people with ID/DD during the day and with jobs. There are a lot of people with ID/DD who want to work in regular jobs in the community, but not many do. Most people with ID/DD still work in places that only employ people with ID/DD or spend their day being supported to do non-work activities.



Figure 2. The two black people represents the 2 out of every 10 adults with ID/DD receive employment services to work in a regular job along with people without disabilities. The eight grey people represent the 8 out of every 10 adults with ID/DD who do not work in a regular job along with people without

[Self-directed services](#) are another important option to help people with ID/DD make their own choices about how they will be supported. Having [self-directed services](#) means that a person with ID/DD chooses who gives them support or how to spend their [service budget](#). [Self-directed services](#) work best when states help people with ID/DD learn how to make these choices and keep the paperwork and rules simple. Research shows that most people who use [self-directed services](#) are happy with their services and enjoy their lives.

It is important to make sure that the rights and wants of people with ID/DD who need support are respected and honored. One way to make this happen is by using [Supported Decision-Making](#). [Supported Decision-Making](#) is when friends, family, or other trusted people help a person with ID/DD understand and communicate their choices. It gives people with ID/DD more power to make their own decisions than [guardianship](#). Research shows people under [guardianship](#) are less likely to have a job and more likely to live in a [group home](#) or [institution](#).

Technology also helps people with ID/DD live and work in the community and make their own decisions. People use different kinds of technology for many different reasons, like communicating, organizing, or connecting with others and building friendships. In many states, people with ID/DD also use technology to receive support from [direct support professionals](#) that are not in the same place as them. More and more people are using this mix of technology and human support, and it can give people more independence.

For more information and sources, see pages 20-27 of 'Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences'.



Families are an important part of supports for many people with ID/DD.

Research shows that family members have many different experiences, both good and bad, in supporting their family members with ID/DD.

Families often come up with creative ways to find solutions to support their family members with ID/DD be a part of the community and have a good life.

States are finding ways to help families to be good at providing [person-centered](#) supports for their family members with ID/DD. States offer services for family members such as family education and training, and connecting families to each other.

More and more states are letting family members of people with ID/DD be paid for support services. This can cause problems if family members do not respect the wants of the person with ID/DD. States must have good rules to avoid these problems.

Some people with ID/DD live with elderly family members who need [long-term services and supports](#), too. States are thinking about how to best support these families in a way that meets everyone's needs.

Brothers and sisters have the longest relationships with their siblings with ID/DD. Many brothers and sisters will help support their siblings with ID/DD after their parents die. But brothers and sisters are not often included in the life planning for their siblings with disabilities, which means families can miss good ideas or thoughts.

For more information and sources, see pages 27-29 of 'Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences'.



Direct Support Professionals (DSPs) working with people with ID/DD are very important, but there are lots of problems with how they are paid and treated.

[Direct Support Professionals \(DSPs\)](#) are people who work closely with people with ID/DD to help and support them to live their best lives. [DSPs](#) must be good at many difficult skills to be good at their jobs. They must be able to listen and be respectful of the person with ID/DD that they support. Being a [DSP](#) is different than being a helper who just does personal care. [DSPs](#) provide services that require lots of training and hard work.

Many [DSPs](#) do not stay in the job for a long time for a few different reasons. One is that they are not paid well for all of the hard work they do.

It is important that we find a way to keep [DSPs](#) in their jobs so that they can better support people with ID/DD. It can be frustrating, stressful, or even harmful for people with ID/DD when the [DSPs](#) who support them change all the time.

Many people agree that [DSPs](#) deserve more money, job benefits, and respect, but do not know how to make those things happen. One possible solution is to make the job of [DSPs](#) more like a career that people need to go to school for and do trainings for. Many states and organizations that represent [DSPs](#) are working on solutions.

For more information and sources, see pages 29-31 of 'Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences'.



It can be hard for people with ID/DD to find doctors who work well with them.

Many people with ID/DD say that it is hard to find doctors who take enough time to understand their health wants and needs. Many young adults with ID/DD stay with their childhood doctor as adults because it is too hard to find a new, adult doctor.

Doctors, dentists, and other workers in healthcare need more training and information about people with ID/DD. One change that could help is to have people with ID/DD give trainings to healthcare workers. For example, the [Leadership Education in Neurodevelopmental and Related Disabilities \(LEND\)](#) programs do this kind of training. Another solution could be to include people with ID/DD in a government program called Medically Underserved Populations. This would mean that healthcare workers could get more training and resources on how to work with people with ID/DD.

For more information and sources, see page 31 of 'Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences'.



Behavior supports and mental health supports are important for people with ID/DD.

Many people with ID/DD need support to learn how to stay calm and communicate their needs when they feel stressed or upset. Bad things can happen when people with ID/DD cannot get good, helpful behavior supports. For example, sometimes a person with ID/DD or someone near them can get hurt if the person with ID/DD does not have help to feel calm. Another example is that sometimes people with ID/DD are given medicine to calm down even if they do not want it.

Good mental health is important for all people, including people with ID/DD. When people with ID/DD have a mental health problem, they are more likely to live in [institutions](#) separate from the community and to have physical health problems like high blood pressure or diabetes. Sometimes people with ID/DD have to go to the hospital for help because they cannot get the mental health care they need in the community.

It is important that more mental health providers understand how to work with people with ID/DD so people with ID/DD can stay in the community. In many states, people with ID/DD can get special behavior and mental health supports through [HCBS](#) programs. Some states are working to help all mental health providers understand how to work with people with ID/DD. Some states are trying to get different kinds of providers to work together as a team.

For more information and sources, see pages 32-33 of 'Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences'.



More information and research are needed to better meet the wants and needs of people with ID/DD.

The government and healthcare systems need to do a better job keeping track of information about people with ID/DD. Much of the information is hard to understand or not complete. Sometimes states or providers do not have the technology they need to keep track of all of the information. Another problem is that information about [HCBS](#) is kept in different computer systems than information about medical care, in many states. This makes it hard to find problems and fix them. It also makes it hard to understand how people with ID/DD are receiving services across the whole country.

Some people with ID/DD do not like or trust the tools and tests used to decide which services people may need. Sometimes people with ID/DD have to use a lawsuit to get Medicaid services and supports they need.

States are trying to find better ways to measure how good or bad their [HCBS](#) are, so they can make their systems better. Not everyone agrees on the best way to do this. One system that almost all states use is called the National Core Indicators, which helps states understand what people with ID/DD think about their supports. The Centers for Medicare & Medicaid Services is working on making [HCBS](#) better, too. They are trying to make it better by asking people for ideas about how to measure whether services are good or bad.

Some states are trying to improve [HCBS](#) by paying providers more money if they give better services. For example, some states' employment service providers are paid more money if the employee with ID/DD feels supported at work and is successful at their job, staying in the same job for a long time, and working more hours.

For more information and sources, see pages 33-36 of 'Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences'.

Looking Ahead

This section of the plain language version shares ideas of the report authors on how to make Medicaid services and supports better for people with intellectual and developmental disabilities (ID/DD).

1. More research and information about the health of people with ID/DD would help [policymakers](#) better understand and support the best programs and services for people with ID/DD.
2. Making sure that federal rules support a person with ID/DD's [quality](#) of life, individual choices, and goals, and is not just about filling out paperwork.
3. More research needs to be done on better ways and tools to understand what supports a person with ID/DD needs in their everyday lives, so that states can fairly decide the level of support people should receive.
4. Because most people with ID/DD are living with families, paying attention to both the needs of the people with ID/DD living with families, and the needs of other family members, would be helpful.
5. Many adults with ID/DD would find [Supported Decision-Making](#), where they are supported in making their own decisions, to be helpful, such as when planning and making choices about their supports and services.
6. As states try different things, more research is needed on the best ways to address the [Direct Support Professionals \(DSPs\)](#) workforce issues like pay, skills, qualifications, and abilities.
7. People with ID/DD would benefit from teams of health care, mental health and [Home- and Community-based Services \(HCBS\)](#) providers working together to provide support.
8. In this year of [COVID-19](#) and protests about [racial](#) unfairness, it has become clear that systems that support people with ID/DD need to do more to make sure that services are provided in a way that respects and includes everyone.

For more information and sources, see pages 36-37 of 'Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences'.

Impact of COVID-19

This section of the plain language version talks about how the [COVID-19](#) crisis has changed the lives of people with intellectual and/or developmental disabilities (ID/DD). The original report was mostly finished before the [COVID-19](#) crisis started in March 2020. That means that the report authors did not have research on [COVID-19](#) and the people interviewed did not talk about [COVID-19](#). This section of the report was added at the end of 2020 because of how much [COVID-19](#) has affected supports and services for people with ID/DD.



Information about the number of people with ID/DD who have been infected with [COVID-19](#) has not been made public in all states. States are having a hard time keeping track of people with ID/DD who have or had [COVID-19](#). This makes it hard to know how many people with ID/DD have or have had [COVID-19](#).

Research is showing that people with ID/DD who get [COVID-19](#) are more likely to be very sick or die.

People of color with ID/DD have more health issues when [race](#), being poor and having a disability all come together. This makes [COVID-19](#) even more dangerous for those people. It is also more dangerous for people with ID/DD living with other people like in a [group home](#) or nursing home where it is hard to social distance 6 feet apart.

People with ID/DD are having a hard time with physical distancing rules and are experiencing loneliness. States and providers have tried to help by using technology and checking in with people more often by phone and video chats.



Providing services for people with ID/DD during the [pandemic](#) has been hard. [Direct Support Professionals \(DSPs\)](#) need [personal protective equipment \(PPE\)](#) and have had a hard time getting it.

Hospitals and residential homes (like nursing homes and [group homes](#)) made decisions to stop visitors from seeing people. Guidance from federal agencies has encouraged these places to allow supports and visitors for people with disabilities but it is not clear that residential homes for people with ID/DD are following this advice.

Some states have made policies about health care treatment that are not fair to people with disabilities. People with ID/DD, their families, and advocates have had to file complaints to fix these policies.



State governments have taken some actions to help support people with ID/DD during the [COVID-19](#) crisis. Some states are making it easier for more people to act as service providers, including paying family members. This helps people with ID/DD continue to get their regular services. Some states are paying providers to stay in business even when they are not able to deliver services to people with ID/DD.

Many states are using [telehealth](#) and computers to deliver both medical care and [Home- and Community-based Services \(HCBS\)](#). Providers can follow up with people with ID/DD by phone or video chat so that they can continue to provide employment support and other services.

Many people with disabilities do not have access to all the technology they might need right now. They may not have fast enough internet or not have the computers they need, or know how to use them. Some states are working to provide more access to technology for people with ID/DD and the training to use them.

Many of these changes were supposed to be short-term just for during the [pandemic](#). However, states are now thinking about which changes should be made permanent because they have worked well.

For more information and sources, see pages 37-39 of 'Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences'.

Definitions

This section includes important words from this plain language version of the report and what the words mean. Words are listed in alphabetical order.

Case management: Services that help people living in a community setting or moving to a community setting get the medical, social, education, and other services they need (sometimes called “service coordination” or “support coordination”)

Contract: a legal agreement between two or more people, companies, or organizations



COVID-19: Also known as coronavirus or COVID, it is a new virus making people sick all over the world

Culture: The way of life shared by a group of people; things such as their language, music, religion, art, and more

Direct Support Professionals (DSPs): People whose job is to provide help and support people with disabilities live their best lives. They can provide support for transportation, personal care, housing, home care, community integration and more

Ethnicity: A group of people who share their own culture, history, language, religion, or set of traditions



Federal government: The elected officials and government workers who make laws and decisions about how to spend money and run the government for the entire United States

Group home: A place where 2 or more people with intellectual and/or developmental disabilities live together and receive support services. Some group homes are part of a community, but some are more like institutions that separate people with ID/DD from the community



Guardianship: When a court decides that a person cannot make their own decisions, the court will appoint someone (a guardian) who has the right to make the decisions for them

Home and Community Based Services (HCBS): Supports and services to help people with disabilities live their everyday lives in their communities

Institution: A place where many people with disabilities live together and receive all of their supports and services where they live. It is not living in the community

Leadership Education in Neurodevelopmental and Related Disabilities programs (LENDs): programs at universities that teach people from all different jobs and backgrounds how to be leaders that support and think about people with disabilities. These programs are paid for by the [federal government](#) and are located all over the United States



Life Course: Describes how people and their needs change over time, from children to teenagers to adults to elderly people

Long-term Supports and Services (LTSS): Services that help disabled people live everyday lives. Some examples of LTSS are job coaches, transportation, and personal care assistants that help you do things in your house

Medicaid: A program from both the federal and state governments that helps people with healthcare costs who cannot afford healthcare on their own



Managed Care: A system where a state has a contract with an insurance company or another kind of organization to manage parts of their Medicaid program. It can also be called a “managed care organization”



Pandemic: An outbreak of a disease that spreads among many people over a wide area



Personal Protection Equipment (PPE): Protective clothing, including gloves, goggles, and masks, that protect a person from infection

Person-centered: a focus on the wants and needs of the individual with ID/DD when planning and providing supports and services

Policymakers: People, usually in state and federal government, who make decisions about policy

Quality: How good or how bad something is

Race: A way we talk about groups of people based on how they look or their family history

Self-determination: People choosing and setting their own goals, making life decisions, self-advocating, and working to reach their goals

Self-directed services (or self-direction): System where the person with a disability decides what services they need and who they want to hire to provide those services



Service budget: The amount of money from Medicaid that a person with ID/DD has to spend on their supports and services

Shared Living: When a person with ID/DD lives with a family that is not their own who supports them in daily activities and treats them like a family member



State government: The elected officials and government workers in a state who make laws and decisions about how to spend money and run the state



Supported Decision-Making: Having supports in place to help people make their own decisions, which could be in all decisions or only some decisions, such as for healthcare, finances, or employment, as decided by the person

Supported Living: When a person with ID/DD receives [Home and Community Based Services \(HCBS\)](#) in their own home



Telehealth: Receiving health care services virtually by technology instead of in-person. For example, having doctors' appointments, mental health appointments, or employment services over Zoom or other video chat programs