

*Plain Language Version*

# **Beyond Coercion and Institutionalization: People with Intellectual and Developmental Disabilities and the Need for Improved Behavior Support Services**

**Part 6: What Changes  
We Want to See in  
Behavior Support Services**

# Words to Know in Part 6

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## **988 Lifeline**

A group of mental health crisis service providers people can reach by calling or texting 988. The 988 Lifeline will send the call or text to a local mental health crisis service who can help the person.

## **Applied behavior analysis (ABA)**

A type of behavior support service that is mostly used on autistic children, but can be used on other people with IDD. ABA focuses on making people act “less autistic” by changing the way people behave.

## **Augmentative and alternative communication (AAC)**

Ways of communicating other than speaking with your mouth or using a sign language. AAC includes things like writing, pointing to letters and words, or typing words on a computer.

## **Behavior**

The different ways people act and respond to their feelings and the world around them.

## **Behavior support services**

Services that help people deal with behavior that makes it hard for them to live the lives they want.

## **Behaviorism**

A way of thinking about human behavior that says we should only think about the behavior we can see. Behaviorism focuses on changing a person's behavior but not on the person's thoughts or feelings. ABA is part of behaviorism.

## **Block treatment**

When a group of people with disabilities all get the same services, even if they have different needs and wants.

## **Burnout**

When someone feels really tired and like they cannot focus on their job because their job is so stressful.

## **Centers for Medicare and Medicaid Services (CMS)**

The part of the U.S. government that runs Medicaid on the national level. CMS makes rules that all state Medicaid programs have to follow.

## **Challenging behavior**

A term some people use to talk about behavior that makes it hard for a person to live the life they want.

## **Coercion**

Trying to change someone's behavior, even if that person does not want to change their behavior.

## **Communication**

The different ways people tell each other information and ideas.

## **Community**

A place where you can make choices about your own life.

Communities can be places like neighborhoods, towns, or cities.

## **Community living**

When people with disabilities live in the same places as people without disabilities.

## **COVID-19**

A bad disease that has spread around the world and made a lot of people very sick. COVID-19 has made it hard for people with disabilities to get good services.

## **Crisis respites**

Houses or apartments where people can stay for a few days until a mental health crisis has passed. Crisis respites often have services like support workers or therapy groups.

## **Data**

Facts and information about something.

## **Dual diagnosis**

When someone has both an IDD and a mental health disability.

## **Guardian**

The person a court chooses to make choices for a person under guardianship.

## **Guardianship**

When a court takes away a person with a disability's right to make choices for themselves. The court says another person can make choices for the person with a disability.

## **HCBS Settings Rule**

A rule the U.S. government made. The HCBS Settings Rule says people getting HCBS have rights like the right to respect and privacy, the right to live in the community, and the right to make choices about services.

## **Home and community based services (HCBS)**

LTSS someone gets in their home or in the community.

## **Institution**

A place where a lot of people with disabilities live. People in institutions usually did not decide to live there. They were put there by someone else. Institutions are not run by the people who live in them. Institutions are run by the people who work in them.

## **Interviewing**

Talking to people about a specific topic they know a lot about to learn more about the topic.

## **Long-term services and supports (LTSS)**

Services that help people with disabilities live our everyday lives, such as support workers, transportation, or job coaches.

## **Medicaid**

A health care program run by state governments. Medicaid helps people get health care if they have a disability or don't have a lot of money.

## **Medically underserved population**

A group of people who do not have enough access to health care.

## **Mental health crisis**

When a person is having thoughts or feelings that hurt them that they cannot control. During a mental health crisis, a person might try to hurt themselves or others.

## **Mental health crisis services**

Services that are supposed to help people who are dealing with emotions or behavior that hurt them that they cannot control.

## **Mental health disabilities**

Disabilities that change how people think and feel. Mental health disabilities can make it hard for people to feel in control of their emotions.

## **Mental health services**

Services that help people with mental health disabilities deal with their emotions and live in the community.

## **Mental health therapy**

Talking to a mental health doctor about your emotions and thoughts.

## **Occupational therapy**

A service that helps people learn and practice skills they need in their everyday lives.

## ***Olmstead v L.C.***

A Supreme Court case that said people with disabilities in the United States have the right to live and get services in the community.

## **Operant conditioning**

Changing someone's behavior using rewards and punishments.



## **Person-centered planning**

A way of figuring out what services might help a person live the life they want to live. Person-centered planning asks about a person's needs, wants, hopes, and goals. Then, the person-centered planning team figures out services might help the person get those things.

## **Prevent**

When you prevent something, you stop it from happening in the first place.

## **Primary care doctor**

A doctor you see for regular, general health care, like getting shots or when you have the flu.

## **Provider-owned settings**

When the HCBS provider owns the place people get HCBS in.

## **Providers**

People or places that give people with disabilities health care or services, like doctors or in-home services.

## **Punishment**

Something a person gets for having "bad behavior."

## **Research**

A way people learn new things about the world. When people do research, they collect information about a topic, use that information to answer questions on the topic, and share what they learned with others.

## **Researchers**

People who do research as their jobs.

## **Restraint**

Stopping someone from moving by holding them down, tying them up, or making them take medication to make them tired.

## **Reward**

Something a person gets for having “good behavior.”

## **Seclusion**

Locking someone in an empty room.

## **Secondary trauma**

When someone has trauma from seeing someone else go through a really stressful experience

## **Self-direction**

An option that some people who get HCBS through a waiver use. Self-direction lets a person design and run the HCBS they get.

## **Speech therapy**

A service that helps people learn and practice ways of communicating that work for them.

## **Support workers**

People whose job it is to help people with IDD in our homes and in the community. Support workers are sometimes called direct support professionals.

## **Trauma**

Changes in how a person thinks, feels, and behaves because of a scary situation they went through.

## **Trauma-informed care**

A way to provide services to people with trauma. Trauma-informed care focuses on not making people's trauma worse. Trauma-informed care helps people work through their trauma.

## **Voluntary**

When the person getting services chooses to get the services.  
If the person is forced or coerced into getting services, the services are not voluntary.

## **Waivers**

Medicaid programs that let someone get HCBS instead of getting services in an institution.

# What Changes We Want to See in Behavior Support Services

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We have talked a lot about the problems with **behavior support services** right now. We think there are ways to fix these problems. Service **providers**, state governments, and the U.S. government can all make changes to fix these problems. In this part, we talk about the following changes we want to see in behavior support services:

- **Mental health services** and IDD services should be together, not separate.
- There should be more support for **support workers** and other people who help people with IDD.
- **HCBS** and behavior support services should be more person-centered.
- There should be better ways to **prevent mental health crises** and respond to these crises when they happen.
- The U.S. and state governments should learn more about what kinds of services people can get on **waivers**.

We will talk about each of these changes in more detail.

Note: In this part, we use the term “IDD service providers” a lot. By “IDD service providers,” we mean groups that provide HCBS to people with IDD.

## *Mental health services and IDD services should be together, not separate.*

The first change that we want to see in behavior support services is to bring IDD services and mental health services closer together. Right now, mental health services and IDD services are very far apart. These services are usually provided by different kinds of providers. These services are usually overseen by different parts of state governments. These services are usually paid for by different parts of **Medicaid** (or other health insurance). That makes it very hard for people with IDD to get both IDD services and mental health services.

For example:

Arjun has an intellectual disability. He also has a **mental health disability** called schizoaffective disorder. Arjun should be able to get both IDD services and mental health services in his state. But Arjun's state makes it very hard for him to get both kinds of services.

Arjun applies for both IDD and mental health services. But Arjun's state says he can only get IDD services or mental health services, but not both. Arjun tries applying for IDD services. But the IDD services tell Arjun, "You have a mental health disability, so we cannot help you. You should apply for mental health services."

So Arjun applies for mental health services. But the mental health services tell Arjun, "You have an intellectual disability, so we cannot help you. You should apply for IDD services."

Arjun should be able to get both kinds of services! But because the services in his state do not talk to each other, he cannot get either.

ASAN wants service providers, state governments, and the U.S. government to work together to fix this. We want IDD service providers to work with mental health service providers to make sure people with IDD can get both kinds of services. We want the U.S. and state governments to get rid of rules and policies that keep IDD services and mental health services so separate.

**Service providers should make it easier for people to get both mental health services and IDD services.**

IDD service providers need to make sure people with IDD who get services can get both IDD services and mental health services. IDD service providers need to make sure people with IDD can get different kinds of mental health services, not just mental health crisis services.

IDD service providers also need to change how they run their own services. IDD service providers need to include more services that help people with IDD have good mental health. IDD service providers also need to include more services that help people with IDD deal with trauma. (Trauma is when a scary situation changes how a person thinks, feels, and behaves.)

IDD service providers need to look at all their different services and policies for services. The providers need to look for services and policies that might cause trauma for people with IDD. Then, the providers need to change or get rid of those services or policies.

IDD service providers need to have more training for the support workers and other people who work for them. This includes having training on respecting people with IDD and treating us as people first.

IDD service providers also need to make sure their services and policies let people with IDD make choices about our own services. Part of this means service providers need to stop using **provider-owned settings** that give everyone the same services, such as group homes. Providers need to start using services that meet the needs of each person they serve.

IDD service providers need to work closely with mental health service providers. This is for 2 reasons:

- Working together helps mental health service providers learn how to care for people with IDD.
- Working together helps IDD service providers learn how to support mental health for people with IDD.

Right now, most mental health service providers do not know how to care for people with IDD. Right now, most IDD service providers do not know how to give good mental health support to people with IDD. If IDD service providers and mental health service providers work together, they can learn from each other. This will help both kinds of providers give people with IDD better services.

## States should change how they control mental health services and IDD services to make them less separate.

State governments need to make sure their policies and rules do not keep mental health and IDD services separate. To do this, state governments should look at the different IDD services and mental health services in the states.

State governments should look at policies and rules around services. They should look for policies and rules that make it hard for people with IDD to get mental health services. Then, states should rewrite these policies and rules to make it easier for people with IDD to get mental health services.

The U.S. government says that state governments need to make sure that people with disabilities can get services in the community. The U.S. government says this in:

- The ***Olmstead*** court case.
- The **HCBS Settings Rule**.



State governments need to make sure they follow *Olmstead* and the HCBS Settings Rule. State governments need to make sure that HCBS providers in their states follow the HCBS Settings Rule. When a state government is not following *Olmstead* or the HCBS Settings Rule, they need to fix this right away. When a HCBS provider is not following the HCBS Settings Rule, the state government needs to make sure the provider fixes this right away.

*Olmstead* and the HCBS Settings Rule give people with disabilities certain rights. State governments need to make sure there are ways for people with disabilities to report if a provider does not let us have our rights.

State governments also need to make sure that people with IDD can get good mental health services. State governments need to make sure that people with IDD do not just get behaviorist services. If there are not good mental health services for people with IDD in a state, the state should work to make these services. States should work together to make good mental health services for people with IDD.

State governments need to make sure that any new services are voluntary and in the community. **Voluntary** means the person getting services chooses to get the services. If someone forces or coerces the person into getting services, the services are not voluntary. Services also need to be in the community, not in institutions.

For example:

Let's say California decides to open new community centers for people with mental health disabilities. People can go to the community centers for things like:

- Talking to a therapist or social worker.
- Getting help with applying for or managing services.
- Going to a class or support group.

California wants to make sure the community centers are voluntary. So California decides that anyone who wants to go to a community center has to meet with a social worker. The social worker will make sure the person wants to join the center. California makes a rule that **guardians** and the court system cannot force people to go to a community center.

States governments also need to make sure that people with IDD help design new mental health services for people with IDD. People with IDD know what kinds of mental health services will help us the most. Remember: nothing about us, without us!

The U.S. government should make it easier for states to combine mental health services and IDD services.

The U.S. government needs to help states combine their IDD services and mental health services. Part of this means making sure state governments and providers follow laws and rules around health care access. The U.S. government must make sure state governments and providers follow rules that help people with disabilities get good health care. These rules talk about how state governments and providers cannot treat people with disabilities differently because we have disabilities. Some of these rules are:

- Section 1557 of the Affordable Care Act.

Section 1557 says that health care providers cannot treat people worse because they have a disability.

- Section 504 of the Rehabilitation Act.

Section 504 says that groups that get money from the government cannot treat people worse because they have a disability. Most health care providers get money from the government through Medicaid or another program called Medicare.

The U.S. government needs to use these rules to help people with IDD get good mental health services.

The U.S. government also needs to change how it gives money to states to make sure people with IDD can get good mental health services. The U.S. government should give more money to states that combine mental health and IDD services. Some states are working very hard to make sure people with IDD can get good mental health services. The U.S. government should talk about what these states are doing.

The U.S. government should show other states how they can make mental health services for people with IDD better. The U.S. government should especially focus on mental health services that people with IDD or mental health disabilities helped create.

But the U.S. government needs to make sure that these programs are voluntary for people with IDD or mental health disabilities. The U.S. government cannot say that people with disabilities need to get mental health services in order to get other services, like support workers. People with IDD have the right to say no to services, even when other people disagree with us. People with mental health disabilities have the right to say no to services, even when other people disagree with them.

The U.S. government also must make sure that training for mental health providers focuses more on people with IDD. Training for mental health providers can include things like:

- Medical school for doctors and nurses that work in mental health.
- College and graduate school for therapists and counselors.
- Internships where mental health providers learn by actually working in a mental health clinic.

Right now, these training programs do not talk a lot about people with IDD. The U.S. government must make sure these training programs talk more about caring for people with IDD.

The U.S. government also needs to say that people with IDD are a medically underserved population. **“Medically underserved population”** means a group of people who do not have enough access to health care. Some medically underserved populations are:

- People who are homeless.
- People who do not have a lot of money.
- Indigenous people.

If the U.S. government said that people with IDD were a medically underserved population, it would mean:

- There would be more money for health care for people with IDD.
- There would be more training for providers who want to work with people with IDD.
- There would be more money for research on how to make health care for people with IDD better.

## *More support for support workers and other people who help people with IDD.*

The second change that we want to see in behavior support services is more money and training for support workers. Right now, support workers are not paid well at all. Most support workers do not get enough training on how best to help people with IDD. Support workers' jobs can be hard and stressful. Many support workers have quit their jobs because they are doing very stressful work for not a lot of money.

When there are not enough support workers, it is hard for HCBS providers to give good services to everyone who needs them. When there are not enough support workers, HCBS providers are more likely to use things like **restraint** and **seclusion**. When support workers do not stay at their jobs for very long, HCBS providers are less likely to offer good training for support workers.

All of this has bad effects on people with IDD. It means we cannot get the services we need. It means we have to wait a long time to get services. It means we are more likely to end up in institutions and places that look like institutions.

ASAN wants service providers, state governments, and the U.S. government to work together to fix this. We want service providers to improve training for support workers. We want state governments to spend more money on HCBS, especially on paying support workers.

## Service providers should give support workers more training on mental health needs and trauma-informed care.

IDD service providers need to give support workers training on how to provide good behavior support services. This includes everyday mental health supports, like checking in on how people are feeling. IDD service providers need to make sure that behavior support services actually focus on the person's own goals. IDD service providers need to make sure that behavior support services do not use restraint and seclusion or **coercion**.

IDD service providers also need to make sure their support workers understand things like:

- How to respect people with IDD and treat us well.
- How to follow laws and rules, like the HCBS Settings Rule.
- How to do trauma-informed care.

**Trauma-informed care** is a way to provide services to people with trauma. Trauma-informed care focuses on not making people's trauma worse. Trauma-informed care helps people work through their trauma.

For example:

Caring Hearts, Inc. is an IDD service provider. Caring Hearts, Inc. wants to use more trauma-informed care in their services. So Caring Hearts, Inc. looks for ways to change their services. They look for ways to give people with IDD more chances to take a break when they get services. They look for ways to give people with IDD more options about the services they get. They look for ways to make sure people with IDD always have a way to tell a support worker or therapist "stop!" or "I do not like that!" All of these things help people with IDD who have been through trauma.

When IDD service providers design trainings for support workers, they need to work with different groups of people. IDD service providers need to work with:

- People with IDD.
- Mental health service providers.
- Support workers.
- **Researchers** who study IDD services.

IDD service providers also need to support the mental health of support workers and other staff. Support workers' jobs are often very hard. Support workers often deal with secondary trauma and burnout. The chance that a support worker will end up with secondary trauma and burnout gets bigger the longer they work.

IDD service providers can support the mental health of support workers in a few ways. IDD service providers can set up ways for support workers to talk about how their jobs are going. IDD service providers can offer health insurance and other ways to pay for **mental health therapy** to support workers. IDD service providers can make sure support workers get paid time off work for vacations or sick days.

All of these things will make support workers' mental health better. All of these things will help support workers give better services to people with IDD.

## States should put more money aside for HCBS, especially for support workers.

State governments need to spend more money on HCBS. A lot of this money needs to go to raising pay for support workers. Remember, most support workers do not earn a lot of money. State governments can raise pay for support workers by giving HCBS providers more money.

State governments can require that HCBS providers put a certain amount of the money towards raising pay for support workers. States can also raise support worker pay in other ways. For example, a state could send money directly to support workers who have been at their jobs for at least 1 year.

State governments need to also make training on mental health support better for support workers. States can do this in a few ways. States can give more money to HCBS providers and say the money can only be used for training. States can set up training people have to complete before they can become a support worker. (This is similar to how training for nursing assistants in hospitals works.) States can also design new trainings for HCBS providers to give support workers. That way, support workers will all get the same training, no matter which HCBS provider they work for.

For example:

The National Alliance for Direct Support Professionals (NADSP) is a group that advocates for the needs of support workers. The NADSP has made a list of skills they think all support workers need to have. The NADSP calls these skills “competency areas.”

States can work with the NADSP to create trainings that focus on the competency areas. That way, states can make sure all support workers are getting trained on the same skills.



Finally, state governments need to make sure that HCBS providers report how often they use things like restraint and seclusion. The state governments need to look at how often providers use restraint and seclusion. The state governments need to work with providers to reduce how often providers use restraint and seclusion. The state governments also need to report how often providers are using restraint and seclusion to the U.S. government.

## The U.S. government should give states more money for HCBS and make sure states follow rules about HCBS.

The U.S. government must give states more money for HCBS. Right now, there is not enough money for everyone who needs HCBS to get HCBS. That means people in different states might receive very different HCBS, even if they have the same needs. If the U.S. government gave states more money for HCBS, all states could spend more money on HCBS. That would mean that more people could get good HCBS no matter where they live.

The U.S. government must also make sure that more money for HCBS goes towards paying support workers. The U.S. government should work with state governments to make sure support workers are paid enough for their work.

The U.S. government needs to make sure that states have the money to collect and report data. **Data** is facts or information about something. In this case, states need to collect and report data about what kinds of services providers are using. States need to collect and report data about which providers are using restraint and seclusion. States need to report this data to the U.S. government.

It takes money to design and run good data collection systems. It takes money to pay people to collect data and figure out what the data means. So the U.S. government needs to give states more money to collect and report this data.

The U.S. government also needs to make sure the Centers for Medicare & Medicaid Services (CMS) has enough money to collect data. **CMS** is the part of the U.S. government that runs Medicaid on the U.S. level. CMS makes rules that all state Medicaid programs have to follow. CMS collects data from states to make sure states and providers are following CMS's rules.

CMS needs more money to make sure states are following the rules around reporting data. CMS also needs more money to help states when states do not report the data they need to report.

## *Making HCBS and behavior support services more person-centered.*

Most HCBS providers say all the people they support have their own person-centered plans. Remember, **person-centered planning** is a way of figuring out what services might help a person live the life they want to live.

A person-centered plan is supposed to talk about a person's hopes, goals, and wants as well as the person's needs. But often, person-centered plans do not do this. Often, person-centered plans only talk about what a person needs help with.

Part of the person-centered planning process is supposed to be designing or changing services to work for the person.

For example:

Mickie has a disability. She cannot drive. Mickie needs transportation services to help her get around in the community. Mickie's person-centered planning team is meeting. The team is talking about how Mickie could use paratransit services. Paratransit services require Mickie to schedule rides 3 days in advance. Mickie does not want to paratransit services. She does not want to schedule rides 3 days in advance.

So Mickie's team talks about different options for transportation. Mickie's team decides that Mickie can take taxi cabs to get around the community. Mickie's waiver will pay the cost of the cabs. Mickie's team figured out a way to make transportation services work for Mickie.

But in a lot of cases, people who get HCBS do not get services that are designed or changed to meet their needs. This is sometimes called “block treatment.” **Block treatment** is when a group of people with disabilities all get the same services, even if they have different needs and wants.

For example:

In Part 5, we talked about Viola. Viola lives in a group home. Viola’s group home does not have enough staff. So everyone living in the group home has to do the same activities. If one person in the group home wants to go somewhere, everyone in the group home has to go there. Viola and her housemates do not get to choose where they go most of the time. This is an example of block treatment.

ASAN wants service providers, state governments, and the U.S. government to work together to fix these problems with person-centered planning. We want service providers to give their staff better training and to give people with IDD more choices. We want state governments to make sure service providers follow the HCBS Settings Rule and other rules around HCBS. We want the U.S. government to make sure states follow the HCBS Settings Rule and give people with IDD more chances for **self-direction**.

## Service providers should support person-centered practices through better training and giving people with IDD more choices.

IDD service providers need to make sure people with IDD have actual person-centered plans and services. IDD services providers can do this by:

- Giving support workers and other staff more training on person-centered planning.
- Focusing on the goals people with IDD have for ourselves, not the goals other people have for us.
- Making sure people with IDD have the support we need to create our plans and services.
- Ending restraint, seclusion, and coercion.

IDD service providers need to make sure that person-centered planning focuses on the goals a person with IDD has. IDD service providers should not focus so much on the goals that other people have for the person with IDD.

IDD service providers should make sure that the person with IDD has the support they need to set their own goals. This includes **communication** support. If the person does not already have a way to communicate what they want, IDD service providers should work to get them one. IDD service providers can work with **speech therapists** to do this. IDD service providers can also work with groups that provide assistive technology, like **AAC** devices, to do this.

IDD service providers need to regularly check to make sure a person's plan and services still meet the person's needs and goals. IDD service providers also need to regularly check to make sure a person's plan is still being followed. Person-centered plans can be great tools to help people get services to meet their goals. But even the best person-centered plan is not very helpful if people are not following it.

For example:

Juliana has an intellectual disability. Juliana gets HCBS. Juliana lives with her parents. Juliana is learning to use an AAC device. Juliana's family speaks Spanish and English at home. Juliana's person-centered plan says that she will work with a speech therapist who speaks both English and Spanish. The speech therapist will help Juliana learn to use her AAC device.

But Juliana is not working with a speech therapist who speaks both English and Spanish. Juliana's HCBS provider has not looked for a speech therapist who speaks both English and Spanish. Juliana wants to work with a speech therapist who speaks both English and Spanish. But she cannot because her HCBS provider has not found one.

IDD services providers need to review people's person-centered plans at least once a year. IDD service providers need to also review a person's person-centered plan whenever the person asks them to. IDD service providers need to make sure that people with IDD know how reviewing our person-centered plans works. IDD service providers need to make sure people with IDD know that we should be in charge of making and changing our person-centered plans. IDD service providers need to make sure that staff know how to help people with IDD with our person-centered plans.

Person-centered plans should focus on many different parts of a person's life. Person-centered plan should not just focus on a person's **behavior**. Person-centered plans should especially focus on things like:

- Mental health.
- Sensory needs.
- Good health care in general.

IDD service providers need to make sure that person-centered plans focus on many parts of a person's life. Part of this means IDD service providers need to get rid of **behaviorism** and **ABA** in their services. This includes getting rid of:

- **Operant conditioning.**
- **Rewards** and **punishments.**
- Coercing people into doing things they do not want to do.

IDD service providers also need to make sure that people who get services can get help to deal with trauma from behaviorism and ABA.

IDD service providers must stop using restraint and seclusion. This includes stopping using medication to make someone too tired to move. IDD service providers need to find ways to support people that do not use restraint or seclusion. IDD service providers also need to think about how restraint and seclusion affect people with IDD. IDD service providers need to know that restraint and seclusion can cause a lot of trauma for people with IDD.

IDD service providers need to help people with IDD work through trauma we might have from restraint and seclusion.

States should actually make sure providers follow the HCBS Settings Rule and other rules and laws about HCBS.

State governments must make sure that IDD service providers follow rules and laws about HCBS. State governments also need to make sure that IDD service providers use person-centered practices for their services. State governments also need to make sure that people with IDD and people with mental health disabilities can get good services in the community.

State governments have a lot of power over how IDD service providers use person-centered planning. State governments have this power because they make the rules about HCBS in their states. State governments need to use their power to make sure IDD service providers follow rules and laws around HCBS. State governments need to use their power to make sure IDD service providers use person-centered practices for their services.

To do this, state governments need to make sure their HCBS rules follow U.S. rules for HCBS, like the HCBS Settings Rule. State governments also need to make sure that their HCBS rules include rules around person-centered planning.

If HCBS providers are not following the HCBS Settings Rule or state rules for HCBS, state governments need to talk to those providers. State governments need to make sure the providers are following the rules. Part of this means state governments need to make ways for people to report if a provider does not follow the rules.

States must make sure that people with IDD and people with mental health disabilities can get good services in the community. The *Olmstead* court case said that states need to do this. The HCBS Settings Rule says that states need to do this. States need to get rid of rules and laws that force people with IDD and people with mental health disabilities to get services in institutions. And states need to make sure that there are actual IDD and mental health services in the community.

For example:

A state government might say that people with IDD and people with mental health disabilities can get services in the community. The state government might not have laws requiring people with IDD or mental health disabilities to get services in institutions. But there are no community services for people with IDD or mental health disabilities in the state. People have no choice but to get services in institutions.



It does not matter that the state government says people with IDD or mental health disabilities have the right to services in the community. It does not matter that the state does not have laws that force people with IDD or mental health disabilities into institutions. If there are no community services, people cannot get services in the community.

This is especially important for mental health services. A lot of states still have laws that make it very easy for people with mental health disabilities to get stuck in institutions. And states that do not have these laws often do not have a lot of services in the community for people with mental health disabilities. So people with mental health disabilities get stuck in institutions anyway.

The *Olmstead* court case also applies to people with mental health disabilities. People with mental health disabilities have the same rights as people with other kinds of disabilities. State governments need to make sure that people with mental health disabilities can get good services in the community, too.

State governments need to make sure that people with IDD can self-direct our services if we want to. We should be able to do this no matter what our disability is. We should be able to do this no matter what services we need. Remember, self-direction is when people who get HCBS design and run the services they get. When someone self-directs their services, they tend to:

- Have more control over what services they get (such as choosing what services they need rather than just being assigned to services).
- Be more involved in the services they get (such as being able to hire and fire their support workers without going through an HCBS provider).
- Have more responsibilities around their services (such as having to talk to their case manager and support workers a lot more.)

Most states allow people with IDD to self-direct our services. But most people with IDD who get HCBS do not direct their own services. And most people with IDD who use self-direction do not make all of the choices about their services. Someone else usually makes most of the choices about the person with IDD's services

State governments need to make sure that people with IDD can self-direct our own services. State governments need to make sure that people with IDD are in charge of our own services. State governments need to make sure that people with IDD who live in provider-owned settings can self-direct their own services. State governments need to make sure that people with IDD under guardianship can self-direct their own services.

One way state governments can help people with disabilities have more control over our HCBS is by changing their rules about HCBS.

For example:

In many states, people with disabilities cannot hire our family members as support workers. Family members can include:

- A person's spouse.
- A person's parents.
- A person's children.

During part of **COVID-19**, the U.S. government said states could allow people with disabilities to hire family members as support workers. This was a big help for people with disabilities. It meant we could get support from people who know us well.

Then, the U.S. government changed what it would let states do. The U.S. government said that states could still let people with disabilities hire family members as support workers. But, states would have to change their HCBS rules to do this.

Some states have changed their HCBS rules. These states now let people with disabilities hire family members as support workers. Other states have changed their HCBS rules. These states do not let people with disabilities hire family members as support workers. More states should change their HCBS rules to let people with disabilities hire family members as support workers.

State governments can also support self-direction by making sure all people with IDD have a way to communicate. State governments should make sure that people with IDD can access AAC through Medicaid and waivers.

The U.S. government should make sure states follow rules and laws about HCBS and person-centered practices.

The U.S. government needs to make sure state governments follow the rules and laws around HCBS. The U.S. government also needs to make sure state governments support people with IDD to self-direct our own services.

The U.S. government makes laws and rules around HCBS. This includes the HCBS Settings Rule and the *Olmstead* court case. The U.S. government needs to make sure that state governments follow the HCBS Settings Rule and the *Olmstead* court case. The U.S. government needs to make sure that state governments are making HCBS providers follow the HCBS Settings Rule.

The U.S. government needs to especially focus on whether state governments are working to:

- End the use of restraint and seclusion.
- Make sure people with disabilities can get good services in the community.
- Set up a way for people with disabilities to tell state governments when HCBS providers do not treat us well.

The U.S. government also needs to help state governments make sure people with IDD can self-direct our own services. The U.S. government can do this by:

- Giving states more money for self-directed services.
- Changing U.S. laws and rules to make it easier for states to support self-directed services.
- Helping states solve problems they run into while trying to make self-directed services better.

The U.S. government also needs to make sure that states give people enough support to direct their own HCBS. This can be communication support, like AAC. Or it could be other types of support that help people with IDD be part of person-centered planning.

## *Better ways to prevent mental health crises and respond to mental health crises when they happen.*

Right now, there are a lot of problems with mental health crisis services. **Mental health crisis services** are services that help people who are dealing with **mental health crises**. These services help people dealing with thoughts or feelings that hurt them that they cannot control.

Mental health crisis services are a really important part of behavior support services. But right now, mental health crisis services can cause a lot of trauma for people who need them. Mental health crisis services, especially for people with **dual diagnosis**, often involve the person having to go to an institution. Mental health crisis services often do not actually talk about the reasons *why* the person is in a mental health crisis.

ASAN thinks the current mental health crisis service system needs to be part of a bigger mental health and disability services system. Service providers, states, and the U.S. government all need to be part of this change. IDD service providers can help by improving mental health support and building stronger relationships with health care providers. States can help by making it easier for people with IDD to get good mental health care in the community. This includes mental health crisis services. The U.S. government can help by making sure mental health services and other health care providers treat people with IDD well.

## Service providers should improve mental health services and build stronger relationships with health care providers.

IDD service providers need to improve mental health support and build more and better relationships with health care providers. This needs to include focusing on preventing mental health crises. Service providers should not just focus on responding when a person with IDD has a mental health crisis. This means making sure that people with IDD have good access to health care when we need it. This includes mental health care.

IDD service providers need to focus on **preventing** mental health crises, not just responding to mental health crises. Preventing mental health crises means stopping mental health crises from happening in the first place. Part of this must be treating people with IDD with respect.

People with IDD face a lot of ableism. Ableism is treating someone badly because they have a disability. HCBS providers and staff treat people with IDD very badly sometimes. Our support workers do not always respect us. HCBS providers often do not let us have choices about our services or lives. People often tell us we cannot do the things we want. They do not try to figure out how to help us do those things.

All of these things can hurt people with IDD's mental health. All of these things can make it more likely we will have mental health crises.

IDD service providers can help people with IDD manage our mental health in many ways. IDD service providers can make sure that people with IDD:

- Have access to the community when we want it.
- Control our own services.
- Get good health care, including mental health care.
- Have support to deal with trauma.
- Get support to deal with mental health crises and big emotions when they happen.

IDD service providers need to do all of these things.

IDD service providers also need to develop more and better relationships with health care providers. This includes mental health care providers. IDD service providers need to make sure that people with IDD have access to regular health care. Regular health care can help spot health issues that could lead to crises later on. Regular health care can prevent issues from turning into crises.

States should make it easier for people with IDD to get the care we need, including good mental health crisis services.

State governments need to make it easier for people with IDD to get both regular health care. State governments need to make it easier for people with IDD to get crisis services. Getting regular health care makes it less likely that someone will need crisis services. State governments also need to make sure that mental health crisis services are community-based and do not involve the police.

When people get regular health care, they are less likely to need crisis services. This is true for physical health care. It is also true for mental health care. People who see a primary care doctor are less likely to go to the emergency room for issues that are not emergencies. A **primary care doctor** is a doctor you see for regular, general health care, like getting shots or when you have the flu. People who have good access to mental health care in the community are less likely to be hospitalized for mental health reasons.

State governments need to spend more money on making regular health care accessible to everyone. State governments especially need to spend more money on making regular health care more accessible to:

- People with IDD.
- People with mental health disabilities.

State governments also need to make sure people with disabilities can access good HCBS that are respectful and helpful. HCBS play a big role in making sure people with disabilities can get good health care. Many people with disabilities need support to go to health care appointments. People with disabilities should be able to control our own HCBS. We should get HCBS that are actually in the community. We should get the HCBS we need to make our own choices and live the lives we want. All of these things can help with good mental health.

State governments must make sure that mental health crisis services are actually in the community. A lot of mental health crisis services are not in the community right now. These services only happen in institutions.

Or, mental health crisis services might say they are in the community. The state government might say that the services are in the community. The services might look like they are in the community. But they are really small institutions. People cannot leave the mental health crisis service when they want. They do not have control over their lives in the mental health crisis service.

Mental health services in the community are important for the same reasons IDD services in the community are. If people have to go to an institution to get mental health services, they have to give up a lot of their rights. Sometimes, a person will go to a hospital or other institution to get mental health crisis services. The person only expects to be in the institution for a few days. But then the person gets stuck in the institution for weeks or months or even years!

And, people with IDD who are institutionalized for mental health reasons often cannot return to the community after they leave the institution.



For example:

Karan has an intellectual disability. He lives in his own apartment. He gets support for a few hours every day from a support worker.

Karan starts feeling really nervous all the time. He starts to hear voices that nobody else can hear. Karan goes to the hospital because he is scared he is going to hurt himself. Karan stays in the hospital for two weeks. He gets medications and therapy to help with his mental health.

Karan feels ready to move back into his apartment. But when he is getting ready to leave the hospital, the hospital social worker says he cannot go back to his apartment. The social worker tells Karan that he has to live in a group home instead. The social worker says Karan “needs more help than he can get” in his apartment. The social worker does not listen when Karan says he does not need more help.

When people have to go to an institution to get mental health services, it takes them out of their communities. People can lose important skills for community living while they are institutionalized. And, being institutionalized is not fun. Being institutionalized often causes trauma. For all these reasons, state governments need to make sure that people have access to mental health services in the community.

State governments also need to support mental health crisis services that do not involve the police. State governments need to work with cities and towns to create local mental health crisis services that do not involve the police.

State governments must put more money into designing mental health crisis services that do not involve the police. State governments must put more money into designing mental health crisis services that do not involve coercion. The people working for these services need to have training on how to work with people with IDD. The people working for these services need to understand that people with IDD can have mental health disabilities.

The U.S. government should make sure states and service providers follow laws that protect the rights of people with IDD getting health care.

The U.S. government must make sure states and service providers respect the rights of people with IDD getting health care. The U.S. government must make sure mental health services do not leave out people with IDD. This includes mental health crisis services. The U.S. government also must make sure there are mental health crisis services in the community that do not involve the police.

The U.S. government can do a lot to make sure people with IDD can access good mental health crisis services. One thing the U.S. government can do is make sure people with disabilities have access to good regular health care. The U.S. government needs to make sure that health care providers do not treat people with disabilities worse because we have disabilities. The U.S. government must make sure that people with disabilities have the same rights to get good health care as anyone else.

The U.S. government also needs to make sure that people with IDD are not left out of mental health services because we have IDD. This is something a lot of the people ASAN **interviewed** talked about. A lot of the people we talked to said that mental health service providers will automatically leave out people with IDD. This is not fair! Mental health service providers are not supposed to do this. The U.S. government needs to make sure that mental health service providers do not leave out people with IDD.

One way the U.S. government can do this is by saying that people with IDD are a medically underserved population. A medically underserved population is a group of people who do not have enough access to health care. If the government said people with IDD are a medically underserved population, a few things would happen:

- There would be more money for health care for people with IDD.
- There would be more training for providers who want to work with people with IDD.
- There would be more money for research on how to make health care for people with IDD better.

The U.S. government needs to work with states to make more mental health crisis services in the community. The U.S. government could give more money to states that want to build more mental health crisis services in the community. Some types of mental health crisis services that the U.S. government could help states create are crisis respites.

**Crisis respites** are houses or apartments where people can stay for a few days until the mental health crisis has passed. Crisis respites often have services like support workers or therapy groups. Some crisis respites are peer-run, meaning they are staffed and run by people who have mental health disabilities.

Crisis respites have been studied a lot by researchers who study mental health services. Crisis respites are really good at a few things:

- Preventing people from being institutionalized.
- Saving money.

It costs a lot less money for someone to stay at a crisis respite than in an institution for a few days.

- Getting people set up with long-term mental health services in the community.

The U.S. government also needs to help states, cities, and towns design mental health crisis services that do not use police. One way the U.S. government can do this is through the 988 Lifeline. The **988 Lifeline** is a group of mental health crisis service providers that people can reach by calling 988. 988 is a phone number that people who are having a mental health crisis can call or text. The 988 Lifeline will send the call or text to a local mental health crisis service who can help the person.

But a lot of mental health crisis services still work with the police. And, the group that runs the 988 Lifeline says mental health crisis services must call the police in certain cases. This can be really scary and dangerous for people who are in a mental health crisis.

The U.S. government needs to change how the 988 Lifeline runs so that mental health crisis services do not involve the police. The U.S. government also needs to work with states, towns, and cities to create mental health crisis services that do not involve the police.

## *Set up better systems to collect data on what kinds of behavior support services people can get.*

Right now, there are many different ideas of what behavior support services are. Nobody can agree on exactly what “behavior support services” means. Sometimes, two providers might agree which services are part of behavior support services. But the two providers might do the same service very differently. This means that people with IDD can have different experiences with the same behavior support services.

These differences in services happen because states and the U.S. government do not all have the same definitions of behavior support services. Each state can say that “behavior support services” means something different. And, service providers do not usually send states or the U.S. government information about what kinds of behavior support services they provide. So even if a state says specifically what behavior support services are, service providers in that state may not follow what the state says.

ASAN thinks service providers, states, and the U.S. government need to work together to fix this. Service providers need to collect more data on what services they provide. Service providers need to send that data to state governments. State governments need to collect data from service providers. State governments need to make standard definitions of what different behavior support services are. The U.S. government needs to fix how it collects data from states. The U.S. government needs to tell states to give people more information about waiver services.

Service providers should collect and report more data on what services they provide.

IDD service providers need to collect more detailed data on the services they give people with IDD. Data is facts or information about something. Then, the IDD service providers need to send this data to state governments. Doing this will help state governments and researchers look at how different service providers provide the same service.

Right now, it is very hard to tell what IDD service providers mean when they say they provide certain services.

For example:

Two different IDD service providers might say they both provide **occupational therapy**. But they have different definitions of what occupational therapy is. One service provider only lets people with IDD get occupational therapy once a week for half an hour. The other service provider lets people with IDD get occupational therapy up to 3 times a week for up to 1 hour at a time. That is a big difference in what kinds of occupational therapy people can get!

If IDD service providers sent state governments data on the services they provide, it would let state governments compare services between providers. Then, state governments could see which service providers are doing a good job. The state governments could see which service providers are not doing a good job. Then, the state governments could figure out which service providers need more help from the state.

States should make standard definitions of what different behavior support services are. They should also collect data from service providers.

State governments need to make standard definitions of what different behavior support services are. That way, everyone in the state will know what each behavior support service should look like. State governments need to also work with CMS and researchers. These groups can study how people with IDD are using services within the states. State governments also must work to make sure everyone who needs HCBS can get HCBS. This means getting rid of waiting lists.

State governments need to write standard definitions of different behavior support services. When there is a standard definition of a behavior support service, everyone will know what the service is. Everyone will know how the service should be done.

State governments need to make sure that they write their definitions of behavior support services in plain language. That way, people with IDD can also read the definitions. State governments also need to make sure that their definitions of behavior support services explain the services in enough detail. If there is not enough detail in the definitions, people will not know what the definitions mean.

State governments need to make sure that their HCBS waivers for people with IDD cover mental health services. State governments need to make sure that their HCBS waivers for people with IDD cover occupational therapy. HCBS waivers for people with IDD should cover more than just services to “fix challenging behavior.” HCBS waivers for people with IDD should also cover services that help people with the needs that cause “challenging behavior,” too.

State governments also need to work with the U.S. government and researchers to study how people with IDD use services. State governments, the U.S. government, and researchers can work together to answer questions like:

- What services do states offer to people with IDD on waivers?
- How easy is it for people with IDD to get services like mental health services or occupational therapy?
- How easy is it for people with IDD to get services like ABA?
- Are people with IDD less likely than people with other disabilities to get mental health services or occupational therapy?
- Are people with IDD more likely than people with other disabilities to get ABA?

The other thing state governments must do is make sure that everyone who needs HCBS in their states can get HCBS. State governments must get rid of their waiting lists for HCBS. State governments must make sure that they spend enough money to get everyone who needs HCBS the services they need.

**The U.S. government should fix how it collects data about waiver services from states.**

The U.S. government must change how it collects data on waiver services from states. The U.S. government must make sure that states send the Centers for Medicare & Medicaid Services (CMS) enough detail about their waiver services. The U.S. government should make rules and policies to make sure that states report good data on waiver services.

Right now, CMS has a list of every HCBS waiver in the United States. Remember, CMS is the part of the U.S. government that deals with Medicaid and waivers. The list is online. Anyone can look at it. But the list does not have a lot of information about the different waivers. And the information the list has about the waivers can be really confusing.



CMS needs to make sure states send it a lot of information about each of their waivers. The information needs to include things like:

- Who can get on the waiver.
- What services the waiver will pay for.
- If there are limits to how many people can be on the waiver at one time.

CMS also needs to make sure that it keeps its website with the information about waivers updated.

One way CMS can make sure states give it better data about waivers is to pass new rules and policies. Right now, CMS is trying to pass new rules for states. The new rules say that states need to collect and report better data about HCBS. The new rules also say that states need to collect and report better data on people who are on HCBS waiting lists.

CMS should build on these rules. CMS should also make rules around what data states need to send CMS around services. CMS should especially make rules to say states need to send CMS more data on behavior support services.

Another thing CMS can do is help states collect more data on waiver services. CMS can give states more money to collect data on waiver services. CMS can help states solve problems around collecting data on waiver services. This will help states collect more and better data around waiver services.

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