

Plain Language Version

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

Part 5: Problems with How Behavior Support Services Happen Now

Words to Know in Part 5

Accommodations

Changes that help people with disabilities access the same services as everyone else.

Antipsychotics

A type of mental health medication that treat psychosis.

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.

Burnout

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

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.

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.

HCBS workforce crisis

A problem that is happening right now. The HCBS workforce crisis means that there are not enough support workers to help every person with IDD who needs support in their home or the community.

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.

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.

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.

Peer support

A service where people with IDD or mental health disabilities can talk to a peer worker.

Peer worker

A person with IDD or mental health disabilities who gets special training in helping other people with IDD or mental health disabilities.

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.

Physical therapy

A service that helps people move their bodies in ways that do not cause pain or injury.

Prevent

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

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.

Psychosis

A symptom of some mental health disabilities that causes people to think and experience things most people do not, like hearing or seeing things nobody else can.

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.

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.

Symptoms

Signs that a person has an illness or disability.

Trauma

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

Turnover

When someone gets a job but leaves it within a few months.

Vacancy

When a job is hiring but nobody is applying to the job.

Waiting list

A list of people who the state or a provider says qualify for services but cannot get services yet.

Waivers

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

Problems with How Behavior Support Services Happen Now

There are a lot of problems with how **behavior support services** happen now.

Some of these problems are specific to behavior support services. But a lot of these problems are problems with the whole **HCBS** system.

In this part, we will talk about these problems with HCBS and behavior support services:

- **Mental health services** and behavior support services are very separate right now. They should not be very separate.
- Most behavior support services do not actually meet the needs that cause people's "**challenging behavior.**"
- Many behavior support services do not try to figure out *why* someone is doing a **behavior**. Instead, these services just try to change the person's behavior.
- People with IDD need **support workers** to help us. But support workers are not treated very well by HCBS **providers** and states.
- Behavior support services often do things that hurt people with IDD, like **restraint** and **seclusion**.
- People with IDD do not usually get a lot of choices about the services we get.
- Mental health crisis services are not always available. When they are, they can hurt people.
- We do not have a lot of information on what behavior support services people with IDD can actually get.

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

Mental health services and behavior support services are very separate things. But they should not be very separate things.

Some people with IDD also have mental health disabilities. **Mental health disabilities** are disabilities that change how people think and feel. Mental health disabilities can make it hard for people to feel in control of their emotions.

Some different mental health disabilities are:

- Depression.
- Anxiety.
- Schizophrenia.

Researchers think between 3 in 10 and 4 in 10 people with IDD also have mental health disabilities.

In this toolkit, we use the term “**people with dual diagnosis.**” “Dual diagnosis” means having both IDD and a mental health disability. “Dual” means “two” or “both.”

Some people who have mental health disabilities get mental health services. **Mental health services** help people with mental health disabilities deal with their emotions. Mental health services help people with mental health disabilities live in the **community.**

Some types of mental health services are:

- Mental health therapy. **Mental health therapy** means talking to a mental health doctor about your emotions and thoughts. There are many different kinds of mental health therapy.
- Medications. Medications can help with different types of mental health disabilities. Medications can make it easier to deal with mental health disabilities.

- HCBS. Some people with mental health disabilities can get HCBS through a **waiver**. Sometimes this can be having a support worker to help the person at home. Sometimes this can be classes or training to teach the person skills for living in the community.

People with dual diagnosis can get both IDD services and mental health services. But there is a big problem. IDD services and mental health services are usually very separate. Usually, different providers run each service. Usually, different parts of **Medicaid** pay for each service. Usually, different parts of state governments make rules for each service.

IDD and mental health services do not talk to each other that much. There are very few services that combine IDD services and mental health services. It is hard for people with both IDD and mental health disabilities to get services that meet their needs.

For example:

Alejandra has an intellectual disability. She also has a mental health disability called bipolar disorder. Alejandra gets IDD services. She has a support worker that comes to her home. She also goes to art classes for people with IDD. Alejandra also gets mental health services. She goes to a support group at a community center for people with mental health disabilities. She takes medication for her bipolar disorder. But Alejandra cannot get services that help with both IDD and mental health at the same time.

Alejandra wants to make art about living with bipolar disorder. But her art classes do not talk about mental health disabilities. Alejandra needs information in plain language. She needs someone to explain things to her using simple words. But in her support group, people use very complicated language. When she talks to her doctor about medication, her doctor uses very complicated language. Alejandra is getting both IDD and mental health services. But those services are not meeting her needs.

For a long time, providers thought that people with IDD could not have mental health disabilities. Providers thought that people with IDD did not have real thoughts. Providers thought that people with IDD would not get help from mental health services.

This is not true! People with IDD can have mental health disabilities. People with IDD do have real thoughts. People with IDD can get help from mental health services.

For a long time, providers did not think people with IDD had real thoughts. For a long time, providers did not think people with IDD had feelings or emotions. This is part of why so many people with IDD only get ABA and other behaviorist services.

Remember, **behaviorism** does not care about what people think. Behaviorism does not care about what people feel on the inside. Behaviorism only cares about people's behavior that other people can see. Behaviorism only cares about changing the way people behave on the outside.

So, providers thought that behaviorism would be perfect for people with IDD. Providers thought that if people with IDD did not need services that talked about thoughts or emotions. Providers thought people with IDD did not have real thoughts or emotions. This is wrong. But some providers still believe this.

Behavior support services that use behaviorism can hurt people with IDD really badly. Behavior support services that use behaviorism can cause a lot of trauma for people with IDD. **Trauma** is when a scary situation changes how a person thinks, feels, and behaves. This is on top of other reasons people with IDD have a lot of trauma.

People with IDD should get help dealing with trauma. We should be able to get mental health services that help us work through trauma. Behavior support services that use behaviorism do not help people work through trauma. Behavior support services that use behaviorism only cause more trauma.

IDD services and mental health services have been separate for a long time. This has caused a lot of problems. One big problem is that mental health services are often not set up to help people with IDD. Mental health service providers often do not learn in school how to help people with IDD. People with IDD may need accommodations to be part of mental health services. **Accommodations** are changes that help people with disabilities access the same services as everyone else.

Some types of accommodations are:

- Information in plain language instead of difficult language.
- Sign language interpretation.
- Having appointments more often, like having therapy twice a week instead of once a week.

The law says that mental health services should make accommodations for people with IDD who need accommodations. But many mental health services do not make accommodations for people with IDD. This makes it very hard for people with IDD to get mental health services.

Sometimes, mental health services will say they cannot help people with IDD even if they do not need accommodations. Mental health services will sometimes say that they do not know how to help people with IDD. Or, mental health services sometimes say that people with IDD are “too disabled” for mental health services to help us.

This is not true! People with IDD do get help from mental health services. This includes people with IDD who need a lot of support. But mental health services still say they cannot help people with IDD.

It is also very hard for people with IDD to get mental health services from IDD service providers. Most IDD service providers do not offer any kind of mental health services. IDD service providers might offer some types of behavior support services. But a lot of the time, IDD service providers only offer behavior support services that use behaviorism. IDD service providers almost never offer actual mental health services.

When people with IDD do get mental health services, a lot of the time we only get medication. People with IDD are less likely than people without IDD to get **mental health therapy**. This happens even when we have the exact same mental health disability. People with IDD can get help from different types of mental health therapies. We may need accommodations to take part in therapy. But we still can get help from different types of mental health therapies.

People with IDD also are more likely to get mental health medication. This happens even when we do not have a mental health disability that a medication can treat. This happens especially with people with “challenging behavior” and antipsychotics.

Antipsychotics are a type of mental health medication that treat psychosis. **Psychosis** is a symptom of some mental health disabilities. **Symptoms** are signs that a person has an illness or disability. People with psychosis think and experience things that most people do not.

Some types of psychosis are:

- Seeing visions that nobody else in the room can see.
- Hearing voices that nobody else in the room can hear.
- Having very unusual beliefs, like believing government spies are following you around.

Antipsychotics can cause side effects that a lot of people find hard to deal with. Antipsychotics can cause side effects like:

- Being really tired all the time.
- Being really hungry all the time.
- Long-term physical illnesses, like diabetes or high cholesterol.

Most people with IDD who get antipsychotics do not have psychosis. The antipsychotics are supposed to treat “challenging behavior.” But there are other ways of helping people with “challenging behavior” that do not use antipsychotics. People with IDD who have “challenging behavior” should get other kinds of help before they get antipsychotics.

These problems are bad for all people with IDD. But they are especially bad for people with IDD who communicate mostly through behavior. **Communication** is the different ways people tell each other information and ideas.

Some different types of communication are:

- Speaking with your mouth.
- Using a sign language.
- Writing or typing words.
- Pointing to words, pictures, or letters.
- Pointing or bringing someone to the thing you want.
- Other kinds of behavior, like body language, facial expressions, and “challenging behavior.”

For example:

Sienna has an intellectual disability. Sienna does not talk with her mouth. She does not use a sign language. She does not write, type, or point to words. Sienna mostly communicates through her behavior.

Sienna lives with her sister. When Sienna is hungry, she brings her sister to the refrigerator. When Sienna is sad, she curls up into a ball and refuses to move. When Sienna is happy, she smiles and hugs people.

People who communicate through behavior can have a hard time getting other people to understand them.

For example:

Let's continue with the example about Sienna.

When Sienna gets upset, she pulls her hair out. Sienna can show other people she is upset by pulling her hair out. But it is much harder for Sienna to show other people *why* she is upset.

One day, Sienna's friend Liza was supposed to come take Sienna to a movie. But Liza got sick and could not come. Sienna is upset about this. So she pulls her hair out. Sienna does not have another way to tell people she is upset about Liza.

Another day, Sienna is upset that her favorite baseball team lost their game. So she pulls her hair out. Sienna does not have another way to tell people she is upset about the baseball game. It is really hard for Sienna to show people around her *why* she is upset.

A lot of people think that people who communicate through behavior cannot get help from mental health services. A lot of people think that people who communicate through behavior are not having “real” thoughts or emotions. A lot of people think that to get help from mental health services, a person has to be able to:

- Speak with their mouth.
- Use a sign language.
- Write or type what they want to say.

This is not true! But a lot of people believe it. A lot of people who provide IDD services believe this. When IDD service providers believe this, they do not help people who communicate through behavior get mental health services. Instead, the IDD service providers put people with IDD who communicate through behavior in behaviorist services. For example, ABA.

Behaviorist services focus on getting people to stop doing “challenging behaviors.” Behaviorist services do not focus on *why* people are doing the “challenging behaviors.” Behaviorist services do not help people with IDD.

Putting people who communicate through behavior in behaviorist services also hurts research. **Research** is a way that people learn new things about the world. When people do research, they:

- Collect information about something.
- Use that information to answer a question or solve a problem.
- Share what they learned with others.

Researchers do research to answer questions about IDD services and mental health services. One question that researchers try to answer with research is “What types of services work best for people with IDD who communicate through behavior?” A lot of the researchers who have researched this question have said that behaviorist services work best.

But there is a problem! Very few people who communicate through behavior get services other than ABA. So researchers do not think to look at whether other services could help people who communicate through behavior. Researchers only look at whether ABA can help people who communicate through behavior.

IDD service providers look at what researchers are researching. The IDD service providers see that researchers are mostly researching how ABA can help people who communicate through behavior. The IDD service providers see that researchers are not researching whether services other than ABA could help people with IDD who communicate through behavior. So the IDD service providers say, “See? People with IDD who communicate through behavior only need ABA!”

And the cycle starts over again.

Some people with IDD do not speak with their mouths but can communicate in other ways than just behavior. Some people with IDD who do not speak with their mouths use a sign language to communicate.

Some people with IDD who do not speak with their mouths use AAC. AAC stands for augmentative and alternative communication. **AAC** is ways of communicating other than speaking with your mouth or using a sign language. AAC can include:

- Writing on a piece of paper.
- Pointing to words, pictures, or letters on a board or book.
- Typing words on a computer. The computer reads the words you type out loud.

People with IDD who use a sign language or AAC to communicate may be able to communicate what they mean really easily. Or, they may not be able to communicate what they mean as easily. But even people with IDD who can communicate what they mean easily do not get good mental health services.

For example:

Harvey is autistic. Harvey types on an iPad to communicate. The iPad reads out what Harvey types. Harvey is really fast at typing. He can easily type what he wants to say on the iPad. Harvey has been using an iPad to communicate for many years.

But when Harvey tries to get mental health services, the service provider tells him they cannot help him. The mental health service provider says Harvey typing on the iPad would “take too long.” The mental health service provider says none of their therapists know “how to work with someone who does not speak.”

There are other problems people with IDD who use a sign language or AAC face in getting good mental health services. Some of these problems include:

- Mental health service providers do not know a lot about working with people who use a sign language or AAC.
- Appointments that are too short. Using a sign language or AAC takes longer than speaking with your mouth to communicate. So, people who use a sign language or AAC need longer appointments. But they often cannot get longer appointments.
- Only being able to make an appointment by calling the mental health service provider on the phone. Many people who use a sign language or AAC cannot use the phone.

- Telehealth programs that are not accessible. Telehealth is when you see a health care provider over a video call instead of in-person. When something is accessible, it means people with disabilities can use it.

A telehealth program might not have a text chat feature. Or, the telehealth program might make it hard to understand the person's AAC device. Both of these things make telehealth not accessible to people who use a sign language or AAC.

Even people with IDD who can speak with their mouths can have trouble getting good mental health services. ASAN looked at studies of autistic people who had tried to get mental health services. The autistic people in the studies could speak with their mouths most of the time. But most of the autistic people in the studies still had trouble getting good mental health services. They still had trouble getting mental health service providers to listen to them. They still had trouble making appointments with mental health service providers. They still had trouble getting the kinds of services they wanted or needed from the mental health service providers.

One big barrier to people with IDD getting good mental health services is that mental health doctors and therapists do not get training on IDD. One study looked at mental health therapists and doctors who work with children. The study found that only half of the therapists and doctors had training on IDD.

Also, most training that mental health therapists and doctors get about IDD focuses on children. Mental health therapists and doctors get much less training about working with adults with IDD. This makes it hard for adults with IDD to get good mental health services.

When there are mental health service providers who can help people with IDD, those service providers often have long waiting lists. A **waiting list** is a list of people who a provider says qualify for services but cannot get services yet. So people with IDD can often end up waiting months and months for mental health services.

Sometimes, researchers who research IDD services and mental health services will look at mental health services. The researchers will see that there are not many people with IDD getting mental health services. So the researchers say, "Oh, people with IDD must not need mental health services." The researchers do not realize that people with IDD do not get mental health services because mental health services are not accessible to people with IDD.

The researchers write reports about what they found. Mental health service providers read those reports. The mental health service providers think that people with IDD must not need mental health services. So the mental health service providers do not try to make their services more accessible to people with IDD. And so the problem gets worse.

Behavior support services do not include services to meet needs causing “challenging behavior.”

We just talked about how people with IDD often cannot get good mental health services. But people with IDD often cannot get other services that help with other problems we may be having. Sometimes, these problems cause “challenging behavior.”

But when people with IDD have “challenging behavior,” we often only get certain kinds of services. We may only get behavior support services. We may only get certain kinds of behavior support services, like ABA. We may not get other services to help us live the lives we want to live.

There are many types of services that can help someone with problems that cause “challenging behavior.” These services include:

- Mental health services, such as mental health therapy.
- Occupational therapy. **Occupational therapy** is a service that helps people learn and practice skills they need in their everyday lives.
- Physical therapy. **Physical therapy** is a service that helps people move their bodies in ways that do not cause pain or injury.
- Speech therapy. **Speech therapy** is a service that helps people learn and practice ways of communicating that work for them.
- Peer support. **Peer support** is a service where people with IDD or mental health disabilities can talk to a peer worker. A **peer worker** is another person with IDD or mental health disabilities. Peer workers get special training in helping other people with IDD or mental health disabilities.
- Fun activities, like arts or sports classes for people with IDD. Sometimes, these activities help people learn or practice skills for everyday life. Other times, these activities are just a fun place to hang out and talk with other people.

But people with IDD can have a much harder time getting these services. This is especially true when someone has “challenging behavior.” When people with IDD have “challenging behavior,” we are often only given behavior support services. We are not given other types of services that could help with the problems causing our “challenging behavior.”

For example:

Aisha has an intellectual disability. Aisha lives in a group home. Aisha is really lonely. She does not have any friends. Because Aisha is lonely, she gets angry really easily. When Aisha gets angry, she kicks furniture and walls in the group home. Aisha has kicked holes in the walls before.

The group home provider says that Aisha has “challenging behavior.” The group home provider wants to send Aisha to ABA for her “challenging behavior.”

Aisha tells the group home provider that she wants to go to art classes in the community. Aisha says she could make friends at the art classes. Then, she would be less lonely. Then, she would not get angry as often. But the group home provider does not think Aisha is “ready” to go to art classes in the community. The group home provider says Aisha needs ABA for her “challenging behavior” before she can go to art classes.

A lot of the people we interviewed talked about how Medicaid will only pay for behavior support services. They said Medicaid will not pay for other services that could help people with IDD who have “challenging behavior.”

This has to do with how Medicaid waivers work. Remember, waivers are Medicaid programs that let people with disabilities get services in the community. Many states have different Medicaid waivers for different groups of people with disabilities. The Medicaid waivers for people with IDD might pay for behavior support services. But the Medicaid waivers

for people with IDD might not pay for other kinds of services. So, in many states, it is much harder for people with IDD on Medicaid waivers to get other kinds of services.

Some of the people we interviewed talked about how Medicaid waivers often do not cover occupational therapy for people with IDD. A lot of people with IDD have specific sensory needs. We may be much more sensitive to certain things, like certain smells or noises, than most people. Or we may be much less sensitive to certain things, like pain or hunger, than most people. Occupational therapy can help with these needs. But it is often very hard for people with IDD on waivers to get Medicaid to pay for occupational therapy for us.

For example:

Carlos is autistic. Carlos is very sensitive to bright lights. Carlos cannot go to many places in the community because those places have such bright lights. This is affecting Carlos's life. He is missing work because he cannot stand bright lights. He is not able to go to the store to run errands because of the bright lights.

Carlos wants to work with an occupational therapist. An occupational therapist could help Carlos figure out ways to deal with bright lights. An occupational therapist could help Carlos advocate to have his workplace use different kinds of lightbulbs.

But Medicaid will not pay for Carlos to see an occupational therapist. Medicaid says that Carlos needs behavior support services because he is "avoiding work." But none of the behavior support services Carlos could get would help with his sensitivity to bright lights.

Many behavior support services try to change behavior, without fixing the problem causing the behavior.

All behavior happens for a reason. People behave in certain ways to express needs. People behave in certain ways to express emotions. People behave in certain ways because it feels good.

Good behavior support services look at *why* someone is doing a certain behavior. Good behavior support services find ways to meet the needs behind a person's behavior. Good behavior support services try to fix the problem that is causing the behavior.

For example:

JoAnna has an intellectual disability. JoAnna lives in an adult foster care home. There is another woman with a disability, Maisie, who also lives in the adult foster care home. JoAnna does not like Maisie. Maisie steals JoAnna's food. If JoAnna leaves any of her snacks in the kitchen pantry, Maisie will steal them. So JoAnna starts to hide food in her bedroom.

JoAnna's foster parents notice that JoAnna is hiding food in her bedroom. There are ants in JoAnna's bedroom because of the food. JoAnna's foster parents bring her to a therapist to talk about why she is hiding food in her room. JoAnna explains that she is hiding food in her room so Maisie will not steal it.

The therapist and JoAnna's foster parents decide to talk to Maisie about stealing JoAnna's food. After they talk to Maisie, Maisie stops stealing JoAnna's food. JoAnna stops hiding food in her room. JoAnna, her foster parents, and the therapist solved the problem that was causing her behavior.

But a lot of behavior support services do not do these things. A lot of behavior support services only try to make the person stop doing the behavior. A lot of behavior support services do not try to figure out *why* the person is doing the behavior. A lot of behavior support services do not try to meet the needs behind the person's behavior. This is especially true of ABA and other behavior support services that use behaviorism.

For example:

Rafael is autistic. Rafael is in high school. Other kids at Rafael's high school bully Rafael. The other kids call Rafael mean names. The other kids hit and kick Rafael. Rafael tries to tell the other kids to stop bullying him. But the other kids do not listen to Rafael.

Rafael gets sick of the other kids bullying him. The next time one of the bullies calls Rafael mean names, he pushes them away. A teacher sees Rafael push the other kid. The teacher sends Rafael to the principal's office for pushing another kid. Rafael tries to explain that he only pushed the other kid because they were bullying him. But nobody listens to Rafael.

Rafael gets sent to ABA. In ABA, Rafael is supposed to be working on "using his words" to explain when he does not like something. Rafael keeps trying to explain that he did tell the bullies to stop picking on him. But nobody listens to him.

Lots of behavior support services only focus on changing people with IDD's behavior. These behavior support services do not focus on meeting the needs that cause the behavior. This happens even when the behavior support services call themselves "person-centered" or "positive." A behavior support service can only use nice language and still treat the people in it really badly. A behavior support service can only use rewards, not punishments, and still treat the people in it really badly.

Focusing only on stopping people with IDD's behaviors treats people with IDD like we are less human. Not focusing on what people with IDD need treats people with IDD like we are less human.

A lot of the "challenging behaviors" people with IDD have are normal ways of reacting to bad treatment. The IDD service system often treats people with IDD really badly. IDD service providers often do not let people with IDD make even simple choices about our lives. IDD service providers often do not respect people with IDD. IDD service providers often make people with IDD follow extra rules. Sometimes, IDD service providers hurt or abuse people with IDD.

All these things are wrong. It would be natural for a person dealing with any of these things to "act out" in response. But when people with IDD "act out" in response to bad treatment, other people say we have "challenging behavior."

For example:

Amy has a brain injury. She is 45 years old. Amy lives in a group home. The staff at Amy's group home treat her like a child. Amy has to ask the staff if she wants to leave the group home. She has to be back at the group home by 5 p.m. every night. She has to ask the group home staff if she wants to have friends over at the group home. She is not allowed to drink alcohol or smoke cigarettes, even though she is an adult.

Amy is stressed all the time because of how the group home staff treat her. She feels upset that the group home staff do not respect her. So Amy starts breaking the rules. She leaves the group home without asking the staff first. She stays out until midnight with her friends. She invites her friends over and asks them to buy her alcohol.

The group home staff say that Amy has "challenging behavior." But Amy is just responding to being treated badly. If the group home staff treated Amy like an adult, she would not "act out."

We have known for a long time that big **institutions** treat people with IDD badly. Some examples of big institutions are:

- Hospitals.
- Nursing homes.

We have known for a long time that people with IDD in big institutions “act out” because of bad treatment.

We also know that smaller institutions also treat people with IDD badly. Some examples of smaller institutions are:

- Group homes.
- Assisted living facilities.

We know that people with IDD in smaller institutions “act out” because of bad treatment.

But the IDD service system has been really slow to agree that smaller institutions also treat people badly. The IDD service system often makes excuses about why smaller institutions are not “as bad.” They make excuses like:

- Smaller institutions are “more like real homes” than bigger institutions.
- Smaller institutions let people with disabilities have more control over our lives than bigger institutions.
- Smaller institutions are more likely to be “part of communities” than bigger institutions.

None of these excuses make it right to put people in institutions, even smaller institutions. Living in an institution causes people a lot of trauma. This is true even if the institution is small. People with IDD in smaller institutions still have fewer choices than people with IDD who do not live in institutions. When people with IDD who live in smaller

institutions “act out,” it is often because they live in an institution. It is often because they do not have control over their lives.

A lot of people with IDD who have “challenging behavior” live in smaller institutions. A lot of people with IDD who have “challenging behavior” get treated badly by staff and service providers in their lives. A lot of people with IDD who have “challenging behavior” do not get to make real choices about their lives. But many behavior support services do not look at these causes of “challenging behavior.” Instead, many behavior support services only focus on changing or stopping the “challenging behavior.”

In Part 4, we talked about a cycle that many people with IDD who have “challenging behavior” go through. The cycle looks like this:

A lot of the time, when providers say a person with IDD has “challenging behavior,” 5 things happen:

1. The provider says the person’s “challenging behavior” needs to change or stop.
2. The provider does not ask *why* the person is having the behavior. The provider also does not ask if the person has some need that is not being met.
3. The person starts to get behavior support services to make them stop or change their behavior. Sometimes, the provider doing the behavior support services hurts the person. The person does not get help for the reason *why* they are having the behavior.
4. The person gets really stressed and upset at the behavior support services because the services are not helping them. Sometimes, the person’s behavior gets worse because of this.
5. The provider sees that the person’s behavior is getting worse. The provider decides the new, worse behavior needs to stop or change. The process starts back over at step 1.

The person with IDD may change their behavior because of behavior support services. But this is not the same as fixing the cause of the behavior. The person has just learned that they cannot express their needs through doing that behavior anymore. Nobody has actually fixed the problem causing the behavior.

For example:

Let's look again at our example of JoAnna from earlier. JoAnna was hiding food in her bedroom so her foster sister, Maisie, would not steal it. JoAnna's foster parents take her to a therapist to figure out why she is hiding food. Let's say the therapist tells JoAnna's foster parents to take all the food out of her bedroom. The therapist tells JoAnna's foster parents to check her bedroom regularly for food.

JoAnna's parents do this. If JoAnna's parents find food in her room, they throw the food out, even if there is a lot left. JoAnna learns that she cannot have food in her bedroom. JoAnna decides to give up. She stops hiding food in her room. Maisie keeps stealing JoAnna's food.

Now, JoAnna cannot keep snacks in a place where Maisie will not get to them. JoAnna is angry and hungry all the time. Nobody fixed the problem that was causing JoAnna's "challenging behavior."

People with IDD need support workers to help us. But support workers are not treated well by HCBS providers.

A lot of people with IDD who get HCBS get help from support workers. **Support workers** are 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.

Right now, there are not enough support workers to help every person with IDD who gets HCBS. This is a big problem. This problem is sometimes called the **HCBS workforce crisis**. There are not enough support workers for several reasons:

- Being a support worker does not pay very well.
- Support worker jobs often do not have the same benefits as other jobs.
- Support workers often help people with IDD with a lot of different things with very little training.
- COVID-19 caused a lot of problems for support workers.

We will talk about each of these reasons next.

Reason 1: Being a support worker does not pay very well.

Support worker jobs do not usually pay very well. In 2020, the average hourly pay for new support workers was \$13.61. That means that in 2020, someone who just started a job as a support worker made about \$13.61 an hour. \$13.61 an hour is not a lot of money to live on! In many states, someone making \$13.61 an hour is not making enough money to survive. And \$13.61 an hour was the average pay for new support workers. That means that half of all new support workers made *less* than \$13.61 an hour.

Being a support worker also tends to pay less than being in similar jobs. One study we found looked at jobs that involve similar tasks to being a support worker. The study found that support workers generally made less per hour than people in similar jobs. This can be because being a support worker does not require the same amount of training as similar jobs. Jobs that require more training can usually pay their workers more.

For example:

Being a support worker is a lot like being a nursing assistant in a hospital. Both jobs involve helping people with disabilities or illnesses take care of their everyday needs. Both jobs involve working with health care providers, like doctors and nurses. Both jobs involve helping people with disabilities or illnesses get or stay independent. But being a nursing assistant takes more training than being a support worker. So being a nursing assistant usually pays more per hour than being a support worker.

One reason support workers do not get paid very well is because states do not set aside enough money for HCBS. Most people with IDD who get HCBS are on Medicaid. Medicaid pays for people with IDD to get HCBS. But states do not set enough money aside to pay for HCBS. So the amount states pay HCBS providers is really low. The HCBS providers do not pay all of the money states give them to support workers. So support workers are only getting paid part of what is already a very small amount of money.

Reason 2: Support worker jobs often do not have the same benefits as other jobs.

Besides paying people money to work, many jobs offer other benefits. Benefits are things like:

- Health insurance that the job pays for.
- Paid time off when you are sick or want to take a vacation.
- Classes or training that the job pays for.

Many support worker jobs do not offer the same benefits as other kinds of jobs. Many support worker jobs do not offer health insurance to the people working for them. (Or, the jobs might offer health insurance. But the health insurance is very bad and does not cover most health care.)

Many support worker jobs do not offer paid time off to the people working for them. That means if a support worker is sick and cannot work, they do not get paid.

Many support worker jobs do not offer to pay for classes or training for the people working for them. The job might pay for some very basic training at the beginning. But the job does not pay for any more training than that.

For example:

Margo works as a support worker. She works with people with IDD. Margo wants to take a training on supporting people with mental health disabilities. Margo knows that if she takes the training, she could work with more people. Margo wants the provider she works for to pay for the training. Margo tells the provider she works for that she would be more useful to them if she took the training. But the provider Margo works for does not want to pay for the training.

Support workers also are less likely to be in a union than people who do similar jobs. A union is when a group of workers comes together to protect their rights at work. Workers in unions tend to make more money at work. Workers in unions tend to have better benefits at their jobs. In some jobs similar to being a support worker, the workers tend to be in unions. For example, workers who work in big state institutions tend to be in unions. But support workers who work in people's homes and in the community are less likely to be in a union.

Reason 3: Support workers often help people with IDD with a lot of different things with very little training.

Support worker jobs often involve helping people with IDD with a lot of different things. Some of the things support workers help people with IDD with are:

- Eating, drinking, and cooking.
- Bathing and getting dressed.
- Doing chores around the house.
- Getting health care.
- Going places in the community.
- Learning new skills.
- Managing money.
- Solving problems that come up in everyday life.

All of these things are hard work! Many of these things take training and practice for support workers to do them properly. But support workers often do not get a lot of training. HCBS providers often ask support workers to do things the providers have not trained the support workers to do. This is not fair! It is not fair to the support workers. And it is not fair to the people with IDD who the support workers help.

Reason 4: COVID-19 caused a lot of problems for support workers.

COVID-19 is a bad disease. COVID-19 has spread around the world. COVID-19 has been going on since 2019. COVID-19 has made a lot of people very sick. To learn more about COVID-19, you can read [our fact sheets on COVID-19](#).

The HCBS workforce crisis has been going on since before COVID-19. For example, a United States government report in 2017 talked about the HCBS workforce crisis. But COVID-19 has made the HCBS workforce crisis a lot worse.

COVID-19 spreads from person to person. COVID-19 especially spreads when people are close together. A lot of support workers have to be really close to the people with IDD they help. A lot of people with IDD need physical support to do things. People are supposed to stay 6 feet away from each other to help stop COVID-19 from spreading. But a lot of a support worker's job cannot be done from 6 feet away.

For the first year of COVID-19, there were not a lot of ways for support workers to keep safe at work. There were no vaccines to help stop COVID-19. People were supposed to wear face masks to help stop COVID-19 from spreading. But it was really hard to find face masks to buy anywhere. A lot of support workers ended up getting sick with COVID-19.

COVID-19 can make people sick for a long time. A person might get COVID-19. They might get better from their original illness. The person is no longer able to spread COVID-19. But they still feel really sick. They might be tired all the time. They might not be able to think clearly.

Some of the support workers who got sick with COVID-19 stayed sick for a long time. A lot of these support workers had to stop working because they were so sick. This made the HCBS workforce crisis even worse.

A lot of support workers who did not get very sick with COVID-19 also ended up leaving their jobs. Being a support worker is a hard job. Being a support worker does not pay very well. Adding the risk of getting sick with COVID-19 was too much for a lot of support workers.

All of these reasons are part of why there are not enough support workers to help everyone with IDD who needs help. Being a support worker is a hard job. Being a support worker does not pay very well. Being a support worker often does not offer good benefits. COVID-19 made support workers' jobs even harder and more dangerous.

A lot of support workers have stopped being support workers in the past few years. When support workers quit their jobs, HCBS providers often cannot hire new support workers to replace them. This means that there are a lot of vacancies in support worker jobs. A **vacancy** is when a job is hiring but nobody is applying to get the job. One study found that in 2020, the average vacancy rate for support worker jobs was:

- About 12% for full-time support workers
- About 16% for part-time support workers.

That means:

- For every 100 full-time support worker jobs an HCBS provider had at the end of 2020, about 12 had vacancies.
- For every 100 part-time support worker jobs an HCBS provider had at the end of 2020, about 16 had vacancies.

Support worker jobs also have a high turnover rate. **Turnover** is when someone gets a job but leaves it within a few months. One study found that in 2020, the average support worker turnover rate for HCBS providers was about 44%. That means for every 100 support workers working for an HCBS provider at the end of 2020, about 44 support workers had stopped working for the provider in 2020.

Vacancies and turnover in support worker jobs make it harder for people with IDD to get good services. We will talk about why next.

When there are not enough support workers to help everyone who gets HCBS, people have to wait longer to get HCBS. A person might be approved to get HCBS through their Medicaid waiver. The person's state might agree to pay for the person's HCBS. The person might have already been matched to an HCBS provider to get services. But if the HCBS provider does not have enough support workers, the person cannot get HCBS.

Even when people with IDD can get HCBS, the HCBS workforce crisis makes it harder to get good HCBS. When there are not enough support workers, people with IDD get less 1-to-1 support. When there are not enough support workers, people with IDD are less likely to get support in our own homes. This makes it harder for people with IDD to keep living in our own homes.

Because of the HCBS workforce crisis, some people have had to get HCBS in provider-owned settings instead of their own homes. Provider-owned settings are places like:

- Group homes.
- Assisted living facilities.
- Intentional communities.

The HCBS workforce crisis has also meant that people in provider-owned settings who want to move into their own homes cannot.

People who live in provider-owned settings usually have fewer choices about their lives. People who get HCBS in provider-owned settings usually have fewer choices about their services.

People who live in provider-owned settings have rights under the HCBS Settings Rule. Under the HCBS Settings Rule, people in provider-owned settings have rights like:

- Being able to make their own daily schedules.
- Being able to go out in the community when they want.
- Being able to have visitors when they want.

When there are not enough support workers, it is hard for people living in provider-owned settings to use these rights.

For example:

Viola is autistic and has Down Syndrome. Viola lives in a group home. Viola really likes to go to the park and fly kites. The HCBS Settings Rule says Viola has the right to set her own daily schedule. Viola wants to go to the park every day and fly kites. Viola needs a support worker to go to the park with her.

But there are not enough support workers at Viola's group home for someone to go to the park with Viola every day. So Viola only gets to go to the park once a week. When she gets to go to the park, everyone else at the group home has to come, too. On days when Viola does not go to the park, she has to go to things other people at her group home want.

The HCBS Settings Rule says Viola has the right to set her own daily schedule. The HCBS Settings rule says Viola has the right to go where she wants in the community. The HCBS Settings Rule says Viola has the right to skip going places other people in the group home want to go to. But because there are not enough support workers at her group home, Viola does not get these rights.

We already talked about how many HCBS providers have high turnover rates for support worker jobs. Remember, turnover is when someone gets a job but leaves it within a few months. When HCBS providers have high support worker turnover rates, providers are less likely to offer good training for new support workers.

Training new support workers costs money. Training new support workers takes time. HCBS providers do not want to spend a lot of money and time training support workers who will only stay on the job for a few months. This means HCBS providers are less likely to give good training on a lot of different parts of the job, like doing good behavior support services.

Right now, a lot of training on behavior support services for support workers focuses on what to do when someone has a mental health crisis. A **mental health crisis** is 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. A lot of the training on what to do when someone has a mental health crisis focuses on practices that hurt people, like restraint and seclusion. A lot of the training on what to do when someone has a mental health crisis is based in ABA and behaviorism. Most of the training on what to do when someone has a mental health crisis:

- Does not talk about helping the person calm down.
- Does not talk about asking the person what they need.

There is also not a lot of training for support workers on how to stop mental health crises from happening in the first place. When you **prevent** something, you stop it from happening in the first place.

Most support workers do not get a lot of training on how to do good behavior support services. Most support workers do not get a lot of training on how to work with people who are having mental health crises. When support workers do get this training, the training tends to focus on restraint and seclusion. This makes it really hard for support workers to actually help people who are having mental health crises.

Bad training for support workers also has really bad effects for people with IDD who the support workers help. When support workers are only trained on restraint and seclusion, they will be more likely to use restraint and seclusion. Restraint and seclusion can hurt people really badly. Restraint and seclusion can kill people. Restraint and seclusion can cause a lot of trauma for people.

When support workers are not paid well, they are more likely to stop being support workers. When support workers do not get good training, they are more likely to stop being support workers.

Being a support worker can be really stressful. Doing a hard job for not a lot of money with not a lot of training is stressful. And, support workers often work with people with IDD who behave in ways that can hurt other people.

For example:

John has an intellectual disability. John cannot speak or use a sign language. John mostly communicates through his behavior. When John gets upset, he throws things. John does not want to throw things. But he does not have another way of communicating.

John's support worker is named Marco. One day, John was having a really bad morning. John did not want to go to work. Marco was trying to get John to go to work. So John picked up a glass from the table and threw it at Marco's head.

The glass shattered and cut Marco's forehead. Marco had to go to the hospital to get stitches. Marco is really stressed out because of what John did. Marco knows that John did not mean to hurt him. But John still hurt Marco by throwing the glass at Marco.

A lot of support workers deal with burnout because of stress from their jobs. **Burnout** happens when someone is in a stressful job for a long time. When someone has burnout, they feel really tired. When someone has burnout, they feel like they cannot focus on their job. A lot of support workers who have burnout from their jobs end up leaving their jobs.

Some support workers also deal with secondary trauma from their jobs. **Secondary trauma** is when a person has trauma from seeing someone else go through a really stressful experience.

For example:

Daniz is a support worker. Daniz helps Lukas. Lukas has an intellectual disability. Lukas has a job stocking shelves in a grocery store. Daniz helps Lukas at work.

People at the grocery store treat Lukas really badly. Lukas's coworkers talk about him like he is not there. People shopping at the grocery store call Lukas the r-word. Lukas's boss refuses to give Lukas a pay raise, even though Lukas's coworkers have all gotten pay raises. Lukas is really sad and angry because of how people treat him.

Daniz sees how people treat Lukas every day. Daniz is also sad because of how people treat Lukas. Daniz is also angry because of how people treat Lukas. Daniz has secondary trauma from how people treat Lukas.

Burnout and secondary trauma have bad effects on support workers. Burnout and secondary trauma mean support workers are more likely to leave their jobs. Burnout and secondary trauma mean support workers are less likely to do a good job of helping people with IDD. This can include things like:

- Support workers taking less time to get to know the people they help.
- Support workers being less respectful of the people they help.
- Support workers not giving the people they help as many choices during the day.
- People with IDD having fewer chances to be out in the community.
- People with IDD having fewer chances to be social and hang out with other people.
- Support workers being more likely to use restraint and seclusion on the people they help.

It is really hard for people with IDD to get good help when our support workers are always changing or leaving. It is really hard for people with IDD to build relationships with our support workers when they are always changing or leaving.

People with IDD need support workers who will stick around for a long time. People with IDD need support workers who will get to know us as people first. People with IDD need support workers who will work with us to meet our goals. But all of these things are really hard when there are not enough support workers. All of these things are really hard when support workers do not get paid or trained well.

Behavior support services often do things that hurt people with IDD.

A lot of behavior support services do things that hurt people with IDD.

These include things like:

- Restraint and seclusion, which stop people from moving.
- Coercion, or trying to change people's behavior in ways the person does not want.
- Punishments, like yelling at someone because they had "bad behavior." Punishments are sometimes called "aversives."

These things happen because behavior support services providers do not respect people with IDD. These things happen because behavior support services providers think people with IDD are "less human."

There have been some changes that have made it harder for HCBS and behavior support services to hurt people, like:

- The ***Olmstead*** decision. This said people with disabilities have a right to get services in the community instead of an institution.
- The HCBS Settings Rule. This says that people who get HCBS have the right not to be restrained or secluded.
- State laws and policies that say HCBS providers are not allowed to do things that hurt people.

But, a lot of behavior support services still do these things. Even when there are laws or policies saying HCBS should not do these things, some services still do them.

Restraint and seclusion are some of the most dangerous ways behavior support services try to "change" people's behavior. Restraint and seclusion hurt people very badly. Restraint and seclusion kill people.

Restraint and seclusion cause people a lot of trauma.

Restraint and seclusion are never okay for anyone. People with disabilities have been advocating to get rid of restraint and seclusion for a long time. Now, there are some laws and rules that limit how HCBS providers can use restraint and seclusion.

The HCBS Settings Rule says that people who get HCBS have the right to “freedom from coercion and restraint.” But not all states have taken restraint and seclusion out of their waivers. That means HCBS providers in many states can still restrain or seclude people.

Restraint and seclusion are not the only ways behavior support service providers use coercion on people with IDD who get HCBS. Behavior support service providers use coercion in other ways. Here are some other ways behavior support service providers use coercion:

- Telling a person they cannot have an item they like until they behave a certain way. This happens even if there is no reason for the person not to have the item.
- Telling a person that if they behave a certain way, they will not get a reward. For example: saying, “if you keep sleeping late, you cannot go to the park this weekend.”
- Ignoring a person until the person behaves a certain way, even if the person really needs help.

Some of the people ASAN interviewed talked about coercion in behavior support services. The people we talked to said:

- Behavior support service providers use coercion even when the services are supposed to be “positive.”
- When behavior support services use coercion, it is often because the people giving the services are trained very well.
- Coercion in behavior support services is a sign the services are not using the right kinds of support.

The people ASAN talked to thought:

- It is important for people with IDD to be able to set our own goals for behavior support services.
- Behavior support services should help people with IDD meet our goals without coercion, rewards, or punishment.

A big part of HCBS is that people have person-centered plans. Person-centered planning is a way of figuring out what services might help a person live the life they want to live. Person-centered planning starts by asking the person and their supporters about the person's:

- Needs.
- Wants.
- Goals.
- Hopes.

Then, the person-centered planning team figures out ways to help the person meet their needs, wants, goals, and hopes. The person-centered planning team thinks about what services could help the person live the life they want to live. The person-centered planning team then writes a person-centered plan. The person-centered plan talks about how different services will help the person live the life they want to live.

But a lot of the people ASAN interviewed said that many people with IDD get very bad person-centered plans. These plans are supposed to talk about the person's own goals. The person who gets HCBS is supposed to be in charge of the person-centered planning team and meetings.

But often, this does not happen. Often, the person-centered planning team does not even ask the person what their goals are. The person-centered planning team only asks the person's family or caregivers what their goals are for the person. The person-centered planning team does not look at what kind of services the person needs to live the life they want to live. The person-centered planning team just decides what services the person needs based on the person's type of disability.

Most people do not like it when someone else decides what their goals should be for them! People who get HCBS often feel upset and angry when someone else decides their goals for them. People who get HCBS are less likely to work towards the goals other people set for them. This is especially true if the person does not like the goals or think the goals are not helpful.

When someone does not work on the goals in their HCBS plan, other people say they are “non-compliant.” “Non-compliant” means the person is not doing what other people want them to do. This can lead to other people using coercion on the person.

For example:

Omar is autistic and has a mental health disability. When Omar gets upset, he scratches his face and neck until they bleed. Omar’s parents, support worker, and case manager all meet to talk about his HCBS goals for the year. They decide that Omar should have the goal of not scratching his face and neck anymore. They decide that Omar should get ABA to teach him not to scratch his face and neck anymore.

Omar does not like this goal. He thinks a better goal would be for him to find a mental health therapist and go to weekly therapy appointments. But nobody listens to what Omar wants. Omar tries to get out of going to ABA. He hides under his bed when he is supposed to get ready to go to ABA appointments.

Omar’s parents, support worker, and case manager see this. They decide that Omar should no longer get to play video games until he starts going to ABA. So they take away Omar’s video games. Omar is being punished for not working on a goal he did not want in the first place.

People with IDD do not get choices about the services we get.

We have talked about how even though HCBS and behavior support services are supposed to be “person-centered,” they often are not. But even when people with IDD get actual person-centered services, we do not get much choice in our services. There are a few reasons for this:

- The HCBS workforce crisis means there are often very few providers to get HCBS from.
- HCBS providers may have “menus” of services instead of changing services to meet people’s needs.
- Most IDD HCBS waivers let people direct their own services. But there are often barriers to actual self-direction.
- If a person is under guardianship, their guardian usually gets to make all the choices about the person’s services.

We will go over each of these reasons in more detail.

Reason 1: The HCBS workforce crisis means there are often very few providers to get HCBS from.

The HCBS workforce crisis means many HCBS providers do not have enough support workers to help everyone who gets HCBS. The HCBS workforce crisis has forced some HCBS providers to shut down and stop offering services. This means there are fewer providers for people who get HCBS to choose from.

This can be really hard for people who get HCBS. There might only be one HCBS provider in someone’s area who offers the services the person needs. Then, people in that area do not have any choice in their HCBS provider. People in that area can only get the services the one HCBS provider in the area offers. If a person does not like the provider, the person does not have a lot of choices. If the provider does not offer a service someone needs, that person does not have a lot of options.

For example:

Xenia is autistic and has a mental health disability. Xenia gets HCBS. Xenia lives out in the countryside. There is only one HCBS provider in her entire county. When Xenia gets upset, she burns her arms with a cigarette lighter. Xenia does not want to do this anymore.

Xenia asks the one HCBS provider in her county if they have behavior support services. The HCBS provider says they have behavior support services. But the behavior support services are just ABA. Xenia does not want to do ABA. But the HCBS provider in her county does not offer other behavior support services.

Reason 2: HCBS providers may have “menus” of services instead of offering services to meet people’s needs.

Even when people do have a real choice in their HCBS provider, it does not mean that everyone gets the services they need. One person ASAN interviewed talked about how some HCBS providers offered “menus” of services people could get.

Think about menus at restaurants. You can only order food that is on the menu. The restaurant might have different menus for different meals. For example, a breakfast menu, a lunch menu, a dinner menu, and a children’s menu. During each meal, you can only choose food from the menu for that meal. Some foods are only available on certain menus. For example, you might be able to get pancakes for breakfast or lunch, but not dinner.

“Menus” of services people who get HCBS work the same way. HCBS providers put together different “menus” of services for different types of disabilities. Then, people who get HCBS can only choose services from the “menu” for their particular disability.

For example:

Caring Hearts, Inc. is an HCBS provider. Caring Hearts, Inc. makes “menus” of services they offer people with different disabilities. Caring Hearts, Inc. makes one “menu” for people with cerebral palsy. Caring Hearts, Inc. makes a different “menu” for autistic people.

The “menu” for people with cerebral palsy says people with cerebral palsy can get occupational therapy. But the “menu” for autistic people says autistic people cannot get occupational therapy. The “menu” for autistic people says autistic people can only get ABA.

“Menus” of HCBS make it hard for people with IDD to get what services we need. People can only get services that are on the “menu” for their disability. They cannot get services that are not on the “menu” for their disability. Even if someone can get a service they need, it may not help them very much.

For example:

Kalla has an intellectual disability and a mental health disability. Kalla wants to go to a day program that can help with her mental health disability. Kalla gets services from Caring Hearts, Inc.. Caring Hearts, Inc. has day programs for people with mental health disabilities.

So Kalla asks Caring Hearts, Inc. if she can be part of their day program for people with mental health disabilities. Caring Hearts, Inc. says no. Caring Hearts, Inc. says that Kalla can only be part of the day program for people with intellectual disabilities. Caring Hearts, Inc. says that Kalla will not get anything out of the day program for people with mental health disabilities.

This is not true! But it means Kalla cannot get into a day program that would actually help her.

Reason 3: Most IDD HCBS waivers let people direct their own services. But there are often barriers to actual self-direction.

Some people who get HCBS through a waiver use self-direction. **Self-direction** is an option that lets 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. For example, choosing what services they need rather than just being assigned to services.
- Be more involved in the services they get. For example, being able to hire and fire their support workers without going through an HCBS provider.
- Have more responsibilities around their services. For example, having to talk to their case manager and support workers a lot more.

It can be hard to self-direct your services. But it can also be really helpful to self-direct your services.

Most state HCBS waivers let people with disabilities self-direct our services. Most state IDD waivers let people with IDD self-direct our services. But people with IDD are less likely to self-direct our own services than other people with disabilities. One study found that about 2 in 10 people with IDD who get HCBS self-direct their services. A similar study found that about 4 in 10 people with physical disabilities who get HCBS use self-direction.

There are barriers to people with IDD self-directing our own services. One barrier is that people with IDD who use self-direction do not actually have to be in charge of our services. We just talked about a study that found only 2 in 10 people with IDD who get HCBS self-direct their services.

The same study found that only about 2 in 10 people who used self-direction made most of the choices about their services. The rest of the people with IDD who have “self-directed services” do not make most of the choices about their services. Someone else makes the choices for the person. This could be:

- A family member.
- A guardian.
- A case manager.

Sometimes the person with IDD gets to make some choices about their services. But in most cases, someone else makes most choices for the person with IDD.

There is another big barrier to self-directed services for a lot of people with IDD. Many states say that only people in certain situations who get HCBS can direct their own services. A lot of states say that to self-direct their services, a person has to live in their own home or their family’s home. These states say that people living in provider-owned settings, like group homes, cannot self-direct their services.

For example:

Brian lives in a group home. Brian gets HCBS. Because Brian lives in a group home, he cannot self-direct his own services. Brian is stuck with whatever services the group home gives him. Brian’s group home does not offer the kinds of behavior support services that Brian wants.

Brian would like to hire his own support worker for behavior support services. If Brian could self-direct his services, he could hire a support worker to help him. But because Brian lives in a group home, he cannot self-direct his services. So he cannot hire extra support workers. Brian cannot get the kinds of behavior support services he wants.

A third barrier to people with IDD self-directing our services is that self-direction tends to be all or nothing. That means people on self-directed waivers have to direct almost all of their services themselves. People are usually not allowed to only self-direct some of their services.

For example:

Jolene gets HCBS. Jolene self-directs her own services. The self-direction waiver rules say that Jolene has to be in charge of all of her services. Jolene can get help from a case manager with some parts of the process. Jolele can get help from an HCBS provider to help her manage her HCBS budget. But Jolene still has to write her HCBS support plan on her own. Jolene still has to explain why she needs a service or item every time she needs one.

Jolene likes self-directing her HCBS. Self-direction makes it easier for Jolene to get weekly art therapy in her own home. She would not be able to get in-home art therapy if she was not self-directing her services. The weekly in-home art therapy helps Jolene. It makes her a lot calmer and happier.

But self-directing her services also means Jolene has to manage all her regular support workers. She is responsible for hiring all her support workers. She is responsible for filling out timesheets so her support workers can get paid. Jolene hates doing timesheets. She wishes she could get support workers through an HCBS provider. She wishes she could only self-direct some of her services and let an agency handle the rest.

Reason 4: If a person is under guardianship, their guardian usually gets to make all the choices about the person's services.

Some people with disabilities are under guardianship. **Guardianship** is 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. The person the court says can make choices for the person with a disability is called a **guardian**. Then, the person's guardian can make choices about things like:

- Where the person can live.
- What kinds of care or services the person can get.
- Who the person is allowed to see or be friends with.

Guardianship hurts people with disabilities. It takes away our rights to make choices about our own lives. When someone is under guardianship, their guardian can usually make choices about the HCBS they get. This is true even if the person has a "person-centered plan." This is true even if someone has self-directed services.

For example:

Shiloh is autistic and has a mental health disability. Shiloh is under guardianship. Shiloh's mother is Shiloh's guardian. Shiloh gets HCBS. His HCBS are supposed to be "person-centered."

Shiloh has self-directed HCBS. He is supposed to have more control over his HCBS. But because Shiloh is under guardianship, his mother gets to make all the decisions about his HCBS. Shiloh's mother gets the final say about what services Shiloh gets.

Shiloh's mother does not ask Shiloh what kinds of services he wants. None of Shiloh's HCBS providers ask what Shiloh wants, either. They only ask his mother. Shiloh is the one getting HCBS. But it is like what he wants from HCBS does not matter!

All of these are reasons why people with IDD often do not have a lot of choice and control over our HCBS. Not having a lot of choice and control over our HCBS hurts people with IDD. Not having choice and control makes it hard for us to get the HCBS we want and need. This is especially true when it comes to behavior support services.

People with IDD often get behavior support services for behaviors that hurt us or other people. Or, we get behavior support services for behaviors we are really embarrassed about. It can be really hard to not have control over services that are supposed to "help" with these behaviors. We should get as much choice and control as possible over behavior support services. But we often do not get much choice and control.

Mental health crisis services are not always available. When they are, they can be harmful.

People with IDD should be able to get good mental health services in the community. This is especially true of people with dual diagnosis. **Dual diagnosis** means someone has an IDD and a mental health disability.

But many people with IDD or dual diagnosis do not get good mental health services in the community. Mental health services are often not set up to help people with IDD. We talk more about why this is in the section "Mental Health Services and Behavior Support Services Are Different Things. But They Should Not Be Different Things."

People with IDD often have to rely on mental health crisis services. A mental health crisis is 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 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. Sometimes mental health crisis services happen in the community. Community-based mental health crisis services tend to be things like:

- Walk-in clinics that offer therapy without an appointment.
- Services that will send a therapist or social worker to the home of a person who is in a mental health crisis.
- 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. That means they are staffed and run by people who have mental health disabilities.

- Day programs for people with mental health disabilities. Day programs usually offer things like:
 - ◇ Therapy groups.
 - ◇ Medications.
 - ◇ Peer support. **Peer support** is a service where people with IDD or mental health disabilities can talk to a peer worker. A **peer worker** is another person with IDD or mental health disabilities. Peer workers get special training in helping other people with IDD or mental health disabilities.

Day programs for people with mental health disabilities are often called intensive outpatient programs or partial hospitalization programs.

Sometimes mental health crisis services happen in institutions. Institutions that offer mental health crisis services tend to be things like:

- Emergency rooms in hospitals. Emergency rooms can sometimes help a person in a mental health crisis calm down. Emergency rooms can also sometimes help people find mental health services in the community.

Some hospitals have separate psychiatric emergency rooms. Psychiatric emergency rooms are emergency rooms that just help people who are in mental health crises.

- Psychiatric hospitals and psychiatric wards at general hospitals. Psychiatric hospitals are hospitals that take care of people in mental health crises. Psychiatric wards are units that take care of people in mental health crises inside larger hospitals. Most people who are in mental health crises only stay in a psychiatric hospital or psychiatric ward for less than a week. But some psychiatric hospitals and psychiatric wards will hold people for weeks, months, or even years.
- Residential treatment facilities. Residential treatment facilities are smaller mental health institutions in a community. Residential treatment facilities are kind of like a cross between a psychiatric hospital and a group home. Residential treatment facilities focus on mental health services.

Residential treatment facilities have a lot of the same rules as psychiatric hospitals. Residential treatment facilities usually have more people living in them than a group home. But residential treatment facilities are often in a community, like many group homes.

- People usually stay at a residential treatment facility for a couple weeks to a few months. Some residential treatment facilities offer services for certain kinds of mental health disabilities, like addiction or eating disorders.

- Group homes. Some group homes offer specific mental health services for the people living there. Sometimes these are group homes meant for people with mental health disabilities. Sometimes these are group homes meant for people with dual diagnosis. Sometimes, the people in these group homes live there for years and years. Other times, these group homes only provide mental health crisis services for a few weeks or months.

All of these services are supposed to help people get through and recover from mental health crises. But there are a lot of problems with these services. One big problem is that there are not enough community-based mental health crisis services to help everyone who needs them. So many people have to use mental health crisis services in institutions. And mental health crisis services in institutions have all the same problems that institutions have.

Mental health crisis services should help people stay in the community. Mental health crisis services in institutions should get people back into the community as soon as possible. But a lot of the time, this does not happen. And a lot of the time, the mental health crisis service does not help solve the problem causing the mental health crisis.

For example:

Natalia is autistic and has depression. Natalia has been under a lot of stress from school lately. Natalia tells her therapist that she is thinking about hurting herself because she is so stressed out. The therapist tells Natalia to go to the hospital if she is thinking about hurting herself. Natalia goes to the hospital. The hospital emergency room sends Natalia to the hospital's psychiatric ward.

Natalia is not allowed to leave the psychiatric ward until a doctor says she can. She is not allowed to go outside. She is not allowed to see her friends. On the psychiatric ward, Natalia does not get much help. She gets medication that is supposed to make her feel better. But the medication just makes her tired all the time.

On the psychiatric ward, Natalia can go to a therapy group twice a day. But the therapy group goes too fast for Natalia. She cannot understand what is going on. One day, Natalia gets upset in the therapy group. So the therapist running the group has Natalia restrained and put in seclusion until Natalia can “calm down.”

Natalia stays on the psychiatric ward for a week. But she does not get help with what is stressing her out. And being restrained and secluded makes her even more stressed. The mental health crisis services did not help Natalia. They just gave her more trauma when she tried to get help.

Most states have some kind of mental health crisis services. But a lot of the time, these services are not accessible to people with IDD.

For example:

The Center for START Services is a group of researchers. They study how to make mental health services better for people with dual diagnosis. The Center for START Services looked at mental health crisis services in two states: Wisconsin and Rhode Island. The Center for START Services found that in Wisconsin and Rhode Island:

- There are not enough mental health crisis services in general.
- The mental health crisis services that do exist often do not want to accept people with IDD as patients.
- People with IDD and their families often have to rely on police or hospital emergency rooms for mental health crisis services.

When someone is having a mental health crisis, people around them often call 911 for emergency services. In many places, 911 sends police officers to respond to a call about someone having a mental health crisis. The police are not trained to respond to mental health crises.

The police carry guns. The police are trained to shoot people they think might hurt them. This is very dangerous for people in mental health crises. Across the United States, police have shot and killed many people in mental health crises. Across the United States, the police have shot and killed many people with IDD.

The police especially shoot and kill people of color. This is because of racism in police departments. Racism is treating people of color badly because they are not white. For more about racism and police violence, you can read:

- ASAN's toolkit on [equity and fairness](#).
- ASAN's toolkit on [structural racism in the United States](#).
- ASAN and Green Mountain Self Advocates' [booklet about police violence](#).

The police may not shoot or physically hurt the person who is having a mental health crisis. But the police still often hurt the person in other ways. Police often arrest people who are having mental health crises. The police will take the person having the mental health crisis to jail.

The person having the mental health crisis has not done anything wrong! But the police still arrest them and take them to jail. Then, the person has to sit in jail until the police figure out what to do with them. They can have to wait for hours or days. They may have to go to court because they were arrested. This can cause a lot of trauma for the person who is already having a mental health crisis.

The police might take the person to a psychiatric hospital or a general hospital with a psychiatric ward. The police might take the person to a psychiatric hospital or psychiatric ward even if the person does not want to go. Psychiatric hospitals and psychiatric wards are supposed to be better for people having mental health crises than jail. But psychiatric hospitals and psychiatric wards are still institutions. And institutions still hurt people, no matter how "nice" or "helpful" they look.

In some places, the police are not the ones who respond to 911 calls about people having mental health crises. In these places, the people who respond to people having mental health crises are trained to work with people in mental health crises. These people can include:

- Therapists.
- Social workers.
- Peer workers.

People trained in working with people in mental health crises are usually better at helping people in mental health crises. But many places only have police respond to people in mental health crises. And some places will send police officers along with people trained in working with people in mental health crises.

Also, people who are trained in helping people in mental health crises are usually not trained in helping people with IDD. This makes it hard for them to know how to best help people with IDD who are in mental health crises. This can make the mental health crisis worse for the person with IDD.

Another big problem with mental health crisis services is that people can only get them once they are in a mental health crisis. Mental health crisis services usually will not help people who are not in a mental health crisis. Mental health crisis services will usually tell people who are not in mental health crises to go to other mental health services, like mental health therapy.

But a lot of these services are not easy to get into. These services often have long waiting lists. These services are often not set up to help people with dual diagnosis. This makes it less likely that people can access mental health services before they are in a mental health crisis.

Mental health crises do not usually “come out of nowhere.” People in mental health crises have often been dealing with a lot of stress for a long time. But they often cannot get the mental health services they need to stop the mental health crisis from happening. So they often only get help after they fall into a mental health crisis and can get help from mental health crisis services.

Mental health crisis services tend to cost more than mental health services for people not in crisis. Mental health crisis services tend to involve institutionalization more than mental health services for people not in crisis. Mental health crisis services tend to cause more trauma for people than mental health services for people not in crisis.

ASAN thinks that mental health crisis services are important. But mental health crisis services cannot be the *only* mental health services people with IDD get. People with IDD need better access to general mental health services. We need better access to mental health services that can help prevent crises.

We do not have enough information on what type of behavior support services people can actually get.

One big problem we had while writing this toolkit is that nobody can agree on what “behavior support services” means. Different states had different definitions of behavior support services. And we could not find much information on what behavior support services people actually get in different states.

We looked at state websites that talk about the different waivers the states have. We looked at information states have given the federal government about their different waivers. We looked at surveys of people with IDD who get HCBS in different states. None of these places had information about what kinds of behavior support services different states’ waivers offer.

This was a big problem for us when we wrote this paper. It is also a big problem for people with IDD who are on a waiver. It is also a big problem for people with IDD who want to apply for a waiver. It is hard to find good information about what services you can get through a specific waiver.

And if you can find this information, the information is not usually in plain language. The information is usually only in hard language. Many people with IDD cannot read hard language. Plain language helps people with IDD understand information. If someone with IDD cannot understand information about their waiver, they will have a hard time. This makes it less likely they will feel like they actually have choices about their services.

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