



*Plain Language Version*

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

**Part 4: The Big Question:  
What Does “Behavior Support Services” Even Mean?**

# Words to Know in Part 4

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## **Appendix**

An extra part of a toolkit that gives more information.

## **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.

## **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.

## **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.

## **Data**

Facts and information about something.

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

LTSS someone gets in their home or in the community.

## **Institution**

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

## **Interviewing**

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

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

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

## **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 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.

## **Operant conditioning**

Changing someone's behavior using rewards and punishments.

## **Physical therapy**

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

## **Positive behavior supports (PBS)**

A newer kind of behavior support service that is based in ABA. PBS focuses more on community living and a person's own goals than ABA does. PBS also uses some ideas from other kinds of psychology.

## **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.

## **Psychology**

The study of how people think, feel, and act. Psychology includes behaviorism, but psychology is also bigger than behaviorism.

## **Punishment**

Something a person gets for having “bad behavior.”

## **Research**

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

## **Restraint**

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

## **Reward**

Something a person gets for having “good behavior.”

## **Seclusion**

Locking someone in an empty room.

## **Speech therapy**

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

## **Trauma**

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

# The Big Question: What Does “Behavior Support Services” Even Mean?

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In this part, we talk about what “**behavior support services**” means. One thing we found in our **research** is that nobody can agree on what behavior support services are. Everyone has different ideas of what the term “behavior support services” means. Everyone also has different ideas of what kinds of services can be behavior support services.

But there was one thing most of the people we **interviewed** could agree on. That was about how “**behavior**” gets used to label people with IDD as less human. People talked about how **HCBS providers** use “**challenging behavior**” as a reason to not let people have control over their lives. They talked about how people with “challenging behavior” get stuck in behavior support services that hurt them.

Another thing that a lot of people talked about was how confusing the term “challenging behavior” is. The people we interviewed told us how there is no one definition for “challenging behavior.” This means that “challenging behavior” gets used to talk about many different kinds of behavior. Some “challenging behavior” is actually dangerous to the person doing it or to other people. But other “challenging behavior” is just annoying to other people.

We will talk about all these things in more detail in this part.



## *Everyone has different ideas of what “behavior support services” are.*

Most of the material we read and most of the people we interviewed *kind of* agreed on what “behavior support services” means. Most people agreed “behavior support services” means services that help people deal with behavior that makes it hard for them to live the lives they want. But people did not agree on much beyond that.

Different people had different ideas on what kinds of services fit under the “behavior support services” label. Some people thought only certain services, like **ABA** or **PBS**, could be behavior support services. Other people thought that other kinds of services could be behavior support services. Some of these other services included:

- **Occupational therapy**, that helps people learn and practice skills they need in their everyday lives.
- **Speech therapy**, that helps people learn and practice ways of communicating that work for them.
- **Physical therapy**, that helps people move their bodies in ways that do not cause pain or injury.
- **Mental health therapy.**

Some of the people did not like the label “behavior support services” at all. These people thought that “behavior support services” was not a useful way to talk about services.

We looked at how different states talked about behavior support services, too. We looked at what kinds of behavior support services states would pay for. Some states would only pay for certain services, like ABA or PBS, as behavior support services. Other states would pay for a lot of other services as behavior support services.

Some states said that anyone who gets HCBS could get behavior support services. Other states said only specific people, like people who live in group homes, could get behavior support services.

We think that what behavior support services a state pays for shows what the state thinks is important.

For example:

Some states only pay for certain services, like ABA or PBS, as behavior support services. These states do not pay for other services, like speech therapy or mental health therapy, as behavior support services. These states might require people with IDD to get ABA or PBS before they can get other services. We think these states think it is more important to “control” people with IDD’s behavior. We think these states think it is less important to let people with IDD live the lives they want to live.

Here is another example:

Some states pay for a lot of services as behavior support services. These services can be things like ABA or PBS, or things like speech therapy or mental health therapy. These states do not require people with IDD to get ABA or PBS before they can get other services. We think these states think it is more important to let people with IDD live the lives they want to live. We think these states think it is less important to “control” people with IDD’s behavior.

## *Other people use “behavior” to call people with IDD less human.*

Nobody really agrees on what services should be part of behavior support services. Nobody really agrees on how to provide good behavior support services for people with disabilities. These two things are related!

A lot of behavior support services in the past have used a lot of behaviorism. In the past, “behavior support services” meant “only ABA and no other services.” This was because providers and states wanted to control the behavior of people with IDD. Providers and states did not want to help people with IDD live the lives the people with IDD wanted to live. This is still happening in some places, and some providers and states still want to control the behavior of people with IDD.

A lot of the time, providers and states use “behavior” as a label to call people with IDD less human. Providers and states might say things like, “Oh, that person is not ready for the **community** until they get control of their behaviors.” Or, providers and states might say things like, “That person has challenging behavior, so they need to stay in an **institution** until their behavior changes.”

Everyone can live in the community, and nobody needs to live in an institution! Even if someone has behaviors that cause them a lot of trouble, they still can live in the community. Living in the community is a human right, and nobody should have to earn living in the community. Using behavior as a reason to keep someone in an institution is treating that person as less human because they do certain behaviors.

The language around behavior support services has changed a lot, just like how language around disability has changed a lot.

For example:

Other people used to call people with intellectual disabilities the r-word. Almost everyone used the r-word to talk about people with intellectual disabilities. The r-word was “the right way” to talk about people with intellectual disabilities. But people with intellectual disabilities started speaking up about how the r-word hurt them. People with intellectual disabilities talked about how they were people first, and worked to get other people to stop using the r-word. Now, most people do not use the r-word to talk about people with intellectual disabilities.

Here is a similar example about behavior support services:

Other people used to say that people with IDD had “bad behavior.” Over time, other people realized that calling behavior “bad” hurt people with IDD. Over time, other people started saying people with IDD had “challenging behavior” instead. Other people said this was because “challenging behavior” judged people with IDD less than “bad behavior.” Other people said that saying “challenging behavior” hurt people with IDD less than saying “bad behavior.”

But in both cases, even though people started using a different word, how they thought about people with disabilities did not change. Other people stopped calling people with intellectual disabilities the r-word, and started talking about them as “people first.” But other people still did not see people with intellectual disabilities as people first. Other people still did not see people with intellectual disabilities as real people like them.

Other people stopped saying people with IDD had “bad behavior,” and started talking about how people with IDD had “challenging behavior.” But other people still *thought* that people with IDD had “bad behavior.” Other people kept treating people with IDD as if we had “bad behavior,” and punishing people with IDD for having “bad behavior.”

In both cases, the words other people used changed, but what the other people thought about people with disabilities did not change. The way other people treated people with disabilities did not change.

ASAN thinks changes to language can be good. We think that the language people use is powerful. Language can change how other people see people with disabilities. But language is not the only part of how other people see people with disabilities. It is not enough for other people to change how they *talk* about people with disabilities. Other people also need to change how they *think* about and *treat* people with disabilities.

ASAN does not care as much if other people change the language they use about people with disabilities. We care if other people change how they think about and treat people with disabilities. Without those things, language changes are not as helpful.

One problem with a lot of behavior support services is that these services use things a person likes as rewards for “good behavior.” This is especially common with behavior support services that use behaviorism. A lot of behavior supports services providers will figure out what kinds of things someone likes to do or have. Then, the providers will not let the person have those things unless the person has “good behavior.” When providers do this, they use the thing the person likes as a reward. A **reward** is a thing someone gets because they have “good behavior.” Rewards are part of operant conditioning.

Here is an example:

Ginny is 25 and is autistic. Ginny moves out of her parents' house and into an apartment owned by her HCBS provider. Ginny's apartment is a **provider-owned setting**. When Ginny lived with her parents, she liked to have a glass of wine with dinner two or three nights a week. Having a glass of wine was comforting for Ginny, and made her feel relaxed and happy.

The HCBS provider for Ginny's apartment decides that Ginny can't have a glass of wine with her dinner. She has to earn a glass of wine with dinner through "good behavior," and she is only allowed one glass of wine a week. The provider calls the one glass of wine a week a "reward" for Ginny's good behavior. Ginny does not like this. The provider is using something Ginny likes as a way to force her to have "good behavior."

Some people think it is okay to use things people like as rewards for good behavior, but this is not how most adults without disabilities live their lives. Most adults without disabilities do not have to earn things they find comforting through "good behavior."

Let's go back to Ginny's example:

There are other apartments in Ginny's building that are not provider-owned. People without disabilities live in those apartments. The adults without disabilities who live in the other apartments can have glasses of wine whenever they want. They do not need permission to have a glass of wine with dinner, or to earn a glass of wine through "good behavior." Only Ginny has to do that. Ginny is being treated differently because she has a disability, and that is not fair.

Some behavior support services also use punishments. **Punishments** are the opposite of rewards. A punishment is a thing someone gets because they have “bad behavior,” and are also part of operant conditioning.

Punishments can look like:

- Taking something away from someone.

For example: Not letting a child play with toys because they pulled their friend’s hair.

- Not giving someone something they want.

For example: Not letting someone go to the park on the weekend because they did not do their chores.

- Making someone do something they do not want to do.

For example: Someone having to pay a traffic ticket because they did not stop for a red light.

- Hurting someone in some way, like kicking them, hitting them, or yelling at them.

Not as many behavior support services providers use punishments anymore. Part of positive behavior support (PBS) is supposed to be not using punishments, and using punishments to change behavior can look really bad. O. Ivar Lovaas used punishments when he hit autistic kids to change their behavior.

A lot of behavior support services providers do not want people to think they hurt people with punishments. But some behavior support services providers still use punishments. And a lot of people with disabilities who get behavior support services say not earning a reward still feels like a punishment.



Let's go back to Ginny's example:

If Ginny does not do all her chores during the week, her apartment provider does not let her have a glass of wine with dinner on Fridays. The provider says Ginny is "working towards" a glass of wine on Fridays. The provider says the glass of wine on Fridays is a reward for Ginny doing all her chores. But Ginny feels like *not* getting the glass of wine is a punishment for not doing all her chores. Ginny knows her neighbors can drink wine whenever they want, and don't have to do all their chores before they can have a glass of wine. Ginny feels like she is being punished for having a disability.

Not all behavior support services use rewards and punishments. But even when behavior support services do not use rewards and punishments, behavior support services can still use coercion. **Coercion** means trying to change people's behavior even if the people do not want to change their behavior. Behavior support services use coercion to force people with IDD to do things they do not want to do.

Behavior support services can also still collect a lot of data about someone's behavior. **Data** is facts and information about something.

People who get behavior support services often know that the behavior support services providers are looking closely at their behavior. People who get behavior support services often know that the behavior support services providers are taking lots of notes on their behavior. This can make people who get behavior support services really uncomfortable. It can make people who get behavior support services feel like they cannot talk about what is going on without being punished. It can make people who get behavior support services feel like they have to behave "correctly" all the time, no matter what.



Behavior support services can have a lot of control over people's lives. This can cause a lot of trauma for people in the behavior support services. **Trauma** is changes in how a person thinks, feels, and behaves after a scary event.

*“Challenging behavior” can mean a lot of things.*

Some behavior support services providers use the term “challenging behavior.” But nobody can agree on what “challenging behavior” actually means. Some people use “challenging behavior” to mean “behavior that puts someone in actual danger of getting hurt.”

For example:

Bex is autistic and has depression. Bex feels sad all the time, and does not know how to deal with feeling sad. So Bex hurts themselves by cutting their arms with a knife. Bex's behavior puts them in actual danger of getting hurt, since they could seriously hurt themselves by cutting their arms! Some people might say that Bex is doing a “challenging behavior” when they cut their arms.

Other people use “challenging behavior” to mean “any behavior that someone finds annoying or hard to deal with.”

For example:

Osbaldo is 7 and in the 2nd grade. Osbaldo does not have a lot of friends. Osbaldo wants to make friends, but he doesn't know how to. So Osbaldo talks a lot during class. Osbaldo figures out that if he makes funny jokes during class, other people will pay attention to him. Osbaldo's teacher does not like that Osbaldo talks a lot, and does not like having to tell Osbaldo to stop talking. Osbaldo's teacher says Osbaldo has “challenging behavior.”

These are two very different ideas of what “challenging behavior” is. ASAN thinks it is bad when people use “challenging behavior” to mean “any behavior that someone finds annoying or hard to deal with.” This is for a few reasons:

- Not every “challenging behavior” needs behavior support services.
- When “challenging behavior” can mean anything, it is hard to tell what it means.
- “Challenging behavior” does not usually talk about what is causing the behavior.

We will discuss each of these problems next.

### Reason 1: Not every “challenging behavior” needs behavior support services.

A lot of people get sent to behavior support services because they have “challenging behavior.” But not every “challenging behavior” needs behavior support services. A lot of “challenging behavior” happens because someone has a need that is not being met. If the person’s needs were met, they would not do the “challenging behavior.”

For example:

Petra has an ear infection. Her ear is really painful and itchy. Petra keeps hitting her ear with her hand, which makes the ear infection pain go away for a little bit. Petra does not have a way to tell other people she has an ear infection. People around Petra see that she is hitting her ear, and say she has “challenging behavior.” The people around Petra say she needs behavior support services to teach her not to hit her ear. But what Petra really needs is medicine to treat her ear infection! If Petra’s ear infection got treated, she would not hit her ear.

## Reason 2: When “challenging behavior” can mean anything, it is hard to tell what it means.

A lot of people use “challenging behavior” to mean many different things. These people might use “challenging behavior” to mean “behavior that puts someone in actual danger of getting hurt.”

But these people also might use “challenging behavior” to mean “any behavior that someone finds annoying or hard to deal with.” These are two very different ideas, and they need two different solutions.

For example:

In the section above, we talked about Bex and Osbaldo. Bex and Osbaldo both have “challenging behavior.” Bex’s “challenging behavior” is that they cut their arm with a knife, and Osbaldo’s “challenging behavior” is that he talks a lot in class.

Bex’s behavior puts their health and safety at risk, but Osbaldo’s behavior does not put anyone at risk. Other people just find it annoying.

Bex and Osbaldo need different kinds of help. Bex needs mental health therapy, and Osbaldo needs ways to not talk so much during class.

But if someone just said Bex and Osbaldo both have “challenging behavior,” none of that would be clear. Someone else might hear that Bex and Osbaldo both have “challenging behavior.” That person might think that both Bex and Osbaldo are hurting themselves. Or, that person might think that Bex and Osbaldo just need help to stay on topic during class. But Bex and Osbaldo have very different needs!

### Reason 3: “Challenging behavior” does not usually talk about what is causing the behavior.

When people talk about “challenging behavior,” they often do not talk about *why* a person is doing a certain behavior. All behavior happens for a reason. People behave in certain ways to express needs and emotions. People behave in certain ways because it feels good. But the “challenging behavior” label does not talk about those reasons. “Challenging behavior” only says that someone’s behavior is hurting someone or annoying someone. It is important to look at *why* someone is doing a specific behavior.

For example:

We have talked about Bex, Osbaldo, and Petra. Bex, Osbaldo, and Petra all have “challenging behavior.” Bex cuts their arm with a knife, Osbaldo talks during class, and Petra hits her ear with her hand.

Bex, Osbaldo, and Petra all have different reasons for doing their behavior. Bex feels sad all the time and does not know how to deal with being sad. When Bex cuts their arm, they feel less sad for a bit. Osbaldo wants to make friends but does not know how to. Osbaldo finds that if he makes funny jokes in class, people will pay attention to him. Petra has an ear infection, and when Petra hits her ear, the pain from her ear infection goes away for a little bit.

Bex, Osbaldo, and Petra all have different reasons for their behavior, and they all need different kinds of help for their behavior. But just having a “challenging behavior” label does not tell anyone about why they need help.

ASAN does not like it when people use “challenging behavior” to mean “any behavior that someone finds annoying or hard to deal with.” Using “challenging behavior” this way makes it hard to tell when “challenging behavior” might actually hurt someone. There is a big difference between “behavior that is annoying” and “behavior that might actually hurt someone.” Different kinds of behavior have different causes and need different kinds of support. Using “challenging behavior” to mean both “behavior that is annoying” and “behavior that might actually hurt someone” makes it hard to tell what support someone needs.

Some of the people ASAN interviewed talked about people using “challenging behavior” to mean “behavior that is annoying.”

For example:

One person we interviewed talked about a woman they once met. The person we interviewed had been asked by the woman’s support staff to meet with the woman. The support staff said that the woman liked to sit in her room and cut pictures out of magazines. The support staff said that cutting pictures out of magazines was “challenging behavior.” The support staff said that the woman needed behavior support services because she cut pictures out of magazines.

Cutting pictures out of magazines is not “challenging behavior.” Someone does not need behavior support services because they cut pictures out of magazines to relax. The woman’s support staff may have found it weird or annoying that she liked to cut pictures out of magazines. But that did not mean the woman had “challenging behavior.”

ASAN has talked before about how people use “challenging behavior” to mean different things. We have talked about how it is not good when people use “challenging behavior” to talk about behavior that is annoying but does not hurt anyone. We talk about this more in our resource [“For Whose Benefit? Evidence, Ethics, and Effectiveness of Autism Interventions.”](#)

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, or 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, and decides the new, worse behavior needs to stop or change. Then, the process starts back over at step 1.

Some of the people ASAN interviewed talked about how some states still let providers hurt people with disabilities who have “challenging behavior.” Some states still let providers use restraint and seclusion on people who have “challenging behavior.”

**Restraint** is when someone stops someone else from moving. This can mean someone holding another person down, or tying a person down to a chair. It can mean giving someone medication to make them too tired to do much.

**Seclusion** is when someone locks someone else in an empty room. The person cannot leave the room for a certain amount of time. Sometimes, the person might get hurt by getting pushed or pulled into the room. Sometimes the room is too hot or too cold. Sometimes the person will get left there for a very long time. They may get hungry or thirsty, or need to use the bathroom.

Restraint and seclusion hurt people, and are very dangerous. People have gotten hurt very badly because someone restrained them or put them in seclusion. People have died because someone restrained them or put them in seclusion. Nobody should ever be restrained or put in seclusion.

A lot of the time, states say they only allow providers to restrain someone or put them in seclusion if the person has “challenging behavior.” The states use “challenging behavior” to mean “behavior that could hurt someone really badly.” But providers do not just use restraint and seclusion for behavior that could hurt someone really badly. Providers use restraint and seclusion for behavior that they find annoying, too. This is wrong.

ASAN thinks nobody should ever use restraint and seclusion. ASAN also thinks nobody should ever use some kinds of behavior support services, like ABA. ASAN thinks this even when someone has behavior that could really hurt someone. Even when people have behavior that could really hurt someone, restraint and seclusion will not help with the behavior. Even when people have behavior that could really hurt someone, ABA will not help with the behavior.

All behavior happens for a reason. People behave in certain ways to express needs, express emotions, and because it feels good. This is true even when the behavior could really hurt someone.

ASAN thinks that provider’s need to figure out *why* someone is having a certain behavior, and work with the person to solve whatever problem is causing the behavior. If the person needs something, ASAN thinks the provider should figure out how to meet that need. If the person is trying to tell people something with their behavior, ASAN thinks the provider should figure out how to help the person say that.



Some people think that HCBS providers should not use the term “challenging behavior” any more, and ASAN agrees with this. We think “challenging behavior” is not a good way to talk about behavior that gets in the way of people living the lives they want to live. But we also think that getting rid of the term “challenging behavior” is not enough.

The terms other people use to talk about people with IDD’s behavior are important. These terms show what other people think is important to talk about when talking about people with IDD’s behavior. When people use the term “challenging behavior,” they show that they think it is not important to talk about *why* someone does a behavior. When people use the term “challenging behavior,” they show that they think it is not important to meet people with IDD’s needs that cause “challenging behavior.” These are bigger problems within HCBS and behavior support services!

ASAN thinks HCBS providers should not use the term “challenging behavior” any more, but we also think HCBS needs to change. We especially think behavior support services need to change.

The way HCBS and behavior support services are run now makes it hard for people with IDD to:

- Make their own decisions.
- Say what is important to them.
- Get services that meet their needs.



This needs to change! HCBS and behavior support services need to focus more on helping people with IDD:

- Get good health care.
- Learn how to communicate in ways that work for the person. **Communication** is the different ways people tell each other information and ideas.
- Deal with big emotions and mental health crises. 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.
- Live safely in the community.
- Do things that matter to the person, like having a job or seeing friends a lot.
- Meet goals that the person has for themselves.

(We talk a lot more about these goals in Appendix A of this toolkit. To read Appendix A, go to part 8 of this toolkit.)

Just getting rid of the term “challenging behavior” will not solve these problems. There need to be bigger changes in how providers give HCBS and behavior support services to people with IDD. In this toolkit, we will talk about how states and providers can change HCBS and behavior support services. These changes can help meet people with IDD’s needs in better ways.

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