

Plain Language Version

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

Part 7: To Finish

Words to Know in Part 7

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.

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.

Deinstitutionalization

Moving people with disabilities out of institutions and into the community.

Guardianship

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

HCBS Settings Rule

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

Home and community based services (HCBS)

LTSS someone gets in their home or in the community.

Institution

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

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 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.

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.

Providers

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

Punishment

Something a person gets for having “bad behavior.”

Research

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

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.

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.

To Finish

We talked about a lot in this toolkit! We talked about what **behavior support services** are and how they are part of **HCBS**. We talked about **community living** and **deinstitutionalization**. We talked about the **research** we did for this toolkit. We talked about the problems with behavior support services right now. And we talked about what changes we want to see in behavior support services and HCBS in general.

What did we do for this toolkit?

We did a lot of research for this toolkit. We read a lot of materials about behavior support services. We talked to a lot of people who knew a lot about behavior support services. We looked at the problems with behavior support services right now. We looked at how behavior support services can get better. Then, we wrote this toolkit.

What did we find out from our research?

We learned a lot doing research for this toolkit. It would be very hard to quickly talk about everything we learned in this part. But we found that most of the things we learned fell under three big ideas. These ideas are:

- Behavior support services try to control people with IDD. This is because they do not see us as full human beings.
- When people with IDD have “**challenging behavior**,” it is often a normal response to other people treating us badly.
- Behavior support services have gotten better, but still need to change a lot.

We talk about all three ideas in more detail in this section.

Behavior support services try to control people with IDD. This is because these services do not see people with IDD as human beings.

There are many different kinds of behavior support services. And, different service **providers** often have different ways of providing the same kinds of behavior support services.

But there is one big thing most behavior support services have in common. Most behavior support services try to control people with IDD's **behavior**. This is because most behavior support services do not see people with IDD as fully human.

Behavior support services try to control people with IDD's behavior in many ways:

- Behavior support services use **ABA** and other kinds of **behaviorism** to change our behavior.
- Behavior support services use **rewards** and **punishments** to change our behavior.
- Behavior support services use **restraint, seclusion, and coercion** to change our behavior.
- Behavior support services say we are being "bad" or "acting out" when we try to show our needs are not being met.

All these things hurt people with IDD.

If behavior support service providers want to treat people with IDD better, those providers need to start seeing us as fully human. Service providers need to start giving people with IDD choices about our lives and services. Service providers need to stop trying to control people with IDD's behavior just because they find it "challenging." Service providers need to listen to people with IDD when we say the way service providers treat us often hurts us.

“Challenging behavior” is often a normal way of responding to bad treatment.

Often, service providers will say that a person with IDD has “challenging behavior.” The service provider then uses the person’s “challenging behavior” as a reason to put the person in services that hurt them. But “challenging behavior” is often a normal way of responding to bad treatment. Service providers treat people with IDD very badly. Service providers often do not let us make choices about our lives. Service providers often treat us like children even though we are adults. Service providers often do not listen when we tell them we do not like how they treat us.

Most people without disabilities do not like it when other people try to control their lives. Most people without disabilities do not like it when other people use rewards and punishments to change their behavior. It is no different for people with disabilities. When other people try to change and control our lives, we are allowed to be angry. We are allowed to be upset. We are allowed to show and tell others that we do not like what they are doing.

When people without disabilities get angry about being treated badly, other people do not say they have “challenging behavior.” It should be the same for people with disabilities. Calling our responses to bad treatment “challenging behavior” treats us like we are less human.

For example:

In part 5, we gave an example involving Amy. 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.”

If Amy did not have a disability, everyone would say it was unfair for the group home to treat her like that. If Amy did not have a disability, everyone would say she was right to break the rules. But because Amy has a disability, the group home says she has “challenging behavior.” Even though she is just doing what other adults her age would want to do.

Behavior support services have gotten better over the years. But they still have a long way to go.

Behavior support services have gotten better over the years. More behavior support services now talk about people with IDD’s mental health. Fewer behavior support services now use ABA or other types of behaviorism. More behavior support services now let people with IDD set our own goals for services. These are good changes!

But a lot of behavior support services are still very bad. A lot of behavior support services still use coercion, restraint, and seclusion to control people with IDD. A lot of behavior support services still use ABA and other types of behaviorism. A lot of behavior support services still think that people with IDD cannot have **mental health disabilities**.

Behavior support services need to keep changing. Behavior support services need to work with people with IDD to meet our actual needs. Behavior support services and other HCBS need to get rid of restraint, seclusion, and coercion. Behavior support services and other HCBS need to get rid of ABA and other kinds of behaviorism. Until behavior support services and other HCBS do those things, they will not make a whole lot more change.

What changes can HCBS and behavior support services make to get better?

ASAN thinks that HCBS and especially behavior support services can change to get better. We think HCBS and behavior support services can change in ways like:

Providing more and better mental health support for people with IDD.

- Making sure **support workers** know how best to help people with IDD.
- Working more with other kinds of disability services, like **mental health services** or **occupational therapy**.
- Focusing more on the goals people with IDD have for our own services.
- Giving people with IDD more choice and control over our own services.
- Making sure people with IDD can get services in the **community** instead of **institutions**.
- Talking to people who get services to make sure the services are doing the right thing.

All of these are important changes. All these changes will take work. All these changes will take time. Even though these changes will take work and time, they are still worth doing. These changes will make people with IDD's lives better.

Why is this important?

The things we talked about in this paper are not new ideas. In 1992, two disability professionals published a report. The report was called *Supporting People With Severe Reputations in the Community*. The report talked about how support providers can help people with IDD who have a lot of “challenging behavior.”

A lot of the things we talk about in this toolkit were in *Supporting People With Severe Reputations in the Community*. Both talk about how people with IDD do not get good services. Both talk about how people with IDD get trapped in institutions. Both talk about how people with IDD do not get choices in our lives.

It has been over 30 years since *Supporting People With Severe Reputations in the Community* was published. Some things have changed since then. There have been new laws, rules, and policies, like:

- The **Olmstead** court case.
- The **HCBS Settings Rule**.
- State changes to make more people able to get Medicaid and HCBS.

There has been more research showing things like:

- People with IDD can have mental health disabilities.
- People with IDD can live in the community with everyone else.
- Institutions and **guardianship** are bad for everyone.
- There are better ways to do behavior support services than ABA.

Some behavior support services and other HCBS have changed. Some behavior support services and other HCBS have gotten better. But a lot of behavior support services and other HCBS have stayed the same.

The things we talk about in this toolkit matter because they affect people with IDD's lives. People with IDD deserve to have good lives like everyone else. We deserve to make choices about our lives like everyone else. We deserve to live in the community with everyone else. Behavior support services and other HCBS can help us get those things. But these services can only help us if they see us as human. These services can only help us if they treat us like we can make choices for ourselves. These services can only help us if they listen to us and take us seriously.

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