



*Plain Language Version*

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

## **Part 3: How We Made This Toolkit**

# Words to Know in Part 3

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## **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.

## **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.

## **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.

## **Data**

Facts and information about something.

## **Deinstitutionalization**

Moving people with disabilities out of institutions and into 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.

## **Interviewing**

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

## **Literature review**

A way to gather information about a topic. During a literature review, you look at different materials people have written about your topic and take notes on the materials.

## **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.

## **Mental health therapy**

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

## **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.

## **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.

## **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.

## **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.

## **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.

## **Survey**

When scientists ask people about a specific topic and write down what the people say.

## **Themes**

Big ideas that many different people talked about in their interviews.

## **Trauma**

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

## How We Made This Toolkit

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In this part, we talk about the steps we took to make this toolkit. We did research around **behavior support services** to make this toolkit. **Research** is a way that people learn about the world. People do research to learn new things. Research happens when people:

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

When we did research to make this toolkit, we wanted to answer these questions:

- What are behavior support services?
- What are the problems with behavior support services right now?
- How can we solve these problems and make behavior support services better?

To do this, we did a few things.

First, we read what other people have already written about behavior support services. We took notes on what we read.

Then, we talked to people who know a lot about behavior support services. Some of the people we talked to had worked in behavior support services. Some of the people we talked to had gotten behavior support services before. When we talked to these people, we took notes.

Finally, we looked at our notes from reading and talking to people. We looked at the big ideas people wrote and talked about. We used these big ideas to write this toolkit.

We will talk about each of these steps in more detail in this part.



## Step 1: Literature review

We wanted to find out what kinds of behavior support services states and **providers** are giving people with disabilities. So we did a literature review. A **literature review** means that we looked at different materials people have written about behavior support services. We read all those different materials. We took notes on the different materials. Then we used our notes to help us write about different kinds of behavior support services.

Some of the materials we read and took notes on included:

- Research scientists have done about **positive behavior supports**.
- Research scientists have done about how different kinds of behavior support services help people with disabilities.
- A paper that compared different rules and policies states have for behavior support services.
- Research scientists have done about mental health care for people with IDD.
- Research scientists have done about trauma in people with IDD. Sometimes, people are in scary situations that hurt them. The scary situation can change how a person thinks, feels, and behaves. These changes are called **trauma**. Trauma can last a long time. A lot of people with IDD have trauma.
- Papers and blog posts people with IDD have written about their experiences with mental health care and trauma.
- Information on what people with IDD who get behavior support services like about those services. Some of this information came from things people with IDD have written about their experiences with behavior support services. Some of this information came from surveys. A **survey** is when scientists ask people about a specific topic and write down what the people say. The surveys were about people's experiences with behavior support services.

- Information about how much money states spend on behavior support services for people with IDD every year.

We read about 50 different materials for our literature review. We also read other materials about behavior support services as we wrote this toolkit. Some of these materials came from people we interviewed for this toolkit. We will talk more about the interviews in the next section.

## *Step 2: Interviews with people who know about behavior support services*

After we did the literature review, we started to interview people. **“Interviewing”** means we talked to different people about behavior support services. We talked to people who knew a lot about behavior support services. We wrote down what the people said about behavior support services. We used what the people told us to write this toolkit.

Before the interviews, we wrote questions to ask the people we interviewed. We wrote 2 sets of questions. The first set was for people who knew a lot about policies and rules around **HCBS** and behavior support services. The second set was for people with IDD who received behavior support services and their family members. The second set of questions was in plain language.

We interviewed about 25 people. Some of the people knew a lot about policies and rules related to HCBS or behavior support services. Some of the people were researchers who study HCBS or behavior support services. **Researchers** are people who do research as their job. Some of the people knew a lot about providing people with IDD HCBS or behavior support services. Some of the people were people with IDD who get behavior support services. Some of the people were parents of people with IDD who get behavior support services.

Each interview was about 90 minutes (1 and a half hours) long. We held the interviews on Zoom. We used a semi-structured interview format.

“Semi-structured” means that we started out with a list of questions to ask each person we interviewed. We tried to ask all the questions during each interview. But we also talked about what the person we were interviewing wanted to talk about. If the person we were interviewing wanted to talk about something we did not ask a question about, we talked to them about it.

We took notes on what people said during the interviews. We also recorded the interviews. After we held the interviews, we transcribed the interviews. “Transcribed” means we wrote down what people said in the interview.

We used our notes and the interview transcripts to help us write this toolkit.

### *Step 3: Finding common themes*

After the interviews, we started looking through our interview notes and transcripts. We read through our notes and transcripts carefully. We looked for common themes in the notes and transcripts. **Themes** are big ideas that many different people talked about in their interviews. We looked for themes to find out what the most important ideas to talk about in this toolkit were. If a lot of people talked about the same theme, it was probably important to talk about in the toolkit.

We found these themes in our interviews:

- People do not agree on what different terms within behavior support services mean.
- IDD services and mental health services do not talk to each other.
- Behavior support services do not meet people’s needs and need to change.
- There are not enough resources (like people and money) to make sure everyone gets good behavior support services.

- There are a lot of problems with ABA and behaviorist ways of doing behavior support services.
- Behavior support services need to focus a lot more on what the person getting the services wants.
- More schools are using behavior support services. But these services often do not think about what students need and want.
- COVID-19 has made it hard for behavior support services to find workers. This makes it hard for people to get services.
- A lot of behavior support services focus on taking on people's behavior instead of building relationships with people.

We will talk about each of these themes now. We will also talk about these themes more in a later part of the toolkit.

## Theme 1: People do not agree on what different terms within behavior support services mean.

Different people we interviewed had different ideas of what different terms within behavior support services mean. This especially happened with what people thought "positive behavior supports" meant. Different people also had different ideas of what specific services behavior support services should include.

## Theme 2: IDD services and mental health services do not talk to each other.

A lot of 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.

People with both IDD and mental health disabilities need services that understand both IDD and mental health disabilities. **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.

But IDD services and mental health services tend to be very separate. They tend to be run by separate providers. They tend to be paid for by different parts of **Medicaid**. IDD and mental health services do not talk

to each other that much. There are not many 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.

### Theme 3: Behavior support services do not meet people's needs and need to change.

A lot of the systems that provide behavior support services are really old. These systems started during **deinstitutionalization** in the 1970s. These systems started as a way to get people with IDD into the community.

Over time, people with IDD's needs have changed. Fewer people with IDD now have ever lived in an **institution**. What we know about IDD has also changed. We know a lot more about what works for people with IDD and what does not work.

But behavior support services often have not changed. The systems that provide behavior support services often have not changed. People we interviewed talked about how behavior support services need to change. Some of the people we interviewed talked about the ways behavior support services are changing.

### Theme 4: There are not enough resources (like people and money) to make sure everyone gets good behavior support services.

Providing good behavior support services costs money. Providing good behavior support services means providers hiring and training support workers.

But there is not enough money to pay for good behavior support services for people with IDD. Part of this is because HCBS and Medicaid do not get enough money.

Providers often cannot find and keep enough support workers to give people with IDD good behavior support services. Support worker jobs often do not pay a lot of money. So support workers tend to leave their jobs when they find a different job that pays better.

COVID-19 has also caused a lot of problems for support workers and providers. We will talk about the problems COVID-19 has caused in Theme 8.

## Theme 5: There are a lot of problems with ABA and behaviorist ways of doing behavior support services.

A lot of the people we interviewed talked about how many behavior support services use **behaviorism**. ABA uses behaviorism. A lot of kinds of PBS use behaviorism. Some other kinds of behavior support services also use behaviorism.

Most of the people we interviewed did not like behaviorism. They did not like ABA. They did not like the kinds of PBS that use behaviorism.

One thing a lot of people talked about was that behavior support services that use behaviorism are coercive. **Coercive** means that the behavior support services try to change people's behavior even if the people do not want to change their behavior. Coercion is bad. People talked about how behavior support services that use behaviorism are coercive even if the services seem nice on the outside. Behavior support services that use behaviorism are coercive even if they use "positive" ways to change people's behavior.

Theme 6: Behavior support services need to focus a lot more on what the person getting the services wants.

**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.

Behavior support services are supposed to use person-centered planning. Behavior support services providers are supposed to figure out how to make their services work for each person. Behavior support services providers are **not** supposed to set the same goals for all the people they work with.

But often, behavior support services providers do not make sure their services help the person live the life they want to live. Behavior support services providers might say that everyone getting their services has to "follow the same plan." Or behavior support services providers might use the same goals for everyone getting their services. This is not right. It is not person-centered planning.

A lot of the people we interviewed talked about how behavior support services need to use person-centered planning. A lot of the people we interviewed said behavior support services providers need to change their services to fit each person's goals.



Theme 7: More schools are using behavior support services. But these services often do not think about what students need and want.

More schools are using behavior support services. Sometimes these services are just for students with disabilities. Sometimes these services are for all students.

But schools that use behavior support services often do not think about what their students need and want. Schools are supposed to use person-centered planning when they use behavior support services. But a lot of schools do not do this.

Schools also use a lot of coercion when they use behavior support services. Schools do not let students set their own goals for behavior support services. A lot of the time, teachers and school staff make behavior support services goals for students. Then the students have to work towards those goals, even if the goals are not what the students want.

It can be really hard for students to tell the schools they do not like the behavior support services goals they have. It can be really hard for students' parents to tell the schools they do not like the behavior support services goals their children have.

Theme 8: COVID-19 has made it hard for behavior support services to find workers. This makes it hard for people to get services.

**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](#).

COVID-19 also made things worse for a lot of HCBS providers and support workers. This includes behavior support services providers.

A lot of support workers got sick with COVID-19 and could not work anymore. And a lot of support workers quit being support workers because they could get paid more at other jobs. So there are fewer support workers to help people with disabilities. This means fewer people with disabilities can get HCBS. It also means people with disabilities tend to get less attention when they get HCBS.

COVID-19 has also been very stressful on everyone. It has been stressful on people with disabilities. It has been stressful on support workers. It has been stressful on HCBS providers.

There were already a lot of problems with HCBS and behavior support services before COVID-19. COVID-19 made all those problems worse.

Theme 9: A lot of behavior support services focus on taking notes on people's behavior instead of building relationships with people.

Some behavior support services focus a lot on gathering data. **Data** is facts and information about something.

Behavior support services that use behaviorism make the service provider collect a lot of data. This data is often things like:

- How many times a person does a specific behavior in 1 hour.
- How a person reacts when someone tells them to stop doing a behavior.
- What happens around a person before they start doing a certain behavior.

Collecting all this data makes it hard for the service provider to get to know the person using the service. It is hard to get to know someone when you spend all your time counting how many times they do a certain behavior! So behavior support services providers do not get to know the people using their services well.

This makes it harder for people to trust the service providers. It makes it harder for people to feel like the service providers want to help them. It makes people feel like the service providers are only there to get them in trouble when they behave in "wrong" ways.

A lot of the people we interviewed talked about how behavior support services providers should spend less time collecting data on people. The people we interviewed said behavior support services providers should spend more time getting to know the people they work with.

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