ASAN

AUTISTIC SELF ADVOCACY NETWORK

ICDL

WITH

Easy Read Edition

Beyond Coercion and Institutionalization:

People with Intellectual and Developmental Disabilities and the Need for Improved Behavior Support Services

Part 2: Background on Behavior Support Services and Community Living

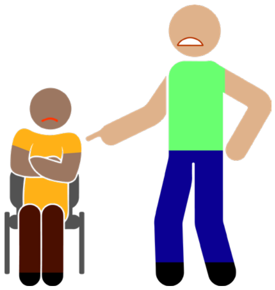
Words to Know in Part 2

Americans with Disabilities Act (ADA)

A law that applies to the whole United States. The ADA says that governments and most public places have to be accessible to people with disabilities.

appendix

An extra part of a toolkit that gives more information.

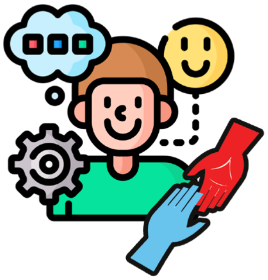


applied behavior analysis (ABA)

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.

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.

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 themself. 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.

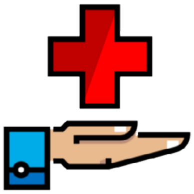
institution

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.

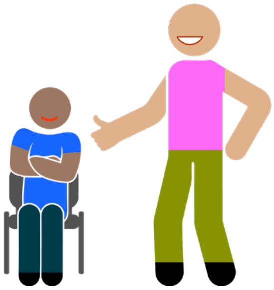
Olmstead v L.C.

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

operant conditioning

Changing someone's behavior using rewards and punishments.

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.”

reward

Something a person gets for having “good behavior.”

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.

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.

Background on Behavior Support Services and Community Living

What is behavior? What are behavior support services?

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

Here are some examples of behavior:

- A person walking back and forth because they are stressed about work.

- A person saying "ow!" and holding their face because they have a toothache.

- A person hugging and talking to a friend they have not seen in a while.

Sometimes, a person's behavior makes it hard for them to live the life they want to live.

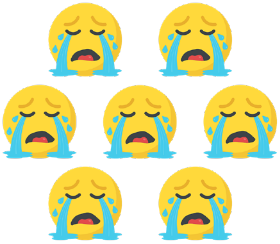
For example:

Joe works at a bank.

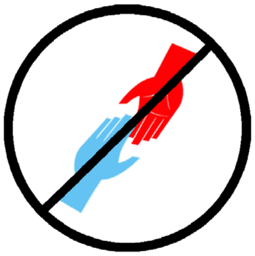
Joe's job is very stressful.

When Joe gets stressed out, he leaves his desk and goes to the back room to cry.

Going to the back room to cry is a type of behavior.



Joe cries in the back room a lot.



When Joe is crying, he cannot help customers at the bank.

Joe is about to lose his job because he cannot stop crying.

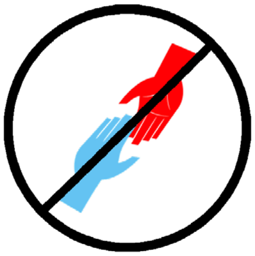
Joe really wants to keep his job.

Joe’s behavior is making it hard for him to live the life he wants to live.

Anyone can have behavior that makes it hard for them to live the life they want to live.

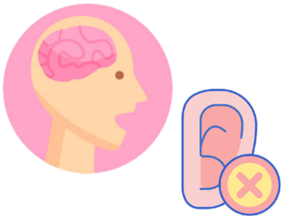
Most people have behavior like this at some point in their lives.

But people with disabilities can especially have behavior that makes it hard for us to live the lives we want to live.



This is especially true for people with disabilities who are not getting the help we need.

Here is an example:

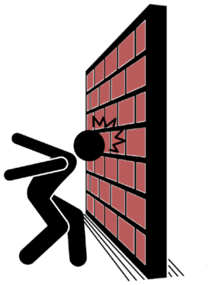


Esther is Deaf and has an intellectual disability.

Esther does not talk.

She does not know sign language.

Esther does not have a good way to tell other people what she needs.



When Esther gets upset, she hits her head on walls.

Esther does not want to hit her head on walls.

Hitting her head hurts. It gets in the way of things she wants to do.

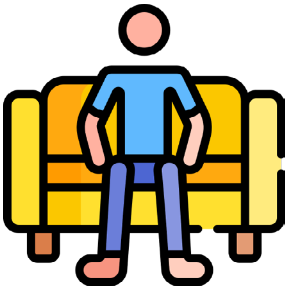
But Esther does not have another way of telling people she is upset.

Here is another example:

Dylan is autistic.

Dylan lives in a group home.

There is not much for Dylan to do in the group home.



They mainly just sit around all day.

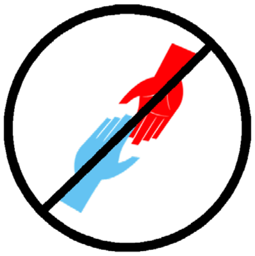
Dylan is very bored and lonely.

When Dylan gets bored and lonely, they try to take apart the furniture in their room.

The group home staff do not like this.

The group home staff say that Dylan might have to find somewhere else to live.

Dylan’s behavior is getting in the way of having a place to live.

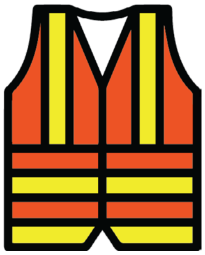


But Dylan is not getting the help they need to keep themself busy.

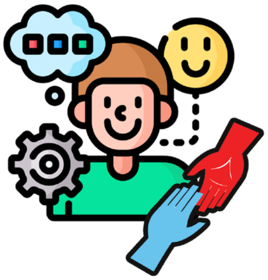
Some people call behavior that gets in the way of a person living the life they want “**challenging behavior**.”

ASAN does not always like how people use the term “challenging behavior.”

We will talk more about this in a later section.



People with disabilities need different services to live safely.



One type of service that some people with disabilities need is **behavior support services**.

It can be hard to explain what behavior support services are.

Different people have different ideas of what behavior support services are.

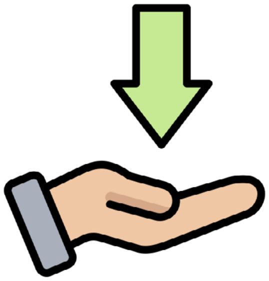
ASAN thinks behavior support services are services that help people deal with behavior that makes it hard for them to live the lives they want.

This can include services like:

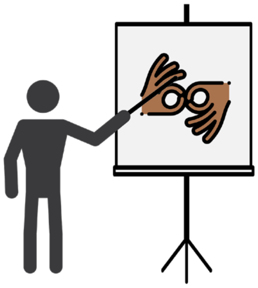
- Looking at what causes someone's behavior.

For example, in Joe's case, he is crying because he is stressed out.

If Joe could get rid of some of the stress in his job, he would not need to cry so much.



- Meeting the needs that cause someone’s behavior.



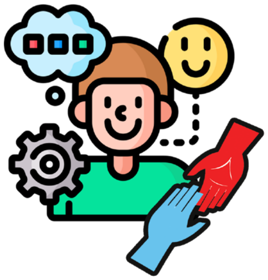
For example, in Esther’s case, someone could teach her sign language.

Then, Esther would have another way to tell people she is upset.

- Giving people other ways to deal with the feelings that cause their behavior.

For example, in Dylan's case, the group home staff could offer to do other activities with them.

Then, Dylan would not try to take apart furniture when they get bored.



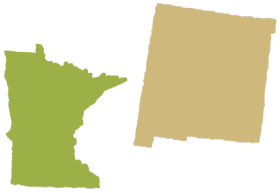
But lots of different groups have different ideas of what behavior support services are.

These ideas are sometimes very different from each other.

That makes it hard to tell what people mean when they say “behavior support services.”

It also makes it hard to compare different kinds of behavior support services to each other.

For example:



Minnesota and New Mexico are both states in the United States.

Minnesota and New Mexico both pay for some people with disabilities who live in them to get behavior support services.

But Minnesota and New Mexico have very different ideas of what behavior support services are.

A person in Minnesota might get some kinds of help from behavior support services.

But a person in New Mexico might get very different kinds of help from behavior support services.

That makes it hard to compare behavior support services in Minnesota to those in New Mexico.

It makes it hard to tell which state is doing a better job with behavior support services.

Community living and people with disabilities

What is community living?

Community living is when people with disabilities live in the same places as people without disabilities.

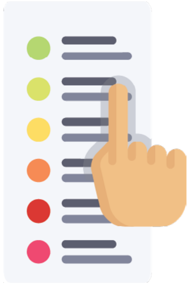
This can be living together in places like:

- Neighborhoods.

- Towns.

- Cities.

ASAN talked to people with disabilities about what “community” means to them.



We learned that “community” means a place you can make choices about your own life.

This includes choices like:

- Where you live.

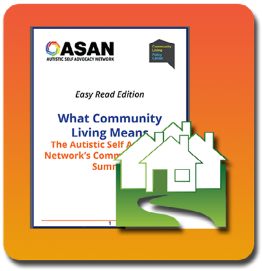
- Who you live with.

- Who helps you.

- Where you work.

- What you do during the day.

- Who you spend time with.



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What Community

You can read more about what people with disabilities think “living in the community” means by reading [ASAN’s toolkit about community living](#).

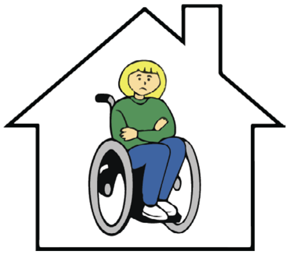
What are institutions?

Community living is different from living in an institution.

Institutions are places where a lot of disabled people live.

People in institutions usually did not decide to live there.

They were put there by someone else.

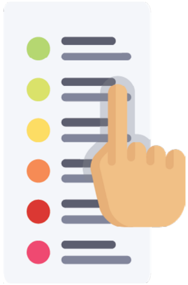


Institutions are not run by the people who live in them.

Institutions are run by the people who work in them

People living in institutions usually cannot leave the institution whenever they want to.

They usually cannot decide how they want to spend their time.



Other people get to make choices about how they live their lives.

Different groups have different ideas about what institutions are.

For example:

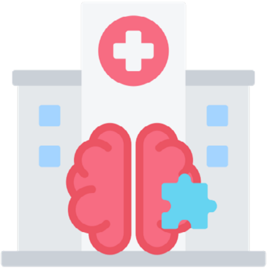
The U.S. government has rules about what an institution is.

The U.S. government says only certain places can be institutions.

The U.S. government says that institutions are places like:

- Hospitals.

- Nursing homes.



- Psychiatric (mental health) hospitals.

The U.S. government does not say that other places, like group homes, are institutions.

Self-advocates with disabilities think lots of different places can be institutions.

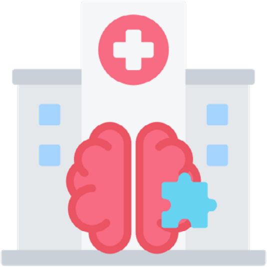
The national self-advocacy group Self Advocates Becoming Empowered (SABE) talks about what they think institutions are.

SABE says that an institution is a “facility or program where people do not have control over their lives.”

This includes places like:

- Hospitals.

- Nursing homes.

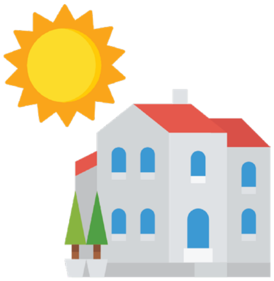


- Psychiatric (mental health) hospitals.

But it also includes places like:

- Group homes.

- Foster care homes.



- Day treatment programs.

- Sheltered workshops.

What is deinstitutionalization?

For most of the history of the United States, people with disabilities did not live in the community.

We lived in institutions instead.

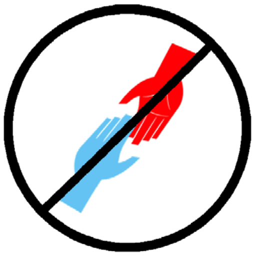
The first institutions opened in the 1840s.

Before that, some people with disabilities lived in prisons.

The institutions were supposed to be better than prisons.

The institutions were supposed to help people with disabilities.

But soon, the institutions became just like prisons.



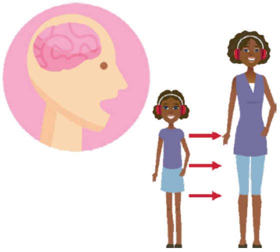
People with disabilities did not get help in institutions.

People with disabilities got hurt a lot in institutions.

Over the next 100 years, a lot more people with disabilities got put in institutions.

In 1967, there were almost 200,000 people with disabilities living in institutions.

People with many different types of disabilities lived in institutions.



People with IDD lived in institutions.

People with physical disabilities lived in institutions.

People with mental health disabilities lived in institutions.

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.

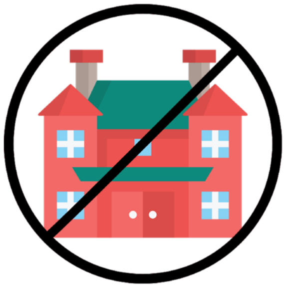
Some different mental health disabilities are:

- Depression.

- Anxiety.

- Schizophrenia.

In the 1950s, parents of children with disabilities started working together.



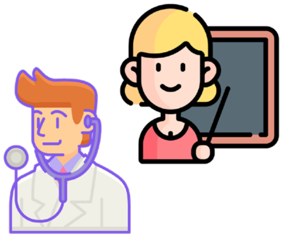
The parents did not want their children to live in institutions.

The parents fought for the rights of their children to live in the community.

Over time, more people started fighting for people with disabilities to live in the community.

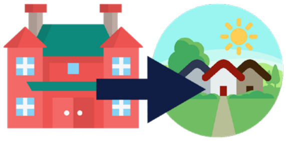
This included people like:

- Parents and family members of people with disabilities.



- Professionals, like doctors and teachers, who helped people with disabilities.

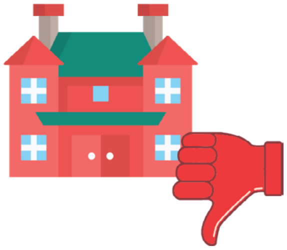
- People with disabilities ourselves.



All these groups fought for deinstitutionalization.

Deinstitutionalization means moving people with disabilities out of institutions and into the community.

Deinstitutionalization happened over time.

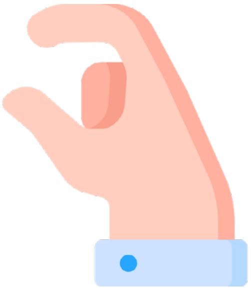


In many cases, there would be a TV or newspaper report on how bad institutions were.

Then, there would be a big push to get people with disabilities out of institutions.

Some people with disabilities would get out of institutions.

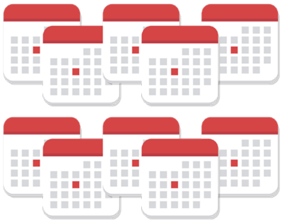
But other people with disabilities would still be stuck in institutions.



Over time, the push to get people with disabilities out of institutions would get smaller and smaller.

Then, a few years later, there would be another TV or newspaper report.

And the push to get people out of institutions would happen all over again.



This process kept happening for decades.

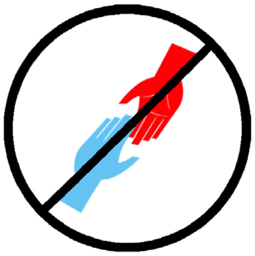
It is still happening today.

You can read more about the history of institutions and deinstitutionalization in ASAN’s toolkits on institutions.

Since the 1950s, a lot of people with disabilities moved out of institutions and into the community.

And, a lot of people with disabilities who would have been put in institutions got to stay in the community.

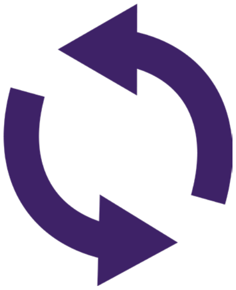
But there is still a big problem!



People with disabilities often cannot get the services we need to live in the community.

People with disabilities might need lots of different services to live in the community.

We might need services like:



- Changes to the house or apartment we live in to make it safer for us.

- Someone to help in our homes or the community.

- Help at work or at school.

- Health care that is specific for our disability.

For example:

Liza is autistic.

She also has an intellectual disability.

Liza needs different kinds of services to live in the community.

Liza needs someone to come to her home to help her with chores.

She needs a job coach at work to keep on-task.

She needs help learning to ride the bus to run errands.

The Americans with Disabilities Act and *Olmstead v. L.C.*

In 1990, the U.S. government passed a law called the **Americans with Disabilities Act (ADA)**.

The ADA made rules for governments and most public places.

Public places are places like:

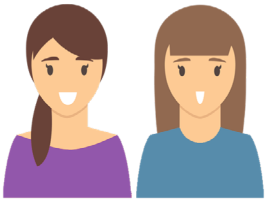
- Libraries.

- Schools.

- Businesses, like salons or grocery stores.

The ADA says that governments and most public places have to be accessible to people with disabilities.

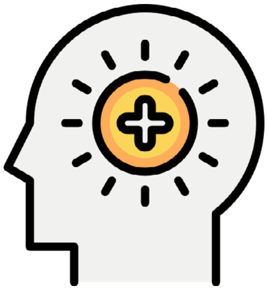
You can learn more about the ADA in ASAN's toolkit about it.



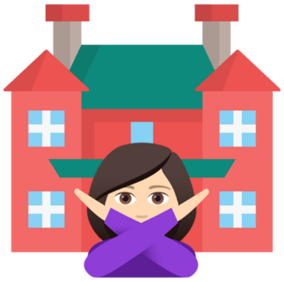
In the 1990s, two women were living in an institution in Georgia.

The women were named Lois Curtis and Elaine Wilson.

Lois and Elaine both had intellectual disabilities.



They also both had mental health disabilities.



Lois and Elaine did not want to live in the institution.

They wanted to live in the community.

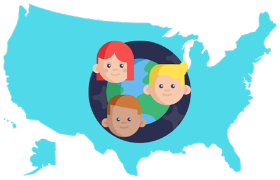
But they needed services to live in the community.

So Lois and Elaine went to court.

They told the court that the ADA gave them the right to live in the community.

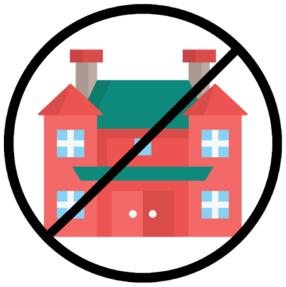
Lois and Elaine's case went all the way to the Supreme Court.

The Supreme Court is the highest court in the United States.



The decisions the Supreme Court makes apply to everyone in the United States.

The Supreme Court decided that Lois and Elaine did have the right to live in the community.



The Supreme Court said that the ADA means states cannot force people with disabilities to live in institutions to get services.

The Supreme Court said that people with disabilities have the right to receive services in the community.

Lois and Elaine's case was called ***Olmstead v L.C.*** (or *Olmstead* for short).

Olmstead means that people with disabilities can get services in our communities.

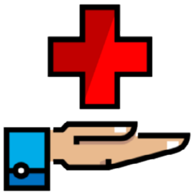
There have been other court cases since *Olmstead*.

These cases have said that states must provide services in the community to more people with disabilities.

These cases have meant more people with disabilities can live and get services in the community.

Community living and home and community based services (HCBS)

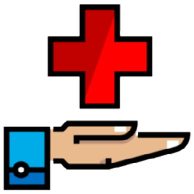
What are HCBS?



A lot of people with disabilities are on Medicaid.

Medicaid is a health care program in the United States.

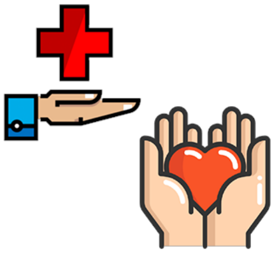
Medicaid is run by the government.



Every state has its own Medicaid program.

Medicaid helps people get health care if they do not have a lot of money.

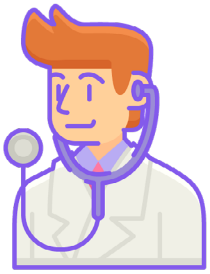
You can learn more about Medicaid in our Medicaid Toolkit.



Medicaid programs work with providers.

Providers are people or places that give you health care or services.

Some types of providers are:



- Doctors.

- Hospitals.

- Housing for people with disabilities.

Medicaid pays for long-term services and supports (LTSS).

LTSS are services that help disabled people live our everyday lives.

Some examples of LTSS are:

- 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.

- Transportation for people with disabilities.

- Job coaches at work.

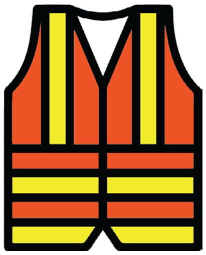
There are different kinds of LTSS providers.

Some people get LTSS in institutions.

Other people get LTSS in their community.

When people get LTSS in their community, it is called **home and community-based services (HCBS)**.

Problems with community living and HCBS



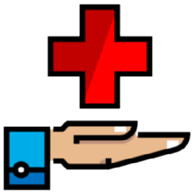
Many people with disabilities need HCBS to live safely in our communities.

But there are still a lot of problems that make it hard for people with disabilities to get HCBS.

These problems are:

- Not enough money for HCBS.

- States do not have to provide HCBS under Medicaid.



- States can put limits on who can get HCBS under Medicaid.

- Provider-owned settings and guardianship can take away people’s rights.

We will talk about each of these problems.

Problem 1: The U.S. government and states do not set aside enough money for HCBS.

There are a lot of people with disabilities in the United States who need HCBS.

Paying for HCBS costs the government money.

Some of the money comes from the U.S. government.

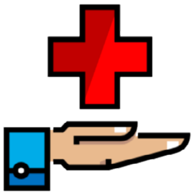
Some of the money comes from state governments.

But the U.S. governments and state governments do not put enough money towards paying for HCBS.

That means there is not enough money to pay for HCBS for everyone who needs it.

So some people with disabilities cannot get HCBS, even if they need it.

Problem 2: States do not have to provide HCBS under Medicaid.



The U.S. government says some Medicaid services are mandatory.

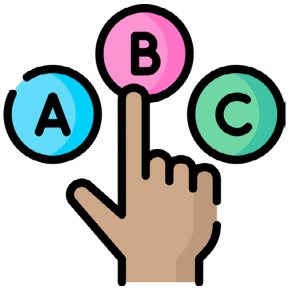
“Mandatory” means all state Medicaid programs must pay for these services.

Some kinds of mandatory Medicaid services are:

- Doctor’s appointments.

- Hospital services, like surgeries.

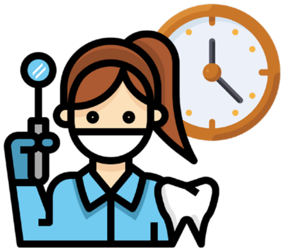
- LTSS in an institution.



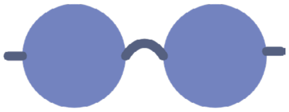
The U.S. government says other Medicaid services are optional.

“Optional” means that state Medicaid programs do not have to pay for these services.

Some kinds of optional Medicaid services are:



- Dentist appointments.



- Eyeglasses.

- HCBS.

LTSS in institutions are a mandatory Medicaid service.

But HCBS are not!

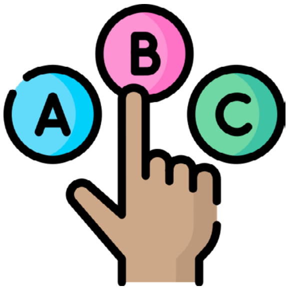
That means states do not have to pay for HCBS.

If states want to offer HCBS for people on Medicaid, states can set up Medicaid waivers.

Waivers are a Medicaid program.

Waivers let people on Medicaid get HCBS.

Right now, every state does offer Medicaid waivers for HCBS.



But because HCBS is an optional Medicaid service, states can put limits on who can get a waiver.

We will talk about that in the next section.

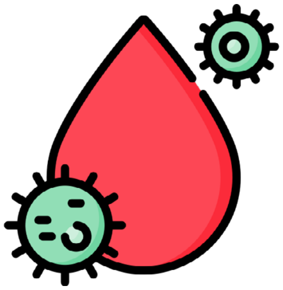
Problem 3: States can put limits on who can get HCBS under Medicaid.

States can set up waiver programs to let people on Medicaid get HCBS.

Most states have waivers for:

- Older adults.

- People with certain disabilities.



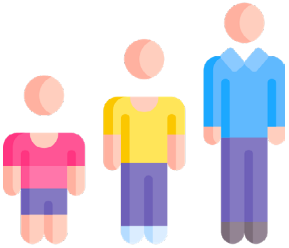
- People with illnesses that last a long time (like HIV/AIDS).

States can decide who can get on one of their waivers.

States can make waivers that are only for:

- People with one kind of illness.

- People with a specific disability.



- People in a specific age group.

States do not have to give people HCBS unless those people are in a group covered by a waiver.

For example:

Miles is an autistic adult. He is on Medicaid.

Miles wants his Medicaid to pay for HCBS.

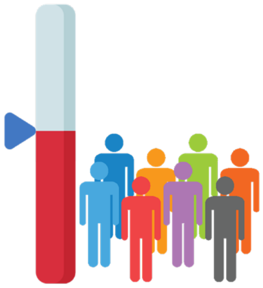
Miles’s state has a waiver for autistic people.

But the waiver is only for autistic children.

The waiver does not cover autistic adults.

So Miles cannot get on his state’s autism waiver.

He cannot get HCBS.



States can also set limits on how many people can be on a waiver.

This means that only a certain number of people in the state can get HCBS through a waiver.

This means people who want HCBS may get put on a waiting list.

When someone is on the waiting list, they don’t get HCBS.

Instead, they have to wait until their name comes up next on the list to get HCBS.

So they wait on the waiting list.

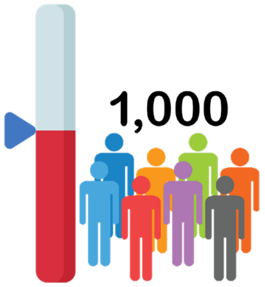
They can be on the waiting list for many years.

For example:

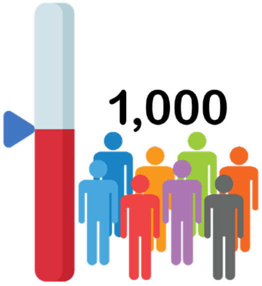
Dianne has a brain injury. She is on Medicaid.

Dianne wants her Medicaid to pay for HCBS.

Dianne's state has a waiver for people with brain injuries.



But only 1,000 people can be on the brain injury waiver at one time.



There are already 1,000 people on the brain injury waiver.

So Dianne gets put on a waiting list.

She has to wait until her name gets to the top of the waiting list.

Problem 4: Provider-owned settings and guardianship limit what choices people with disabilities can make about HCBS.

Fewer people with disabilities live in big institutions now.

But that does not mean every person with a disability has choice and control over their life.

Some people with disabilities live in places that do not give them choice and control over their lives.

These places call themselves HCBS.

But these places look a lot like institutions.

These places tend to be provider-owned settings.

Provider-owned settings are when the HCBS provider owns the place people get HCBS in.

Some examples of provider-owned settings are:

- Group homes.

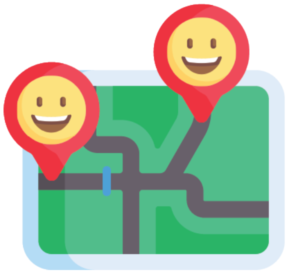
- Assisted living facilities.

- Intentional communities.

People living in these places do not get many choices about their lives.

Often, these places control things like:

- What the people living in them can eat for meals.



- Where the people living in them can go during the day.

- Who the people living in them can spend time with.

For example:

Dario has a disability.

He lives in a group home.

The group home is a provider-owned setting.

Dario’s group home calls itself HCBS.

But Dario does not get to choose what he eats for meals.

Dario does not get to choose what he does during the day.

Dario does not get to choose who he spends time with.

The group home makes all the decisions for Dario.

Dario’s group home calls itself HCBS.

But it looks and feels like an institution.

Even when people with disabilities live in our own homes and get HCBS, we may not have a lot of choice and control.

We may get HCBS from a provider who makes a lot of choices for us.

We may not be able to choose the HCBS provider or staff we work with.

We may not get a say in which kinds of services we get.

For example:

Kayla is autistic and has a mental health disability.

Kayla gets HCBS.

Kayla lives in her own home.

She does not live in a provider-owned setting

But Kayla still does not get a lot of choices about her HCBS.

She does not get to choose which providers she works with.

She does not get to choose which services she gets.

She does not get to choose when and where she works with staff.

Kayla is living in the community.

But she still is not in control of her HCBS.

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 themself.

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.

A person’s guardian might choose to put the person in a group home.

Or, the person’s guardian might choose all the services a person gets.

For example:

Xue has an intellectual disability.

He is under guardianship.

Xue gets HCBS.

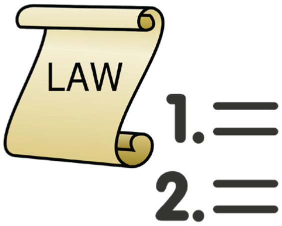
Xue’s guardian decides to put Xue in a group home.

The group home does not let Xue make choices about his everyday life.

When Xue does have a chance to make choices about his life, the group home does not ask Xue.

The group home asks Xue’s guardian instead.

The HCBS Settings Rule



There are supposed to be rules and laws to help people with disabilities get good HCBS.

One of these rules is the HCBS Settings Rule.

The **HCBS Settings Rule** is a rule the U.S. government made.

The HCBS Settings Rule says that people who get HCBS have certain rights.

These rights include:

- The right to respect from HCBS providers.

- The right to live in the community.

- The right to make choices about our services.

The HCBS Settings Rule says that people living in provider-owned settings have extra rights.

These rights include:

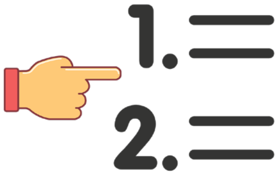
- The right to lock the door to their room.

- The right to make choices about their daily lives.

- The right to have visitors at any time.

The HCBS Settings Rule started working in 2023.

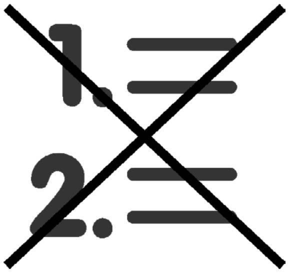
But there are still a lot of problems with the HCBS Settings Rule.



The U.S. government said state governments should make sure HCBS providers follow the rule.

But a lot of state governments are not making sure HCBS providers follow the rule.

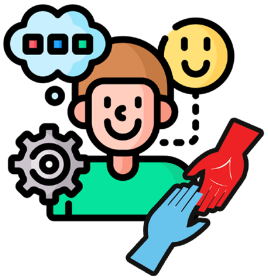
And it can be hard for people to tell the state or U.S. government when their HCBS provider breaks the rule.



So HCBS providers can often get away with breaking the rule.

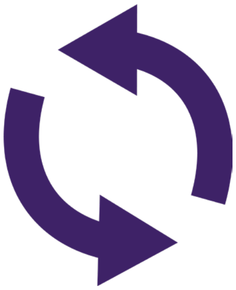
For more about the HCBS Settings Rule, you can read ASAN's toolkits on it.

History of behavior support services



Some people with intellectual and developmental disabilities (IDD) get behavior support services.

Sometimes, this is to help us deal with behavior that gets in the way of living the lives we want.



Other times, this is because other people want us to change our behavior that bothers them.

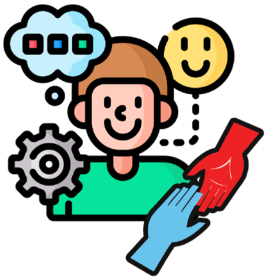
For example:

Solvig is autistic. She is 15 years old.

When Solvig gets nervous, she stims by flapping her hands.

Solvig's parents and teachers do not like this.

They think Solvig flapping her hands makes her look "childish" and "inappropriate."



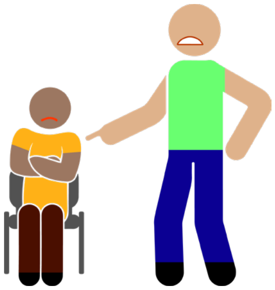
So they send Solvig to behavior support services to “get rid of her flapping.”

There is nothing wrong with Solvig flapping her hands.

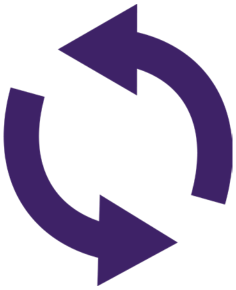
Solvig flapping her hands does not get in the way of the life she wants to live.

But her parents and teachers do not like that she flaps her hands.

Applied behavior analysis and behaviorism

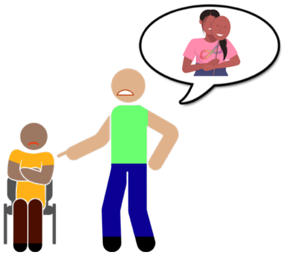


One type of behavior support service is **applied behavior analysis (ABA)**.



ABA focuses on changing how autistic children act.

ABA wants autistic children to look and act like they are not autistic.

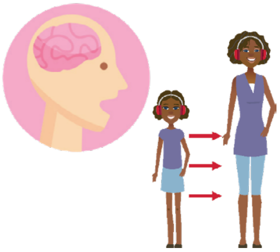


It teaches autistic children to hide the things that make them “look” autistic.

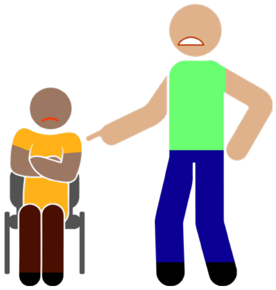
ASAN thinks ABA is a bad service that hurts autistic people.

ABA mostly gets used on autistic children.

But ABA is sometimes used on autistic adults, too.

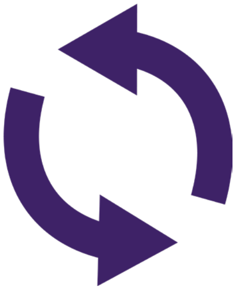


ABA is also sometimes used on other people with IDD, too.



ABA is part of behaviorism.

Behaviorism is a way of thinking about human behavior.

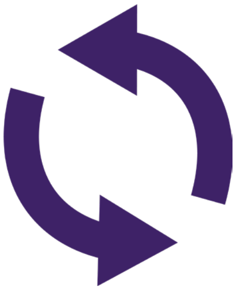


Behaviorism says that to change behavior, we should only look at things we can see.

This includes things like:

- How a person behaves.

- How other people around a person behave.



- Other things that can change a person's behavior, like how hot or cool a room is.

Behaviorism says we should **not** focus on things we cannot see, like thoughts or feelings.

Behaviorism says that thoughts and feelings do not matter for how a person behaves.

A lot of the ABA done today started in the 1970s.

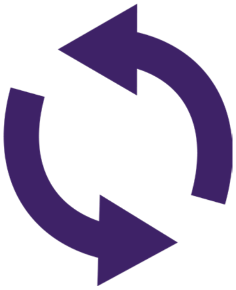
It started mainly with the work of O. Ivar Lovaas.

O. Ivar Lovaas was a scientist studying behavior.

He studied the behavior of autistic children.

O. Ivar Lovaas wanted to know how to make autistic children look and act more “normal.”

He wanted to know how to make autistic children look and act just like non-autistic children.



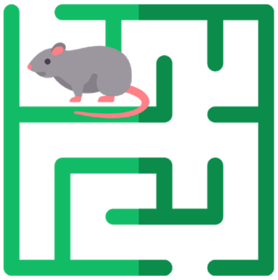
O. Ivar Lovaas worked to change the behavior of autistic children using operant conditioning.

Operant conditioning means changing someone’s behavior using rewards and punishments.

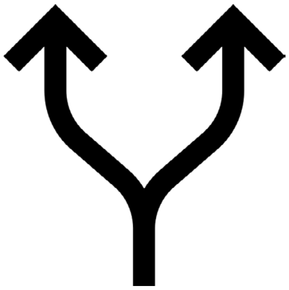
A **reward** is something a person gets for having “good behavior.”

A **punishment** is something a person gets for having “bad behavior.”

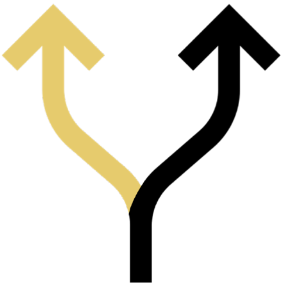
Here is an example of operant conditioning:



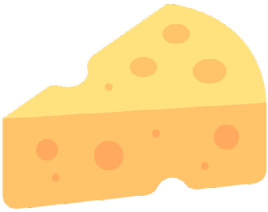
A scientist puts a mouse in a maze.



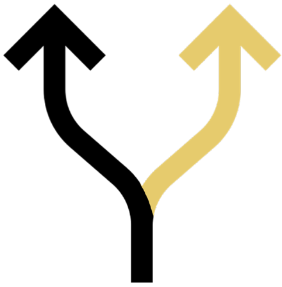
The maze has a left path and a right path.



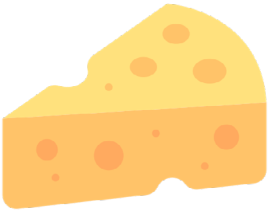
The scientist wants the mouse to go down the left path.



So every time the mouse goes down the left path, the scientist gives it a piece of food.

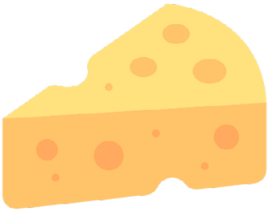


Every time the mouse goes down the right path, the scientist shocks it with electricity.



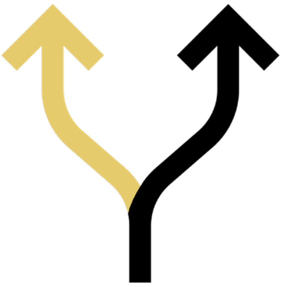
The mouse learns that if it goes down the left path, it gets food.

The mouse learns that if it goes down the right path, it gets shocked with electricity.

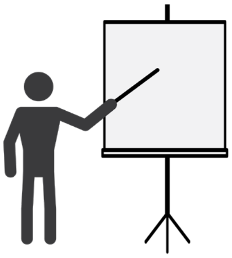


The mouse wants food.

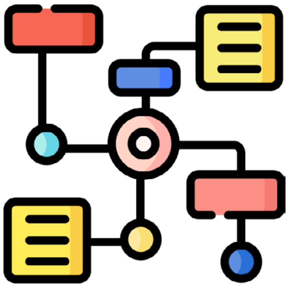
The mouse does not want to be shocked with electricity.



So the mouse learns to go down the left path.



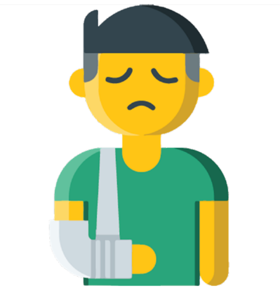
Operant conditioning does work to teach animals, like mice or dogs, to do certain tasks.



But human behavior is a lot more complex than mouse or dog behavior.

Operant conditioning is not a good way to teach humans how to do certain tasks.

O. Ivar Lovaas used operant conditioning to “teach” autistic children how to act and look like non-autistic children.

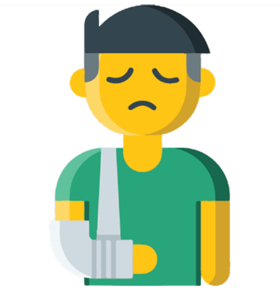


When the autistic children looked or acted autistic, O. Ivar Lovaas would hurt them.

He would hit the children.

He would scream at them.

He would shock them with electricity.



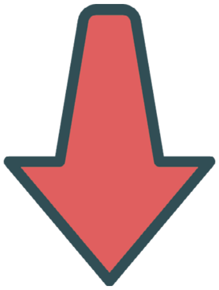
A lot of early ABA therapists also hurt autistic children.

Early ABA therapists used the same methods as O. Ivar Lovaas.

They would hit autistic children.

They would scream at autistic children.

They would shock autistic children with electricity.



Not as many ABA therapists do this anymore.

But some still do.

Even when ABA therapists do not hurt autistic children, ABA is still a bad therapy.

ABA still focuses on making autistic people look and act “not autistic.”

Trying to make autistic people look and act “not autistic” is wrong.

ABA still uses operant conditioning to teach skills.

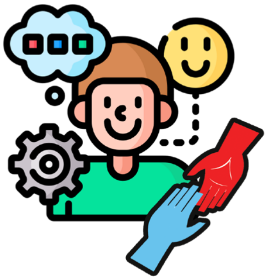
But operant conditioning is not a good way to teach people skills.

ABA is still part of behaviorism.

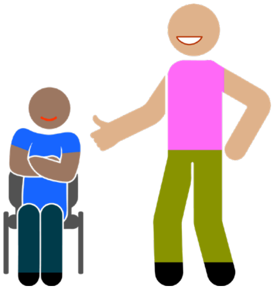
Behaviorism does not care about people's thoughts and feelings.

To learn more about ABA and its history, you can read ASAN's toolkit about good and bad autism services.

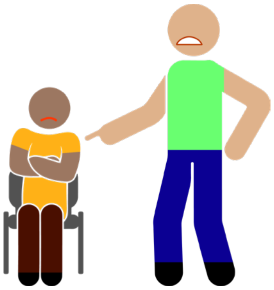
Positive behavior supports



Starting in the 1990s, many states and providers started to use a new kind of behavior support service for people with IDD.



This new kind of service is called **positive behavior supports (PBS)**.



PBS is like ABA in some ways.

PBS still uses some of the same tools ABA does.

PBS still sometimes uses operant conditioning to teach skills or get rid of behavior.

PBS still uses a lot of ideas from behaviorism.

But PBS is also different from ABA in other ways.

PBS focuses more on being included in the community than ABA.

PBS focuses more on goals that the person getting services has than ABA does.

PBS also sometimes uses ideas from other parts of psychology.

Psychology is the study of how people think, feel, and act.

Behaviorism is one part of psychology.

But psychology is bigger than behaviorism.

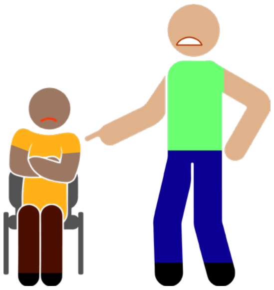
Psychology thinks a lot more about how people think and feel.

PBS sometimes uses parts of psychology that have to do with how people think and feel.

There are a few problems with PBS.

The first problem is that nobody can agree on what PBS means.

Different states and different providers say PBS means different things.



Some states and providers say PBS is basically ABA with a few small changes.

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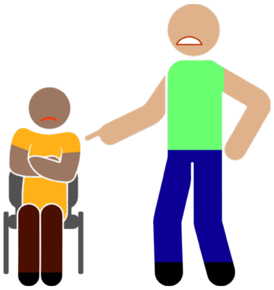
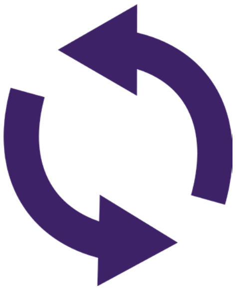
Other states and providers say PBS is not like ABA at all.

It can be very hard to tell what a specific state or provider means when they say they offer PBS.

And, it is hard to compare PBS services between states or providers when nobody can agree on what PBS means.



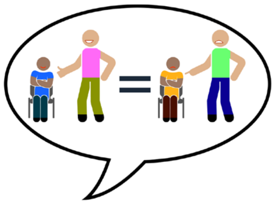
The second problem is that PBS usually still keeps a lot of the parts of ABA.



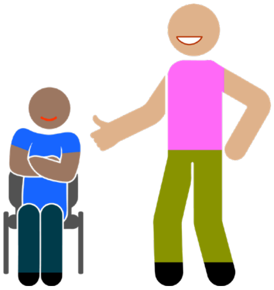
PBS still focuses on changing people with IDD’s behavior.

PBS still uses some kinds of operant conditioning to change behavior.

PBS still uses ideas from behaviorism.



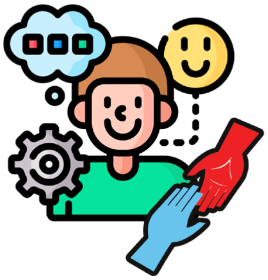
Some people who do not like PBS say that PBS is just ABA.



A lot of people with IDD say this about PBS.

Many therapists and providers who do PBS do not agree with this.

But because there is no one definition for PBS, it is hard to say who is right.

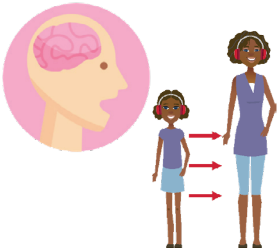


ABA and PBS are still the main behavior support services most states and providers offer.

A lot of money goes towards ABA and PBS.

This means there is less money for other types of behavior support services.

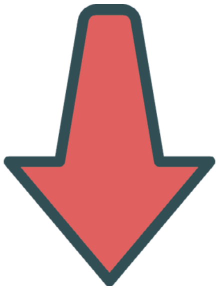
Some other types of behavior support services are:



- Mental health care for people with IDD.

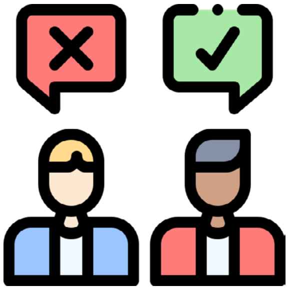
- Services to meet the sensory needs of people with IDD.

- Services to help people with IDD live more independently.

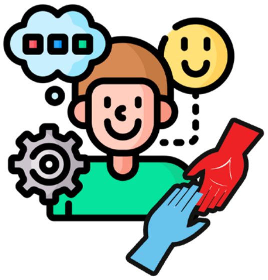


When there is less money for these types of behavior support services, not as many people can get these types of behavior support services.

What do we want to do in this paper?



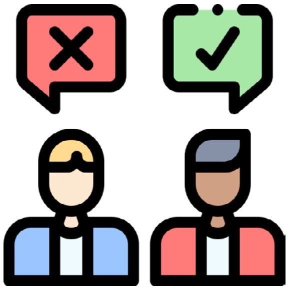
Right now, nobody can really agree on what “behavior support services” means.



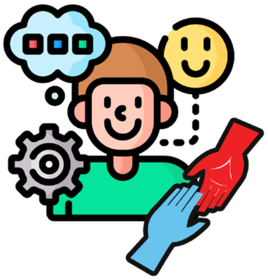
Nobody really agrees on what behavior support services look like.

Most people and groups agree that people with disabilities should get help dealing with behavior that hurts us or other people.

Most people and groups agree that people with disabilities should get help dealing with behavior that gets in the way of the lives we want to live.



But nobody can agree on how best to do this.



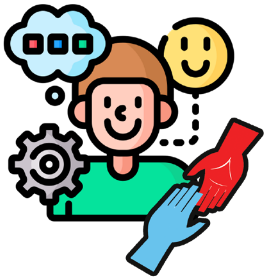
That means that people with disabilities in different states can get very different behavior support services, even if the services are called the same thing.

This is a problem!

Everyone should be able to get good services that help them live the lives they want.

But if there is no way to tell what “behavior support services” are or what makes them good, it is hard to tell if people are getting good services.

That is why ASAN wrote this toolkit.



We wanted to explain what behavior support services are.

We wanted to explain what makes behavior support services good.

We wanted to explain what makes behavior support services bad.

In this toolkit, we do a few things.

First, we will talk about community living and services for people with disabilities in the United States.

(We already did this.)

Next, we will talk about what different people think behavior support services are.

We will talk about what people who write about behavior support services think these services are.

We will talk about what people we talked to about behavior support services think these services are.

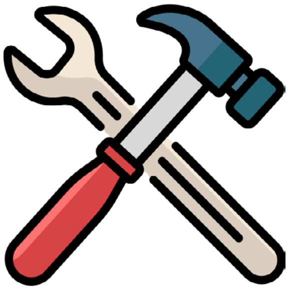
(We have done some of this but will do more in a later section.)

Then, we will talk about problems with behavior support services.

We will talk about problems that make it hard for people to get good behavior support services.

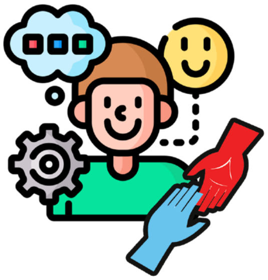
We will talk about problems that make it hard for groups to give people good behavior support services.

(We have done some of this but will do more in a later section.)

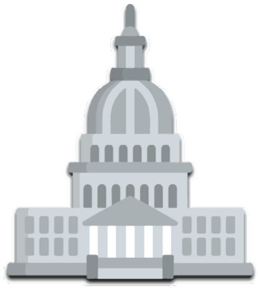


Last, we will talk about what different groups can do to fix problems with behavior support services.

We will talk about groups like:



- Groups that give people behavior support services.



- State governments.

- The U.S. (national) government.

There are also two appendixes to this toolkit.

An **appendix** is an extra part of the toolkit that gives more information.

In the appendix, we talk about good goals for behavior support services.

We talk about how groups that give people behavior support services can set good goals.

We talk about how groups that give people behavior support services should think about their services.

One big theme we kept seeing as we wrote this toolkit was that HCBS and behavior support services do not meet the needs of people with IDD right now.

These services were made decades ago to help people with disabilities coming out of institutions.

But people's needs have changed a lot since then.

Scientists, providers, and governments have learned a lot about disabilities and behavior since then.

If states and providers keep using old ways of providing services, they will not meet people’s needs.

ASAN thinks the U.S. government, states, and providers need to make big changes to make HCBS and behavior support services work for more people with disabilities.

We talk about those changes in this toolkit.

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