ASAN
AUTISTIC SELF ADVOCACY NETWORK

ICDL

WITH

Plain Language Version

Beyond Coercion and Institutionalization:

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

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Part 1: To Start

To Start

This is a toolkit about behavior support services for people with intellectual and developmental disabilities (IDD).

This toolkit will answer questions like:

- What is behavior?
- What is “challenging behavior”?
- Why do people do “challenging behavior”?
- What is community living?
- What are HCBS?
- What are behavior support services?
- How are behavior support services part of HCBS?
- How can behavior support services help people with IDD?
- How can behavior support services hurt people with IDD?
- How have behavior support services changed over time?
- What problems are there with how behavior support services happen now?
- What changes could make behavior support services better?
- What are mental health services?
- How can mental health services help people with IDD?
- What are good goals for behavior support services?
- What can people with IDD do to prepare for times when we might not be able to control our behavior?

This toolkit is based on a research paper ASAN wrote. The research paper is not in plain language or Easy Read. You can read more about how we wrote the research paper and this toolkit in Part 3: How We Made This Toolkit.

In this toolkit, we talk about some topics that some people might find hard to deal with.

We talk about topics like:

- Institutions.
- Restraint and seclusion.
- Abuse.
- Services that hurt people with IDD.

It is okay to take a break from reading this toolkit if you need to. It is okay to not read this toolkit if you need to.

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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.

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 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. People living in institutions usually can’t leave the institution whenever they want to. They usually can’t 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 federal government has rules about what an institution is. The federal government says only certain places can be institutions. The federal government says that institutions are places like:

- Hospitals.
- Nursing homes.
- Psychiatric (mental health) hospitals.

The federal government doesn’t 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 federal 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 don't 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 people with disabilities 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. government 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 federal 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 federal 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. A **waiting list** is a list of people who the state says qualify for services but cannot get services yet. 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 federal 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 federal 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 federal 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. The food is a reward for having the correct behavior. Every time the mouse goes down the right path, the scientist shocks it with electricity. The shock is a punishment for having the wrong behavior.

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 providers also hurt autistic children. Early ABA providers 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 providers do this anymore. But some still do.

Even when ABA providers do not hurt autistic children, ABA is still a bad service. 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. 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. government.

There are also two appendixes to this toolkit. An appendix is an extra part of the toolkit that gives more information.

In Appendix A, 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.

In Appendix B, we talk about different tools and resources that can help people with IDD get support for mental health problems.

One big idea 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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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

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.

Psychology

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

Providers

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

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

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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Part 4: The Big Question: What Does "Behavior Support Services" Even Mean?

Words to Know in Part 4

Appendix

An extra part of a toolkit that gives more information.

Applied behavior analysis (ABA)

A type of behavior support service that is mostly used on autistic children, but can be used on other people with IDD. ABA focuses on making people act “less autistic” by changing the way people behave.

Behavior

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

Behavior support services

Services that help people deal with behavior that makes it hard for them to live the lives they want.

Behaviorism

A way of thinking about human behavior that says we should only think about the behavior we can see. Behaviorism focuses on changing a person’s behavior but not on the person’s thoughts or feelings. ABA is part of behaviorism.

Challenging behavior

A term some people use to talk about behavior that makes it hard for a person to live the life they want.

Coercion

Trying to change someone's behavior, even if that person does not want to change their behavior.

Communication

The different ways people tell each other information and ideas.

Community

A place where you can make choices about your own life. Communities can be places like neighborhoods, towns, or cities.

Community living

When people with disabilities live in the same places as people without disabilities.

Data

Facts and information about something.

Home and community based services (HCBS)

LTSS someone gets in their home or in the community.

Institution

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

Interviewing

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

Long-term services and supports (LTSS)

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

Mental health crisis

When a person is having thoughts or feelings that hurt them that they cannot control. During a mental health crisis, a person might try to hurt themselves or others.

Mental health therapy

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

Occupational therapy

A service that helps people learn and practice skills they need in their everyday lives.

Operant conditioning

Changing someone's behavior using rewards and punishments.

Physical therapy

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

Positive behavior supports (PBS)

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

Provider-owned settings

When the HCBS provider owns the place people get HCBS in.

Providers

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

Psychology

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

Punishment

Something a person gets for having “bad behavior.”

Research

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

Restraint

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

Reward

Something a person gets for having “good behavior.”

Seclusion

Locking someone in an empty room.

Speech therapy

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

Trauma

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

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

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

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

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

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

Everyone has different ideas of what "behavior support services" are.

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

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

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

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

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

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

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

For example:

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

Here is another example:

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

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

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

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

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

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

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

For example:

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

Here is a similar example about behavior support services:

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

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

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

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

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

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

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

Here is an example:

> Ginny is 25 and is autistic.Ginny moves out of her parents' house and into an apartment owned by her HCBS provider. Ginny's apartment is a **provider-owned setting**. When Ginny lived with her parents, she liked to have a glass of wine with dinner two or three nights a week. Having a glass of wine was comforting for Ginny, and made her feel relaxed and happy.
>
> The HCBS provider for Ginny's apartment decides that Ginny can't have a glass of wine with her dinner. She has to earn a glass of wine with dinner through "good behavior," and she is only allowed one glass of wine a week. The provider calls the one glass of wine a week a "reward" for Ginny's good behavior. Ginny does not like this. The provider is using something Ginny likes as a way to force her to have "good behavior."

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

Let's go back to Ginny's example:

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

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

Punishments can look like:

- Taking something away from someone.

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

- Not giving someone something they want.

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

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

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

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

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

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

Let’s go back to Ginny’s example:

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

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

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

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

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

"Challenging behavior" can mean a lot of things.

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

For example:

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

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

For example:

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

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

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

We will discuss each of these problems next.

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

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

For example:

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

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

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

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

For example:

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

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

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

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

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

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

For example:

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

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

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

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

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

For example:

> One person we interviewed talked about a woman they once met. The person we interviewed had been asked by the woman’s support staff to meet with the woman. The support staff said that the woman liked to sit in her room and cut pictures out of magazines. The support staff said that cutting pictures out of magazines was “challenging behavior.” The support staff said that the woman needed behavior support services because she cut pictures out of magazines.
>
> Cutting pictures out of magazines is not “challenging behavior.” Someone does not need behavior support services because they cut pictures out of magazines to relax. The woman’s support staff may have found it weird or annoying that she liked to cut pictures out of magazines. But that did not mean the woman had “challenging behavior.”

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

- Get good health care.
- Learn how to communicate in ways that work for the person. **Communication** is the different ways people tell each other information and ideas.
- Deal with big emotions and mental health crises. A **mental health crisis** is when a person is having thoughts or feelings that hurt them that they cannot control. During a mental health crisis, a person might try to hurt themselves or others.
- Live safely in the community.
- Do things that matter to the person, like having a job or seeing friends a lot.
- Meet goals that the person has for themself.

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

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

ASAN
AUTISTIC SELF ADVOCACY NETWORK

ICDL

WITH

Plain Language Version

Beyond Coercion and Institutionalization:

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

Part 5: Problems with How Behavior Support Services Happen Now

Words to Know in Part 5

Accommodations

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

Antipsychotics

A type of mental health medication that treat psychosis.

Applied behavior analysis (ABA)

A type of behavior support service that is mostly used on autistic children, but can be used on other people with IDD. ABA focuses on making people act “less autistic” by changing the way people behave.

Augmentative and alternative communication (AAC)

Ways of communicating other than speaking with your mouth or using a sign language. AAC includes things like writing, pointing to letters and words, or typing words on a computer.

Behavior

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

Behavior support services

Services that help people deal with behavior that makes it hard for them to live the lives they want.

Behaviorism

A way of thinking about human behavior that says we should only think about the behavior we can see. Behaviorism focuses on changing a person’s behavior but not on the person’s thoughts or feelings. ABA is part of behaviorism.

Burnout

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

Challenging behavior

A term some people use to talk about behavior that makes it hard for a person to live the life they want.

Coercion

Trying to change someone’s behavior, even if that person does not want to change their behavior.

Communication

The different ways people tell each other information and ideas.

Community

A place where you can make choices about your own life. Communities can be places like neighborhoods, towns, or cities.

Community living

When people with disabilities live in the same places as people without disabilities.

COVID-19

A bad disease that has spread around the world and made a lot of people very sick. COVID-19 has made it hard for people with disabilities to get good services.

Crisis respites

Houses or apartments where people can stay for a few days until a mental health crisis has passed. Crisis respites often have services like support workers or therapy groups.

Dual diagnosis

When someone has both an IDD and a mental health disability.

Guardian

The person a court chooses to make choices for a person under guardianship.

Guardianship

When a court takes away a person with a disability’s right to make choices for 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.

HCBS workforce crisis

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

Home and community based services (HCBS)

LTSS someone gets in their home or in the community.

Institution

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

Long-term services and supports (LTSS)

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

Medicaid

A health care program run by state governments. Medicaid helps people get health care if they have a disability or don’t have a lot of money.

Mental health crisis

When a person is having thoughts or feelings that hurt them that they cannot control. During a mental health crisis, a person might try to hurt themselves or others.

Mental health crisis services

Services that are supposed to help people who are dealing with emotions or behavior that hurt them that they cannot control.

Mental health disabilities

Disabilities that change how people think and feel. Mental health disabilities can make it hard for people to feel in control of their emotions.

Mental health services

Services that help people with mental health disabilities deal with their emotions and live in the community.

Mental health therapy

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

Occupational therapy

A service that helps people learn and practice skills they need in their everyday lives.

Olmstead v L.C.

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

Peer support

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

Peer worker

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

Person-centered planning

A way of figuring out what services might help a person live the life they want to live. Person-centered planning asks about a person's needs, wants, hopes, and goals. Then, the person-centered planning team figures out services might help the person get those things.

Physical therapy

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

Prevent

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

Provider-owned settings

When the HCBS provider owns the place people get HCBS in.

Providers

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

Psychosis

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

Research

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

Researchers

People who do research as their jobs.

Restraint

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

Seclusion

Locking someone in an empty room.

Secondary trauma

When someone has trauma from seeing someone else go through a really stressful experience.

Self-direction

An option that some people who get HCBS through a waiver use. Self-direction lets a person design and run the HCBS they get.

Speech therapy

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

Support workers

People whose job it is to help people with IDD in our homes and in the community. Support workers are sometimes called direct support professionals.

Symptoms

Signs that a person has an illness or disability.

Trauma

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

Turnover

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

Vacancy

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

Waiting list

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

Waivers

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

Problems with How Behavior Support Services Happen Now

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

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

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

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

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

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

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

Some different mental health disabilities are:

- Depression.
- Anxiety.
- Schizophrenia.

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

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

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

Some types of mental health services are:

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

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

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

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

For example:

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

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

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

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

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

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

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

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

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

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

Some types of accommodations are:

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

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

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

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

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

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

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

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

Some types of psychosis are:

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

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

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

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

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

Some different types of communication are:

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

For example:

> Sienna has an intellectual disability. Sienna does not talk with her mouth. She does not use a sign language. She does not write, type, or point to words. Sienna mostly communicates through her behavior.
>
> Sienna lives with her sister. When Sienna is hungry, she brings her sister to the refrigerator. When Sienna is sad, she curls up into a ball and refuses to move. When Sienna is happy, she smiles and hugs people.

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

For example:

> Let's continue with the example about Sienna.
>
> When Sienna gets upset, she pulls her hair out. Sienna can show other people she is upset by pulling her hair out. But it is much harder for Sienna to show other people *why* she is upset.
>
> One day, Sienna's friend Liza was supposed to come take Sienna to a movie. But Liza got sick and could not come. Sienna is upset about this. So she pulls her hair out. Sienna does not have another way to tell people she is upset about Liza.
>
> Another day, Sienna is upset that her favorite baseball team lost their game. So she pulls her hair out. Sienna does not have another way to tell people she is upset about the baseball game. It is really hard for Sienna to show people around her *why* she is upset.

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

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

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

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

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

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

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

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

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

And the cycle starts over again.

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

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

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

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

For example:

> Harvey is autistic. Harvey types on an iPad to communicate. The iPad reads out what Harvey types. Harvey is really fast at typing. He can easily type what he wants to say on the iPad. Harvey has been using an iPad to communicate for many years.
>
> But when Harvey tries to get mental health services, the service provider tells him they cannot help him. The mental health service provider says Harvey typing on the iPad would “take too long.” The mental health service provider says none of their therapists know “how to work with someone who does not speak.”

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

For example:

> Aisha has an intellectual disability. Aisha lives in a group home. Aisha is really lonely. She does not have any friends. Because Aisha is lonely, she gets angry really easily. When Aisha gets angry, she kicks furniture and walls in the group home. Aisha has kicked holes in the walls before.
>
> The group home provider says that Aisha has “challenging behavior.” The group home provider wants to send Aisha to ABA for her “challenging behavior.”
>
> Aisha tells the group home provider that she wants to go to art classes in the community. Aisha says she could make friends at the art classes. Then, she would be less lonely. Then, she would not get angry as often. But the group home provider does not think Aisha is “ready” to go to art classes in the community. The group home provider says Aisha needs ABA for her “challenging behavior” before she can go to art classes.

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

This has to do with how Medicaid waivers work. Remember, waivers are Medicaid programs that let people with disabilities get services in the community. Many states have different Medicaid waivers for different groups of people with disabilities. The Medicaid waivers for people with IDD might pay for behavior support services. But the Medicaid waivers for people with IDD might not pay for other kinds of services. So, in many states, it is much harder for people with IDD on Medicaid waivers to get other kinds of services.

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

For example:

> Carlos is autistic. Carlos is very sensitive to bright lights. Carlos cannot go to many places in the community because those places have such bright lights. This is affecting Carlos's life. He is missing work because he cannot stand bright lights. He is not able to go to the store to run errands because of the bright lights.
>
> Carlos wants to work with an occupational therapist. An occupational therapist could help Carlos figure out ways to deal with bright lights. An occupational therapist could help Carlos advocate to have his workplace use different kinds of lightbulbs.
>
> But Medicaid will not pay for Carlos to see an occupational therapist. Medicaid says that Carlos needs behavior support services because he is "avoiding work." But none of the behavior support services Carlos could get would help with his sensitivity to bright lights.

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

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

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

For example:

> JoAnna has an intellectual disability. JoAnna lives in an adult foster care home. There is another woman with a disability, Maisie, who also lives in the adult foster care home. JoAnna does not like Maisie. Maisie steals JoAnna's food. If JoAnna leaves any of her snacks in the kitchen pantry, Maisie will steal them. So JoAnna starts to hide food in her bedroom.
>
> JoAnna's foster parents notice that JoAnna is hiding food in her bedroom. There are ants in JoAnna's bedroom because of the food. JoAnna's foster parents bring her to a therapist to talk about why she is hiding food in her room. JoAnna explains that she is hiding food in her room so Maisie will not steal it.
>
> The therapist and JoAnna's foster parents decide to talk to Maisie about stealing JoAnna's food. After they talk to Maisie, Maisie stops stealing JoAnna's food. JoAnna stops hiding food in her room. JoAnna, her foster parents, and the therapist solved the problem that was causing her behavior.

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

For example:

> Rafael is autistic. Rafael is in high school. Other kids at Rafael's high school bully Rafael. The other kids call Rafael mean names. The other kids hit and kick Rafael. Rafael tries to tell the other kids to stop bullying him. But the other kids do not listen to Rafael.
>
> Rafael gets sick of the other kids bullying him. The next time one of the bullies calls Rafael mean names, he pushes them away. A teacher sees Rafael push the other kid. The teacher sends Rafael to the principal's office for pushing another kid. Rafael tries to explain that he only pushed the other kid because they were bullying him. But nobody listens to Rafael.
>
> Rafael gets sent to ABA. In ABA, Rafael is supposed to be working on "using his words" to explain when he does not like something. Rafael keeps trying to explain that he did tell the bullies to stop picking on him. But nobody listens to him.

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

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

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

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

For example:

> Amy has a brain injury. She is 45 years old. Amy lives in a group home. The staff at Amy's group home treat her like a child. Amy has to ask the staff if she wants to leave the group home. She has to be back at the group home by 5 p.m. every night. She has to ask the group home staff if she wants to have friends over at the group home. She is not allowed to drink alcohol or smoke cigarettes, even though she is an adult.
>
> Amy is stressed all the time because of how the group home staff treat her. She feels upset that the group home staff do not respect her. So Amy starts breaking the rules. She leaves the group home without asking the staff first. She stays out until midnight with her friends. She invites her friends over and asks them to buy her alcohol.
>
> The group home staff say that Amy has "challenging behavior." But Amy is just responding to being treated badly. If the group home staff treated Amy like an adult, she would not "act out."

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

- Hospitals.
- Nursing homes.

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

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

- Group homes.
- Assisted living facilities.

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

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

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

None of these excuses make it right to put people in institutions, even smaller institutions. Living in an institution causes people a lot of trauma. This is true even if the institution is small. People with IDD in smaller institutions still have fewer choices than people with IDD who do not live in institutions. When people with IDD who live in smaller institutions “act out,” it is often because they live in an institution. It is often because they do not have control over their lives.

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

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

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

1. The provider says the person’s “challenging behavior” needs to change or stop.

2. The provider does not ask *why* the person is having the behavior. The provider also does not ask if the person has some need that is not being met.

3. The person starts to get behavior support services to make them stop or change their behavior. Sometimes, the provider doing the behavior support services hurts the person. The person does not get help for the reason *why* they are having the behavior.

4. The person gets really stressed and upset at the behavior support services because the services are not helping them. Sometimes, the person’s behavior gets worse because of this.

5. The provider sees that the person’s behavior is getting worse. The provider decides the new, worse behavior needs to stop or change. The process starts back over at step 1.

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

For example:

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

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

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

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

A lot of people with IDD who get HCBS get help from support workers. **Support workers** are people whose job it is to help people with IDD in our homes and in the community. Support workers are sometimes called direct support professionals.

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

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

We will talk about each of these reasons next.

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

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

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

For example:

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

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

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

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

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

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

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

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

For example:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

That means:

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

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

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

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

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

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

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

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

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

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

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

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

For example:

> Viola is autistic and has Down Syndrome. Viola lives in a group home. Viola really likes to go to the park and fly kites. The HCBS Settings Rule says Viola has the right to set her own daily schedule. Viola wants to go to the park every day and fly kites. Viola needs a support worker to go to the park with her.
>
> But there are not enough support workers at Viola's group home for someone to go to the park with Viola every day. So Viola only gets to go to the park once a week. When she gets to go to the park, everyone else at the group home has to come, too. On days when Viola does not go to the park, she has to go to things other people at her group home want.
>
> The HCBS Settings Rule says Viola has the right to set her own daily schedule. The HCBS Settings rule says Viola has the right to go where she wants in the community. The HCBS Settings Rule says Viola has the right to skip going places other people in the group home want to go to. But because there are not enough support workers at her group home, Viola does not get these rights.

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

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

Right now, a lot of training on behavior support services for support workers focuses on what to do when someone has a mental health crisis. A **mental health crisis** is when a person is having thoughts or feelings that hurt them that they cannot control. During a mental health crisis, a person might try to hurt themselves or others. A lot of the training on what to do when someone has a mental health crisis focuses on practices that hurt people, like restraint and seclusion. A lot of the training on what to do when someone has a mental health crisis is based in ABA and behaviorism. Most of the training on what to do when someone has a mental health crisis:

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

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

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

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

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

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

For example:

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

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

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

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

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

For example:

> Daniz is a support worker. Daniz helps Lukas. Lukas has an intellectual disability. Lukas has a job stocking shelves in a grocery store. Daniz helps Lukas at work.
>
> People at the grocery store treat Lukas really badly. Lukas's coworkers talk about him like he is not there. People shopping at the grocery store call Lukas the r-word. Lukas's boss refuses to give Lukas a pay raise, even though Lukas's coworkers have all gotten pay raises. Lukas is really sad and angry because of how people treat him.
>
> Daniz sees how people treat Lukas every day. Daniz is also sad because of how people treat Lukas. Daniz is also angry because of how people treat Lukas. Daniz has secondary trauma from how people treat Lukas.

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

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

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

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

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

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

These include things like:

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

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

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

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

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

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

Restraint and seclusion cause people a lot of trauma.

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

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

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

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

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

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

The people ASAN talked to thought:

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

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

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

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

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

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

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

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

For example:

> Omar is autistic and has a mental health disability. When Omar gets upset, he scratches his face and neck until they bleed. Omar’s parents, support worker, and case manager all meet to talk about his HCBS goals for the year. They decide that Omar should have the goal of not scratching his face and neck anymore. They decide that Omar should get ABA to teach him not to scratch his face and neck anymore.
>
> Omar does not like this goal. He thinks a better goal would be for him to find a mental health therapist and go to weekly therapy appointments. But nobody listens to what Omar wants. Omar tries to get out of going to ABA. He hides under his bed when he is supposed to get ready to go to ABA appointments.
>
> Omar’s parents, support worker, and case manager see this. They decide that Omar should no longer get to play video games until he starts going to ABA. So they take away Omar’s video games. Omar is being punished for not working on a goal he did not want in the first place.

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

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

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

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

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

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

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

For example:

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

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

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

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

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

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

For example:

> Caring Hearts, Inc. is an HCBS provider. Caring Hearts, Inc. makes “menus” of services they offer people with different disabilities. Caring Hearts, Inc. makes one “menu” for people with cerebral palsy. Caring Hearts, Inc. makes a different “menu” for autistic people.
>
> The “menu” for people with cerebral palsy says people with cerebral palsy can get occupational therapy. But the “menu” for autistic people says autistic people cannot get occupational therapy. The “menu” for autistic people says autistic people can only get ABA.

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

For example:

> Kalla has an intellectual disability and a mental health disability. Kalla wants to go to a day program that can help with her mental health disability. Kalla gets services from Caring Hearts, Inc.. Caring Hearts, Inc. has day programs for people with mental health disabilities.
>
> So Kalla asks Caring Hearts, Inc. if she can be part of their day program for people with mental health disabilities. Caring Hearts, Inc. says no. Caring Hearts, Inc. says that Kalla can only be part of the day program for people with intellectual disabilities. Caring Hearts, Inc. says that Kalla will not get anything out of the day program for people with mental health disabilities.
>
> This is not true! But it means Kalla cannot get into a day program that would actually help her.

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

Some people who get HCBS through a waiver use self-direction. **Self-direction** is an option that lets people who get HCBS design and run the services they get.

When someone self-directs their services, they tend to:

- Have more control over what services they get. For example, choosing what services they need rather than just being assigned to services.
- Be more involved in the services they get. For example, being able to hire and fire their support workers without going through an HCBS provider.
- Have more responsibilities around their services. For example, having to talk to their case manager and support workers a lot more.

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

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

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

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

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

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

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

For example:

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

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

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

For example:

> Jolene gets HCBS. Jolene self-directs her own services. The self-direction waiver rules say that Jolene has to be in charge of all of her services. Jolene can get help from a case manager with some parts of the process. Jolele can get help from an HCBS provider to help her manage her HCBS budget. But Jolene still has to write her HCBS support plan on her own. Jolene still has to explain why she needs a service or item every time she needs one.
>
> Jolene likes self-directing her HCBS. Self-direction makes it easier for Jolene to get weekly art therapy in her own home. She would not be able to get in-home art therapy if she was not self-directing her services. The weekly in-home art therapy helps Jolene. It makes her a lot calmer and happier.
>
> But self-directing her services also means Jolene has to manage all her regular support workers. She is responsible for hiring all her support workers. She is responsible for filling out timesheets so her support workers can get paid. Jolene hates doing timesheets. She wishes she could get support workers through an HCBS provider. She wishes she could only self-direct some of her services and let an agency handle the rest.

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

Some people with disabilities are under guardianship. **Guardianship** is when a court takes away a person with a disability's right to make choices for 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. This is true even if the person has a "person-centered plan." This is true even if someone has self-directed services.

For example:

> Shiloh is autistic and has a mental health disability. Shiloh is under guardianship. Shiloh's mother is Shiloh's guardianship. Shiloh gets HCBS. His HCBS are supposed to be "person-centered."
>
> Shiloh has self-directed HCBS. He is supposed to have more control over his HCBS. But because Shiloh is under guardianship, his mother gets to make all the decisions about his HCBS. Shiloh's mother gets the final say about what services Shiloh gets.

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

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

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

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

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

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

People with IDD often have to rely on mental health crisis services. A mental health crisis is when a person is having thoughts or feelings that hurt them that they cannot control. During a mental health crisis, a person might try to hurt themselves or others.

Mental health crisis services are services that help people who are dealing with mental health crises. These services help people dealing with thoughts or feelings that hurt them that they cannot control. Sometimes mental health crisis services happen in the community. Community-based mental health crisis services tend to be things like:

- Walk-in clinics that offer therapy without an appointment.
- Services that will send a therapist or social worker to the home of a person who is in a mental health crisis.
- Crisis respites. **Crisis respites** are houses or apartments where people can stay for a few days until the mental health crisis has passed. Crisis respites often have services like support workers or therapy groups.

  Some crisis respites are peer-run. That means they are staffed and run by people who have mental health disabilities.
- Day programs for people with mental health disabilities. Day programs usually offer things like:
  - ◊ Therapy groups.
  - ◊ Medications.
  - ◊ Peer support. **Peer support** is a service where people with IDD or mental health disabilities can talk to a peer worker. A **peer worker** is another person with IDD or mental health disabilities. Peer workers get special training in helping other people with IDD or mental health disabilities.

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

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

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

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

- Psychiatric hospitals and psychiatric wards at general hospitals. Psychiatric hospitals are hospitals that take care of people in mental health crises. Psychiatric wards are units that take care of people in mental health crises inside larger hospitals. Most people who are in mental health crises only stay in a psychiatric hospital or psychiatric ward for less than a week. But some psychiatric hospitals and psychiatric wards will hold people for weeks, months, or even years.

- Residential treatment facilities. Residential treatment facilities are smaller mental health institutions in a community. Residential treatment facilities are kind of like a cross between a psychiatric hospital and a group home. Residential treatment facilities focus on mental health services.

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

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

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

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

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

For example:

> Natalia is autistic and has depression. Natalia has been under a lot of stress from school lately. Natalia tells her therapist that she is thinking about hurting herself because she is so stressed out. The therapist tells Natalia to go to the hospital if she is thinking about hurting herself. Natalia goes to the hospital. The hospital emergency room sends Natalia to the hospital's psychiatric ward.
>
> Natalia is not allowed to leave the psychiatric ward until a doctor says she can. She is not allowed to go outside. She is not allowed to see her friends. On the psychiatric ward, Natalia does not get much help. She gets medication that is supposed to make her feel better. But the medication just makes her tired all the time.

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

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

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

For example:

> The Center for START Services is a group of researchers. They study how to make mental health services better for people with dual diagnosis. The Center for START Services looked at mental health crisis services in two states: Wisconsin and Rhode Island. The Center for START Services found that in Wisconsin and Rhode Island:
>
> - There are not enough mental health crisis services in general.
> - The mental health crisis services that do exist often do not want to accept people with IDD as patients.
> - People with IDD and their families often have to rely on police or hospital emergency rooms for mental health crisis services.

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

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

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

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

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

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

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

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

- Therapists.
- Social workers.
- Peer workers.

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

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

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

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

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

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

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

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

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

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

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

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

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Plain Language Version

Beyond Coercion and Institutionalization:

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

Part 6: What Changes We Want to See in Behavior Support Services

Words to Know in Part 6

988 Lifeline

A group of mental health crisis service providers people can reach by calling or texting 988. The 988 Lifeline will send the call or text to a local mental health crisis service who can help the person.

Applied behavior analysis (ABA)

A type of behavior support service that is mostly used on autistic children, but can be used on other people with IDD. ABA focuses on making people act “less autistic” by changing the way people behave.

Augmentative and alternative communication (AAC)

Ways of communicating other than speaking with your mouth or using a sign language. AAC includes things like writing, pointing to letters and words, or typing words on a computer.

Behavior

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

Behavior support services

Services that help people deal with behavior that makes it hard for them to live the lives they want.

Behaviorism

A way of thinking about human behavior that says we should only think about the behavior we can see. Behaviorism focuses on changing a person's behavior but not on the person's thoughts or feelings. ABA is part of behaviorism.

Block treatment

When a group of people with disabilities all get the same services, even if they have different needs and wants.

Burnout

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

Centers for Medicare and Medicaid Services (CMS)

The part of the U.S. government that runs Medicaid on the national level. CMS makes rules that all state Medicaid programs have to follow.

Challenging behavior

A term some people use to talk about behavior that makes it hard for a person to live the life they want.

Coercion

Trying to change someone's behavior, even if that person does not want to change their behavior.

Communication

The different ways people tell each other information and ideas.

Community

A place where you can make choices about your own life. Communities can be places like neighborhoods, towns, or cities.

Community living

When people with disabilities live in the same places as people without disabilities.

COVID-19

A bad disease that has spread around the world and made a lot of people very sick. COVID-19 has made it hard for people with disabilities to get good services.

Crisis respites

Houses or apartments where people can stay for a few days until a mental health crisis has passed. Crisis respites often have services like support workers or therapy groups.

Data

Facts and information about something.

Dual diagnosis

When someone has both an IDD and a mental health disability.

Guardian

The person a court chooses to make choices for a person under guardianship.

Guardianship

When a court takes away a person with a disability’s right to make choices for 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.

Interviewing

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

Long-term services and supports (LTSS)

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

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.

Medically underserved population

A group of people who do not have enough access to health care.

Mental health crisis

When a person is having thoughts or feelings that hurt them that they cannot control. During a mental health crisis, a person might try to hurt themselves or others.

Mental health crisis services

Services that are supposed to help people who are dealing with emotions or behavior that hurt them that they cannot control.

Mental health disabilities

Disabilities that change how people think and feel. Mental health disabilities can make it hard for people to feel in control of their emotions.

Mental health services

Services that help people with mental health disabilities deal with their emotions and live in the community.

Mental health therapy

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

Occupational therapy

A service that helps people learn and practice skills they need in their everyday lives.

Olmstead v L.C.

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

Operant conditioning

Changing someone’s behavior using rewards and punishments.

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.

Prevent

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

Primary care doctor

A doctor you see for regular, general health care, like getting shots or when you have the flu.

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.

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.

Researchers

People who do research as their jobs.

Restraint

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

Reward

Something a person gets for having “good behavior.”

Seclusion

Locking someone in an empty room.

Secondary trauma

When someone has trauma from seeing someone else go through a really stressful experience

Self-direction

An option that some people who get HCBS through a waiver use. Self-direction lets a person design and run the HCBS they get.

Speech therapy

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

Support workers

People whose job it is to help people with IDD in our homes and in the community. Support workers are sometimes called direct support professionals.

Trauma

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

Trauma-informed care

A way to provide services to people with trauma. Trauma-informed care focuses on not making people's trauma worse. Trauma-informed care helps people work through their trauma.

Voluntary

When the person getting services chooses to get the services. If the person is forced or coerced into getting services, the services are not voluntary.

Waivers

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

What Changes We Want to See in Behavior Support Services

We have talked a lot about the problems with **behavior support services** right now. We think there are ways to fix these problems. Service **providers**, state governments, and the U.S. government can all make changes to fix these problems. In this part, we talk about the following changes we want to see in behavior support services:

- **Mental health services** and IDD services should be together, not separate.
- There should be more support for **support workers** and other people who help people with IDD.
- **HCBS** and behavior support services should be more person-centered.
- There should be better ways to **prevent mental health crises** and respond to these crises when they happen.
- The U.S. and state governments should learn more about what kinds of services people can get on **waivers**.

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

Note: In this part, we use the term “IDD service providers” a lot. By “IDD service providers,” we mean groups that provide HCBS to people with IDD.

Mental health services and IDD services should be together, not separate.

The first change that we want to see in behavior support services is to bring IDD services and mental health services closer together. Right now, mental health services and IDD services are very far apart. These services are usually provided by different kinds of providers. These services are usually overseen by different parts of state governments. These services are usually paid for by different parts of **Medicaid** (or other health insurance). That makes it very hard for people with IDD to get both IDD services and mental health services.

For example:

> Arjun has an intellectual disability. He also has a **mental health disability** called schizoaffective disorder. Arjun should be able to get both IDD services and mental health services in his state. But Arjun's state makes it very hard for him to get both kinds of services.
>
> Arjun applies for both IDD and mental health services. But Arjun's state says he can only get IDD services or mental health services, but not both. Arjun tries applying for IDD services. But the IDD services tell Arjun, "You have a mental health disability, so we cannot help you. You should apply for mental health services."
>
> So Arjun applies for mental health services. But the mental health services tell Arjun, "You have an intellectual disability, so we cannot help you. You should apply for IDD services."
>
> Arjun should be able to get both kinds of services! But because the services in his state do not talk to each other, he cannot get either.

ASAN wants service providers, state governments, and the U.S. government to work together to fix this. We want IDD service providers to work with mental health service providers to make sure people with IDD can get both kinds of services. We want the U.S. and state governments to get rid of rules and policies that keep IDD services and mental health services so separate.

Service providers should make it easier for people to get both mental health services and IDD services.

IDD service providers need to make sure people with IDD who get services can get both IDD services and mental health services. IDD service providers need to make sure people with IDD can get different kinds of mental health services, not just mental health crisis services.

IDD service providers also need to change how they run their own services. IDD service providers need to include more services that help people with IDD have good mental health. IDD service providers also need to include more services that help people with IDD deal with trauma. (Trauma is when a scary situation changes how a person thinks, feels, and behaves.)

IDD service providers need to look at all their different services and policies for services. The providers need to look for services and policies that might cause trauma for people with IDD. Then, the providers need to change or get rid of those services or policies.

IDD service providers need to have more training for the support workers and other people who work for them. This includes having training on respecting people with IDD and treating us as people first.

IDD service providers also need to make sure their services and policies let people with IDD make choices about our own services. Part of this means service providers need to stop using **provider-owned settings** that give everyone the same services, such as group homes. Providers need to start using services that meet the needs of each person they serve.

IDD service providers need to work closely with mental health service providers. This is for 2 reasons:

- Working together helps mental health service providers learn how to care for people with IDD.
- Working together helps IDD service providers learn how to support mental health for people with IDD.

Right now, most mental health service providers do not know how to care for people with IDD. Right now, most IDD service providers do not know how to give good mental health support to people with IDD. If IDD service providers and mental health service providers work together, they can learn from each other. This will help both kinds of providers give people with IDD better services.

States should change how they control mental health services and IDD services to make them less separate.

State governments need to make sure their policies and rules do not keep mental health and IDD services separate. To do this, state governments should look at the different IDD services and mental health services in the states.

State governments should look at policies and rules around services. They should look for policies and rules that make it hard for people with IDD to get mental health services. Then, states should rewrite these policies and rules to make it easier for people with IDD to get mental health services.

The U.S. government says that state governments need to make sure that people with disabilities can get services in the community. The U.S. government says this in:

- The ***Olmstead*** court case.
- The **HCBS Settings Rule**.

State governments need to make sure they follow *Olmstead* and the HCBS Settings Rule. State governments need to make sure that HCBS providers in their states follow the HCBS Settings Rule. When a state government is not following *Olmstead* or the HCBS Settings Rule, they need to fix this right away. When a HCBS provider is not following the HCBS Settings Rule, the state government needs to make sure the provider fixes this right away.

Olmstead and the HCBS Settings Rule give people with disabilities certain rights. State governments need to make sure there are ways for people with disabilities to report if a provider does not let us have our rights.

State governments also need to make sure that people with IDD can get good mental health services. State governments need to make sure that people with IDD do not just get behaviorist services. If there are not good mental health services for people with IDD in a state, the state should work to make these services. States should work together to make good mental health services for people with IDD.

State governments need to make sure that any new services are voluntary and in the community. **Voluntary** means the person getting services chooses to get the services. If someone forces or coerces the person into getting services, the services are not voluntary. Services also need to be in the community, not in institutions.

For example:

> Let’s say California decides to open new community centers for people with mental health disabilities. People can go to the community centers for things like:
>
> - Talking to a therapist or social worker.
> - Getting help with applying for or managing services.
> - Going to a class or support group.

California wants to make sure the community centers are voluntary. So California decides that anyone who wants to go to a community center has to meet with a social worker. The social worker will make sure the person wants to join the center. California makes a rule that **guardians** and the court system cannot force people to go to a community center.

States governments also need to make sure that people with IDD help design new mental health services for people with IDD. People with IDD know what kinds of mental health services will help us the most. Remember: nothing about us, without us!

The U.S. government should make it easier for states to combine mental health services and IDD services.

The U.S. government needs to help states combine their IDD services and mental health services. Part of this means making sure state governments and providers follow laws and rules around health care access. The U.S. government must make sure state governments and providers follow rules that help people with disabilities get good health care. These rules talk about how state governments and providers cannot treat people with disabilities differently because we have disabilities. Some of these rules are:

- Section 1557 of the Affordable Care Act.

  Section 1557 says that health care providers cannot treat people worse because they have a disability.

- Section 504 of the Rehabilitation Act.

  Section 504 says that groups that get money from the government cannot treat people worse because they have a disability. Most health care providers get money from the government through Medicaid or another program called Medicare.

The U.S. government needs to use these rules to help people with IDD get good mental health services.

The U.S. government also needs to change how it gives money to states to make sure people with IDD can get good mental health services. The U.S. government should give more money to states that combine mental health and IDD services. Some states are working very hard to make sure people with IDD can get good mental health services. The U.S. government should talk about what these states are doing.

The U.S. government should show other states how they can make mental health services for people with IDD better. The U.S. government should especially focus on mental health services that people with IDD or mental health disabilities helped create.

But the U.S. government needs to make sure that these programs are voluntary for people with IDD or mental health disabilities. The U.S. government cannot say that people with disabilities need to get mental health services in order to get other services, like support workers. People with IDD have the right to say no to services, even when other people disagree with us. People with mental health disabilities have the right to say no to services, even when other people disagree with them.

The U.S. government also must make sure that training for mental health providers focuses more on people with IDD. Training for mental health providers can include things like:

- Medical school for doctors and nurses that work in mental health.
- College and graduate school for therapists and counselors.
- Internships where mental health providers learn by actually working in a mental health clinic.

Right now, these training programs do not talk a lot about people with IDD. The U.S. government must make sure these training programs talk more about caring for people with IDD.

The U.S. government also needs to say that people with IDD are a medically underserved population. “**Medically underserved population**” means a group of people who do not have enough access to health care. Some medically underserved populations are:

- People who are homeless.
- People who do not have a lot of money.
- Indigenous people.

If the U.S. government said that people with IDD were a medically underserved population, it would mean:

- There would be more money for health care for people with IDD.
- There would be more training for providers who want to work with people with IDD.
- There would be more money for research on how to make health care for people with IDD better.

More support for support workers and other people who help people with IDD.

The second change that we want to see in behavior support services is more money and training for support workers. Right now, support workers are not paid well at all. Most support workers do not get enough training on how best to help people with IDD. Support workers' jobs can be hard and stressful. Many support workers have quit their jobs because they are doing very stressful work for not a lot of money.

When there are not enough support workers, it is hard for HCBS providers to give good services to everyone who needs them. When there are not enough support workers, HCBS providers are more likely to use things like **restraint** and **seclusion**. When support workers do not stay at their jobs for very long, HCBS providers are less likely to offer good training for support workers.

All of this has bad effects on people with IDD. It means we cannot get the services we need. It means we have to wait a long time to get services. It means we are more likely to end up in institutions and places that look like institutions.

ASAN wants service providers, state governments, and the U.S. government to work together to fix this. We want service providers to improve training for support workers. We want state governments to spend more money on HCBS, especially on paying support workers.

Service providers should give support workers more training on mental health needs and trauma-informed care.

IDD service providers need to give support workers training on how to provide good behavior support services. This includes everyday mental health supports, like checking in on how people are feeling. IDD service providers need to make sure that behavior support services actually focus on the person's own goals. IDD service providers need to make sure that behavior support services do not use restraint and seclusion or **coercion**.

IDD service providers also need to make sure their support workers understand things like:

- How to respect people with IDD and treat us well.
- How to follow laws and rules, like the HCBS Settings Rule.
- How to do trauma-informed care.

Trauma-informed care is a way to provide services to people with trauma. Trauma-informed care focuses on not making people's trauma worse. Trauma-informed care helps people work through their trauma.

For example:

> Caring Hearts, Inc. is an IDD service provider. Caring Hearts, Inc. wants to use more trauma-informed care in their services. So Caring Hearts, Inc. looks for ways to change their services. They look for ways to give people with IDD more chances to take a break when they get services. They look for ways to give people with IDD more options about the services they get. They look for ways to make sure people with IDD always have a way to tell a support worker or therapist "stop!" or "I do not like that!" All of these things help people with IDD who have been through trauma.

When IDD service providers design trainings for support workers, they need to work with different groups of people. IDD service providers need to work with:

- People with IDD.
- Mental health service providers.
- Support workers.
- **Researchers** who study IDD services.

IDD service providers also need to support the mental health of support workers and other staff. Support workers' jobs are often very hard. Support workers often deal with secondary trauma and burnout. The chance that a support worker will end up with secondary trauma and burnout gets bigger the longer they work.

IDD service providers can support the mental health of support workers in a few ways. IDD service providers can set up ways for support workers to talk about how their jobs are going. IDD service providers can offer health insurance and other ways to pay for **mental health therapy** to support workers. IDD service providers can make sure support workers get paid time off work for vacations or sick days.

All of these things will make support workers' mental health better. All of these things will help support workers give better services to people with IDD.

States should put more money aside for HCBS, especially for support workers.

State governments need to spend more money on HCBS. A lot of this money needs to go to raising pay for support workers. Remember, most support workers do not earn a lot of money. State governments can raise pay for support workers by giving HCBS providers more money.

State governments can require that HCBS providers put a certain amount of the money towards raising pay for support workers. States can also raise support worker pay in other ways. For example, a state could send money directly to support workers who have been at their jobs for at least 1 year.

State governments need to also make training on mental health support better for support workers. States can do this in a few ways. States can give more money to HCBS providers and say the money can only be used for training. States can set up training people have to complete before they can become a support worker. (This is similar to how training for nursing assistants in hospitals works.) States can also design new trainings for HCBS providers to give support workers. That way, support workers will all get the same training, no matter which HCBS provider they work for.

For example:

> The National Alliance for Direct Support Professionals (NADSP) is a group that advocates for the needs of support workers. The NADSP has made a list of skills they think all support workers need to have. The NADSP calls these skills “competency areas.”
>
> States can work with the NADSP to create trainings that focus on the competency areas. That way, states can make sure all support workers are getting trained on the same skills.

Finally, state governments need to make sure that HCBS providers report how often they use things like restraint and seclusion. The state governments need to look at how often providers use restraint and seclusion. The state governments need to work with providers to reduce how often providers use restraint and seclusion. The state governments also need to report how often providers are using restraint and seclusion to the U.S. government.

The U.S. government should give states more money for HCBS and make sure states follow rules about HCBS.

The U.S. government must give states more money for HCBS. Right now, there is not enough money for everyone who needs HCBS to get HCBS. That means people in different states might receive very different HCBS, even if they have the same needs. If the U.S. government gave states more money for HCBS, all states could spend more money on HCBS. That would mean that more people could get good HCBS no matter where they live.

The U.S. government must also make sure that more money for HCBS goes towards paying support workers. The U.S. government should work with state governments to make sure support workers are paid enough for their work.

The U.S. government needs to make sure that states have the money to collect and report data. **Data** is facts or information about something. In this case, states need to collect and report data about what kinds of services providers are using. States need to collect and report data about which providers are using restraint and seclusion. States need to report this data to the U.S. government.

It takes money to design and run good data collection systems. It takes money to pay people to collect data and figure out what the data means. So the U.S. government needs to give states more money to collect and report this data.

The U.S. government also needs to make sure the Centers for Medicare & Medicaid Services (CMS) has enough money to collect data. **CMS** is the part of the U.S. government that runs Medicaid on the U.S. level. CMS makes rules that all state Medicaid programs have to follow. CMS collects data from states to make sure states and providers are following CMS's rules.

CMS needs more money to make sure states are following the rules around reporting data. CMS also needs more money to help states when states do not report the data they need to report.

Making HCBS and behavior support services more person-centered.

Most HCBS providers say all the people they support have their own person-centered plans. Remember, **person-centered planning** is a way of figuring out what services might help a person live the life they want to live.

A person-centered plan is supposed to talk about a person's hopes, goals, and wants as well as the person's needs. But often, person-centered plans do not do this. Often, person-centered plans only talk about what a person needs help with.

Part of the person-centered planning process is supposed to be designing or changing services to work for the person.

For example:

> Mickie has a disability. She cannot drive. Mickie needs transportation services to help her get around in the community. Mickie's person-centered planning team is meeting. The team is talking about how Mickie could use paratransit services. Paratransit services require Mickie to schedule rides 3 days in advance. Mickie does not want to paratransit services. She does not want to schedule rides 3 days in advance.
>
> So Mickie's team talks about different options for transportation. Mickie's team decides that Mickie can take taxi cabs to get around the community. Mickie's waiver will pay the cost of the cabs. Mickie's team figured out a way to make transportation services work for Mickie.

But in a lot of cases, people who get HCBS do not get services that are designed or changed to meet their needs. This is sometimes called "block treatment." **Block treatment** is when a group of people with disabilities all get the same services, even if they have different needs and wants.

For example:

> In Part 5, we talked about Viola. Viola lives in a group home. Viola's group home does not have enough staff. So everyone living in the group home has to do the same activities. If one person in the group home wants to go somewhere, everyone in the group home has to go there. Viola and her housemates do not get to choose where they go most of the time. This is an example of block treatment.

ASAN wants service providers, state governments, and the U.S. government to work together to fix these problems with person-centered planning. We want service providers to give their staff better training and to give people with IDD more choices. We want state governments to make sure service providers follow the HCBS Settings Rule and other rules around HCBS. We want the U.S. government to make sure states follow the HCBS Settings Rule and give people with IDD more chances for **self-direction**.

Service providers should support person-centered practices through better training and giving people with IDD more choices.

IDD service providers need to make sure people with IDD have actual person-centered plans and services. IDD services providers can do this by:

- Giving support workers and other staff more training on person-centered planning.
- Focusing on the goals people with IDD have for ourselves, not the goals other people have for us.
- Making sure people with IDD have the support we need to create our plans and services.
- Ending restraint, seclusion, and coercion.

IDD service providers need to make sure that person-centered planning focuses on the goals a person with IDD has. IDD service providers should not focus so much on the goals that other people have for the person with IDD.

IDD service providers should make sure that the person with IDD has the support they need to set their own goals. This includes **communication** support. If the person does not already have a way to communicate what they want, IDD service providers should work to get them one. IDD service providers can work with **speech therapists** to do this. IDD service providers can also work with groups that provide assistive technology, like **AAC** devices, to do this.

IDD service providers need to regularly check to make sure a person's plan and services still meet the person's needs and goals. IDD service providers also need to regularly check to make sure a person's plan is still being followed. Person-centered plans can be great tools to help people get services to meet their goals. But even the best person-centered plan is not very helpful if people are not following it.

For example:

Juliana has an intellectual disability. Juliana gets HCBS. Juliana lives with her parents. Juliana is learning to use an AAC device. Juliana's family speaks Spanish and English at home. Juliana's person-centered plan says that she will work with a speech therapist who speaks both English and Spanish. The speech therapist will help Juliana learn to use her AAC device.

But Juliana is not working with a speech therapist who speaks both English and Spanish. Juliana's HCBS provider has not looked for a speech therapist who speaks both English and Spanish. Juliana wants to work with a speech therapist who speaks both English and Spanish. But she cannot because her HCBS provider has not found one.

IDD services providers need to review people's person-centered plans at least once a year. IDD service providers need to also review a person's person-centered plan whenever the person asks them to. IDD service providers need to make sure that people with IDD know how reviewing our person-centered plans works. IDD service providers need to make sure people with IDD know that we should be in charge of making and changing our person-centered plans. IDD service providers need to make sure that staff know how to help people with IDD with our person-centered plans.

Person-centered plans should focus on many different parts of a person's life. Person-centered plan should not just focus on a person's **behavior**. Person-centered plans should especially focus on things like:

- Mental health.
- Sensory needs.
- Good health care in general.

IDD service providers need to make sure that person-centered plans focus on many parts of a person's life. Part of this means IDD service providers need to get rid of **behaviorism** and **ABA** in their services. This includes getting rid of:

- **Operant conditioning**.
- **Rewards** and **punishments**.
- Coercing people into doing things they do not want to do.

IDD service providers also need to make sure that people who get services can get help to deal with trauma from behaviorism and ABA.

IDD service providers must stop using restraint and seclusion. This includes stopping using medication to make someone too tired to move. IDD service providers need to find ways to support people that do not use restraint or seclusion. IDD service providers also need to think about how restraint and seclusion affect people with IDD. IDD service providers need to know that restraint and seclusion can cause a lot of trauma for people with IDD.

IDD service providers need to help people with IDD work through trauma we might have from restraint and seclusion.

States should actually make sure providers follow the HCBS Settings Rule and other rules and laws about HCBS.

State governments must make sure that IDD service providers follow rules and laws about HCBS. State governments also need to make sure that IDD service providers use person-centered practices for their services. State governments also need to make sure that people with IDD and people with mental health disabilities can get good services in the community.

State governments have a lot of power over how IDD service providers use person-centered planning. State governments have this power because they make the rules about HCBS in their states. State governments need to use their power to make sure IDD service providers follow rules and laws around HCBS. State governments need to use their power to make sure IDD service providers use person-centered practices for their services.

To do this, state governments need to make sure their HCBS rules follow U.S. rules for HCBS, like the HCBS Settings Rule. State governments also need to make sure that their HCBS rules include rules around person-centered planning.

If HCBS providers are not following the HCBS Settings Rule or state rules for HCBS, state governments need to talk to those providers. State governments need to make sure the providers are following the rules. Part of this means state governments need to make ways for people to report if a provider does not follow the rules.

States must make sure that people with IDD and people with mental health disabilities can get good services in the community. The *Olmstead* court case said that states need to do this. The HCBS Settings Rule says that states need to do this. States need to get rid of rules and laws that force people with IDD and people with mental health disabilities to get services in institutions. And states need to make sure that there are actual IDD and mental health services in the community.

For example:

A state government might say that people with IDD and people with mental health disabilities can get services in the community. The state government might not have laws requiring people with IDD or mental health disabilities to get services in institutions. But there are no community services for people with IDD or mental health disabilities in the state. People have no choice but to get services in institutions.

It does not matter that the state government says people with IDD or mental health disabilities have the right to services in the community. It does not matter that the state does not have laws that force people with IDD or mental health disabilities into institutions. If there are no community services, people cannot get services in the community.

This is especially important for mental health services. A lot of states still have laws that make it very easy for people with mental health disabilities to get stuck in institutions. And states that do not have these laws often do not have a lot of services in the community for people with mental health disabilities. So people with mental health disabilities get stuck in institutions anyway.

The *Olmstead* court case also applies to people with mental health disabilities. People with mental health disabilities have the same rights as people with other kinds of disabilities. State governments need to make sure that people with mental health disabilities can get good services in the community, too.

State governments need to make sure that people with IDD can self-direct our services if we want to. We should be able to do this no matter what our disability is. We should be able to do this no matter what services we need. Remember, self-direction is when people who get HCBS design and run the services they get. When someone self-directs their services, they tend to:

- Have more control over what services they get (such as choosing what services they need rather than just being assigned to services).
- Be more involved in the services they get (such as being able to hire and fire their support workers without going through an HCBS provider).
- Have more responsibilities around their services (such as having to talk to their case manager and support workers a lot more.)

Most states allow people with IDD to self-direct our services. But most people with IDD who get HCBS do not direct their own services. And most people with IDD who use self-direction do not make all of the choices about their services. Someone else usually makes most of the choices about the person with IDD's services

State governments need to make sure that people with IDD can self-direct our own services. State governments need to make sure that people with IDD are in charge of our own services. State governments need to make sure that people with IDD who live in provider-owned settings can self-direct their own services. State governments need to make sure that people with IDD under guardianship can self-direct their own services.

One way state governments can help people with disabilities have more control over our HCBS is by changing their rules about HCBS.

For example:

In many states, people with disabilities cannot hire our family members as support workers. Family members can include:

- A person's spouse.
- A person's parents.
- A person's children.

During part of **COVID-19**, the U.S. government said states could allow people with disabilities to hire family members as support workers. This was a big help for people with disabilities. It meant we could get support from people who know us well.

Then, the U.S. government changed what it would let states do. The U.S. government said that states could still let people with disabilities hire family members as support workers. But, states would have to change their HCBS rules to do this.

Some states have changed their HCBS rules. These states now let people with disabilities hire family members as support workers. Other states have changed their HCBS rules. These states do not let people with disabilities hire family members as support workers. More states should change their HCBS rules to let people with disabilities hire family members as support workers.

State governments can also support self-direction by making sure all people with IDD have a way to communicate. State governments should make sure that people with IDD can access AAC through Medicaid and waivers.

The U.S. government should make sure states follow rules and laws about HCBS and person-centered practices.

The U.S. government needs to make sure state governments follow the rules and laws around HCBS. The U.S. government also needs to make sure state governments support people with IDD to self-direct our own services.

The U.S. government makes laws and rules around HCBS. This includes the HCBS Settings Rule and the *Olmstead* court case. The U.S. government needs to make sure that state governments follow the HCBS Settings Rule and the *Olmstead* court case. The U.S. government needs to make sure that state governments are making HCBS providers follow the HCBS Settings Rule.

The U.S. government needs to especially focus on whether state governments are working to:

- End the use of restraint and seclusion.
- Make sure people with disabilities can get good services in the community.
- Set up a way for people with disabilities to tell state governments when HCBS providers do not treat us well.

The U.S. government also needs to help state governments make sure people with IDD can self-direct our own services. The U.S. government can do this by:

- Giving states more money for self-directed services.
- Changing U.S. laws and rules to make it easier for states to support self-directed services.
- Helping states solve problems they run into while trying to make self-directed services better.

The U.S. government also needs to make sure that states give people enough support to direct their own HCBS. This can be communication support, like AAC. Or it could be other types of support that help people with IDD be part of person-centered planning.

Better ways to prevent mental health crises and respond to mental health crises when they happen.

Right now, there are a lot of problems with mental health crisis services. **Mental health crisis services** are services that help people who are dealing with **mental health crises**. These services help people dealing with thoughts or feelings that hurt them that they cannot control.

Mental health crisis services are a really important part of behavior support services. But right now, mental health crisis services can cause a lot of trauma for people who need them. Mental health crisis services, especially for people with **dual diagnosis**, often involve the person having to go to an institution. Mental health crisis services often do not actually talk about the reasons *why* the person is in a mental health crisis.

ASAN thinks the current mental health crisis service system needs to be part of a bigger mental health and disability services system. Service providers, states, and the U.S. government all need to be part of this change. IDD service providers can help by improving mental health support and building stronger relationships with health care providers. States can help by making it easier for people with IDD to get good mental health care in the community. This includes mental health crisis services. The U.S. government can help by making sure mental health services and other health care providers treat people with IDD well.

Service providers should improve mental health services and build stronger relationships with health care providers.

IDD service providers need to improve mental health support and build more and better relationships with health care providers. This needs to include focusing on preventing mental health crises. Service providers should not just focus on responding when a person with IDD has a mental health crisis. This means making sure that people with IDD have good access to health care when we need it. This includes mental health care.

IDD service providers need to focus on **preventing** mental health crises, not just responding to mental health crises. Preventing mental health crises means stopping mental health crises from happening in the first place. Part of this must be treating people with IDD with respect.

People with IDD face a lot of ableism. Ableism is treating someone badly because they have a disability. HCBS providers and staff treat people with IDD very badly sometimes. Our support workers do not always respect us. HCBS providers often do not let us have choices about our services or lives. People often tell us we cannot do the things we want. They do not try to figure out how to help us do those things.

All of these things can hurt people with IDD's mental health. All of these things can make it more likely we will have mental health crises.

IDD service providers can help people with IDD manage our mental health in many ways. IDD service providers can make sure that people with IDD:

- Have access to the community when we want it.
- Control our own services.
- Get good health care, including mental health care.
- Have support to deal with trauma.
- Get support to deal with mental health crises and big emotions when they happen.

IDD service providers need to do all of these things.

IDD service providers also need to develop more and better relationships with health care providers. This includes mental health care providers. IDD service providers need to make sure that people with IDD have access to regular health care. Regular health care can help spot health issues that could lead to crises later on. Regular health care can prevent issues from turning into crises.

States should make it easier for people with IDD to get the care we need, including good mental health crisis services.

State governments need to make it easier for people with IDD to get both regular health care. State governments need to make it easier for people with IDD to get crisis services. Getting regular health care makes it less likely that someone will need crisis services. State governments also need to make sure that mental health crisis services are community-based and do not involve the police.

When people get regular health care, they are less likely to need crisis services. This is true for physical health care. It is also true for mental health care. People who see a primary care doctor are less likely to go to the emergency room for issues that are not emergencies. A **primary care doctor** is a doctor you see for regular, general health care, like getting shots or when you have the flu. People who have good access to mental health care in the community are less likely to be hospitalized for mental health reasons.

State governments need to spend more money on making regular health care accessible to everyone. State governments especially need to spend more money on making regular health care more accessible to:

- People with IDD.
- People with mental health disabilities.

State governments also need to make sure people with disabilities can access good HCBS that are respectful and helpful. HCBS play a big role in making sure people with disabilities can get good health care. Many people with disabilities need support to go to health care appointments. People with disabilities should be able to control our own HCBS. We should get HCBS that are actually in the community. We should get the HCBS we need to make our own choices and live the lives we want. All of these things can help with good mental health.

State governments must make sure that mental health crisis services are actually in the community. A lot of mental health crisis services are not in the community right now. These services only happen in institutions.

Or, mental health crisis services might say they are in the community. The state government might say that the services are in the community. The services might look like they are in the community. But they are really small institutions. People cannot leave the mental health crisis service when they want. They do not have control over their lives in the mental health crisis service.

Mental health services in the community are important for the same reasons IDD services in the community are. If people have to go to an institution to get mental health services, they have to give up a lot of their rights. Sometimes, a person will go to a hospital or other institution to get mental health crisis services. The person only expects to be in the institution for a few days. But then the person gets stuck in the institution for weeks or months or even years!

And, people with IDD who are institutionalized for mental health reasons often cannot return to the community after they leave the institution.

For example:

Karan has an intellectual disability. He lives in his own apartment. He gets support for a few hours every day from a support worker.

Karan starts feeling really nervous all the time. He starts to hear voices that nobody else can hear. Karan goes to the hospital because he is scared he is going to hurt himself. Karan stays in the hospital for two weeks. He gets medications and therapy to help with his mental health.

Karan feels ready to move back into his apartment. But when he is getting ready to leave the hospital, the hospital social worker says he cannot go back to his apartment. The social worker tells Karan that he has to live in a group home instead. The social worker says Karan “needs more help than he can get” in his apartment. The social worker does not listen when Karan says he does not need more help.

When people have to go to an institution to get mental health services, it takes them out of their communities. People can lose important skills for community living while they are institutionalized. And, being institutionalized is not fun. Being institutionalized often causes trauma. For all these reasons, state governments need to make sure that people have access to mental health services in the community.

State governments also need to support mental health crisis services that do not involve the police. State governments need to work with cities and towns to create local mental health crisis services that do not involve the police.

State governments must put more money into designing mental health crisis services that do not involve the police. State governments must put more money into designing mental health crisis services that do not involve coercion. The people working for these services need to have training on how to work with people with IDD. The people working for these services need to understand that people with IDD can have mental health disabilities.

The U.S. government should make sure states and service providers follow laws that protect the rights of people with IDD getting health care.

The U.S. government must make sure states and service providers respect the rights of people with IDD getting health care. The U.S. government must make sure mental health services do not leave out people with IDD. This includes mental health crisis services. The U.S. government also must make sure there are mental health crisis services in the community that do not involve the police.

The U.S. government can do a lot to make sure people with IDD can access good mental health crisis services. One thing the U.S. government can do is make sure people with disabilities have access to good regular health care. The U.S. government needs to make sure that health care providers do not treat people with disabilities worse because we have disabilities. The U.S. government must make sure that people with disabilities have the same rights to get good health care as anyone else.

The U.S. government also needs to make sure that people with IDD are not left out of mental health services because we have IDD. This is something a lot of the people ASAN **interviewed** talked about. A lot of the people we talked to said that mental health service providers will automatically leave out people with IDD. This is not fair! Mental health service providers are not supposed to do this. The U.S. government needs to make sure that mental health service providers do not leave out people with IDD.

One way the U.S. government can do this is by saying that people with IDD are a medically underserved population. A medically underserved population is a group of people who do not have enough access to health care. If the government said people with IDD are a medically underserved population, a few things would happen:

- There would be more money for health care for people with IDD.
- There would be more training for providers who want to work with people with IDD.
- There would be more money for research on how to make health care for people with IDD better.

The U.S. government needs to work with states to make more mental health crisis services in the community. The U.S. government could give more money to states that want to build more mental health crisis services in the community. Some types of mental health crisis services that the U.S. government could help states create are crisis respites.

Crisis respites are houses or apartments where people can stay for a few days until the mental health crisis has passed. Crisis respites often have services like support workers or therapy groups. Some crisis respites are peer-run, meaning they are staffed and run by people who have mental health disabilities.

Crisis respites have been studied a lot by researchers who study mental health services. Crisis respites are really good at a few things:

- Preventing people from being institutionalized.
- Saving money.

  It costs a lot less money for someone to stay at a crisis respite than in an institution for a few days.
- Getting people set up with long-term mental health services in the community.

The U.S. government also needs to help states, cities, and towns design mental health crisis services that do not use police. One way the U.S. government can do this is through the 988 Lifeline. The **988 Lifeline** is a group of mental health crisis service providers that people can reach by calling 988. 988 is a phone number that people who are having a mental health crisis can call or text. The 988 Lifeline will send the call or text to a local mental health crisis service who can help the person.

But a lot of mental health crisis services still work with the police. And, the group that runs the 988 Lifeline says mental health crisis services must call the police in certain cases. This can be really scary and dangerous for people who are in a mental health crisis.

The U.S. government needs to change how the 988 Lifeline runs so that mental health crisis services do not involve the police. The U.S. government also needs to work with states, towns, and cities to create mental health crisis services that do not involve the police.

Set up better systems to collect data on what kinds of behavior support services people can get.

Right now, there are many different ideas of what behavior support services are. Nobody can agree on exactly what “behavior support services” means. Sometimes, two providers might agree which services are part of behavior support services. But the two providers might do the same service very differently. This means that people with IDD can have different experiences with the same behavior support services.

These differences in services happen because states and the U.S. government do not all have the same definitions of behavior support services. Each state can say that “behavior support services” means something different. And, service providers do not usually send states or the U.S. government information about what kinds of behavior support services they provide. So even if a state says specifically what behavior support services are, service providers in that state may not follow what the state says.

ASAN thinks service providers, states, and the U.S. government need to work together to fix this. Service providers need to collect more data on what services they provide. Service providers need to send that data to state governments. State governments need to collect data from service providers. State governments need to make standard definitions of what different behavior support services are. The U.S. government needs to fix how it collects data from states. The U.S. government needs to tell states to give people more information about waiver services.

Service providers should collect and report more data on what services they provide.

IDD service providers need to collect more detailed data on the services they give people with IDD. Data is facts or information about something. Then, the IDD service providers need to send this data to state governments. Doing this will help state governments and researchers look at how different service providers provide the same service.

Right now, it is very hard to tell what IDD service providers mean when they say they provide certain services.

For example:

> Two different IDD service providers might say they both provide **occupational therapy**. But they have different definitions of what occupational therapy is. One service provider only lets people with IDD get occupational therapy once a week for half an hour. The other service provider lets people with IDD get occupational therapy up to 3 times a week for up to 1 hour at a time. That is a big difference in what kinds of occupational therapy people can get!

If IDD service providers sent state governments data on the services they provide, it would let state governments compare services between providers. Then, state governments could see which service providers are doing a good job. The state governments could see which service providers are not doing a good job. Then, the state governments could figure out which service providers need more help from the state.

States should make standard definitions of what different behavior support services are. They should also collect data from service providers.

State governments need to make standard definitions of what different behavior support services are. That way, everyone in the state will know what each behavior support service should look like. State governments need to also work with CMS and researchers. These groups can study how people with IDD are using services within the states. State governments also must work to make sure everyone who needs HCBS can get HCBS. This means getting rid of waiting lists.

State governments need to write standard definitions of different behavior support services. When there is a standard definition of a behavior support service, everyone will know what the service is. Everyone will know how the service should be done.

State governments need to make sure that they write their definitions of behavior support services in plain language. That way, people with IDD can also read the definitions. State governments also need to make sure that their definitions of behavior support services explain the services in enough detail. If there is not enough detail in the definitions, people will not know what the definitions mean.

State governments need to make sure that their HCBS waivers for people with IDD cover mental health services. State governments need to make sure that their HCBS waivers for people with IDD cover occupational therapy. HCBS waivers for people with IDD should cover more than just services to “fix challenging behavior.” HCBS waivers for people with IDD should also cover services that help people with the needs that cause “challenging behavior,” too.

State governments also need to work with the U.S. government and researchers to study how people with IDD use services. State governments, the U.S. government, and researchers can work together to answer questions like:

- What services do states offer to people with IDD on waivers?
- How easy is it for people with IDD to get services like mental health services or occupational therapy?
- How easy is it for people with IDD to get services like ABA?
- Are people with IDD less likely than people with other disabilities to get mental health services or occupational therapy?
- Are people with IDD more likely than people with other disabilities to get ABA?

The other thing state governments must do is make sure that everyone who needs HCBS in their states can get HCBS. State governments must get rid of their waiting lists for HCBS. State governments must make sure that they spend enough money to get everyone who needs HCBS the services they need.

The U.S. government should fix how it collects data about waiver services from states.

The U.S. government must change how it collects data on waiver services from states. The U.S. government must make sure that states send the Centers for Medicare & Medicaid Services (CMS) enough detail about their waiver services. The U.S. government should make rules and policies to make sure that states report good data on waiver services.

Right now, CMS has a list of every HCBS waiver in the United States. Remember, CMS is the part of the U.S. government that deals with Medicaid and waivers. The list is online. Anyone can look at it. But the list does not have a lot of information about the different waivers. And the information the list has about the waivers can be really confusing.

CMS needs to make sure states send it a lot of information about each of their waivers. The information needs to include things like:

- Who can get on the waiver.
- What services the waiver will pay for.
- If there are limits to how many people can be on the waiver at one time.

CMS also needs to make sure that it keeps its website with the information about waivers updated.

One way CMS can make sure states give it better data about waivers is to pass new rules and policies. Right now, CMS is trying to pass new rules for states. The new rules say that states need to collect and report better data about HCBS. The new rules also say that states need to collect and report better data on people who are on HCBS waiting lists.

CMS should build on these rules. CMS should also make rules around what data states need to send CMS around services. CMS should especially make rules to say states need to send CMS more data on behavior support services.

Another thing CMS can do is help states collect more data on waiver services. CMS can give states more money to collect data on waiver services. CMS can help states solve problems around collecting data on waiver services. This will help states collect more and better data around waiver services.

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 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.

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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Plain Language Version

Beyond Coercion and Institutionalization:

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

Part 8: Appendix A: Writing Good Goals for Behavior Support Services

Words to Know in Part 8

988 Lifeline

A group of mental health crisis service providers people can reach by calling or texting 988. The 988 Lifeline will send the call or text to a local mental health crisis service who can help the person.

Abuse

Hurting someone or treating them badly as a way to control them.

Accommodations

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

Antipsychotics

A type of mental health medication that treat psychosis.

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.

Augmentative and alternative communication (AAC)

Ways of communicating other than speaking with your mouth or using a sign language. AAC includes things like writing, pointing to letters and words, or typing words on a computer.

Behavior

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

Behavior support services

Services that help people deal with behavior that makes it hard for them to live the lives they want.

Behaviorism

A way of thinking about human behavior that says we should only think about the behavior we can see. Behaviorism focuses on changing a person’s behavior but not on the person’s thoughts or feelings. ABA is part of behaviorism.

Block treatment

When a group of people with disabilities all get the same services, even if they have different needs and wants.

Challenging behavior

A term some people use to talk about behavior that makes it hard for a person to live the life they want.

Chronic illnesses

Illnesses that last a long time, like cancer or diabetes.

Communication

The different ways people tell each other information and ideas.

Community

A place where you can make choices about your own life. Communities can be places like neighborhoods, towns, or cities.

Community living

When people with disabilities live in the same places as people without disabilities.

COVID-19

A bad disease that has spread around the world and made a lot of people very sick. COVID-19 has made it hard for people with disabilities to get good services.

Crisis respites

Houses or apartments where people can stay for a few days until a mental health crisis has passed. Crisis respites often have services like support workers or therapy groups.

Crisis support plan

A document that helps people know what to do when someone has a mental health crisis. A crisis support plan talks about:

- What the person does when they are calm and happy.
- What the person does when they start to get upset.
- What the person does when they are in a mental health crisis.
- What things a person might do that look like a mental health crisis but are really not.
- What service providers and support workers can do to make mental health crises less likely.
- What service providers and support workers can do to help the person when they get upset.
- What kinds of things cause the person to get upset.

- How service providers and support workers can help the person stay safe during a mental health crisis.
- What people or groups in the community can help the person during a crisis.

Dangerous behavior

Behavior that:

- Hurts the person doing the behavior badly.
- Hurts someone else around the person badly.
- Could really hurt the person doing the behavior or someone else if the behavior does not stop.
- Could get the person in trouble with the police if the behavior does not stop.

Diagnostic overshadowing

When doctors blame medical problems a person with IDD has on the person's disability.

Dignity of risk

The idea that people have the right to make choices, even if those choices might have risks or end badly.

Dual diagnosis

When someone has both an IDD and a mental health disability.

Environment

The different places a person lives, works, and plays in.

Food insecurity

When someone does not have enough food to eat and does not have money to buy more food.

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.

Hazard

Something that could hurt people. Common household and community hazards are household chemicals, furniture and large appliances, and wet or icy surfaces.

HCBS Settings Rule

A rule the federal 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.

Homeless

When someone does not have a long-term place to live.

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.

Mental health crisis

When a person is having thoughts or feelings that hurt them that they cannot control. During a mental health crisis, a person might try to hurt themselves or others.

Mental health crisis services

Services that are supposed to help people who are dealing with emotions or behavior that hurt them that they cannot control.

Mental health disabilities

Disabilities that change how people think and feel. Mental health disabilities can make it hard for people to feel in control of their emotions.

Mental health services

Services that help people with mental health disabilities deal with their emotions and live in the community.

Mental health therapy

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

Occupational therapy

A service that helps people learn and practice skills they need in their everyday lives.

Peer support

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

Peer worker

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

Physical therapy

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

Prevent

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

Preventive health care

Health care that can prevent, or stop, medical problems from happening or getting worse.

Primary care doctor

A doctor you see for regular, general health care, like getting shots or when you have the flu.

Provider-owned settings

When the HCBS provider owns the place people get HCBS in.

Providers

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

Psychosis

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

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.

Researchers

People who do research as their jobs.

Restraint

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

Seclusion

Locking someone in an empty room.

Secondary trauma

When someone has trauma from seeing someone else go through a really stressful experience

Self-direction

An option that some people who get HCBS through a waiver use. Self-direction lets a person design and run the HCBS they get.

Speech therapy

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

Support workers

People whose job it is to help people with IDD in our homes and in the community. Support workers are sometimes called direct support professionals.

Symptoms

Signs that a person has an illness or disability.

Trauma

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

Trauma-informed care

A way to provide services to people with trauma. Trauma-informed care focuses on not making people's trauma worse. Trauma-informed care helps people work through their trauma.

Waivers

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

Appendix A: Writing Good Goals for Behavior Support Services

This appendix talks about writing good goals for **behavior support services**. An **appendix** is an extra part of a toolkit that gives more information on a certain topic. ASAN wrote this appendix mainly for **support workers** and **HCBS providers** that do behavior support services. But anyone can use this appendix. People with IDD can use this appendix to:

- Learn more about what good behavior support services look like.
- Learn more about different types of goals for behavior support services.
- Set goals for our own behavior support services or other HCBS.
- Advocate for our goals for our own behavior support services or other HCBS.

ASAN had a few big ideas when we wrote this appendix. The big ideas we think are most important in this appendix are:

- People with IDD are people first. We are not just our disabilities. We are not just our "**challenging behaviors**." We are full human beings with full lives. We are full human beings with thoughts and feelings and needs.
- All **behavior** happens for a reason. In many cases, people behave in certain ways to show they want or need something. Helping people with "challenging behavior" means meeting the needs that cause that behavior. Just trying to get rid of the "challenging behavior" will not work. If someone's needs are not being met, their "challenging behavior" will come back.
- Helping people with "challenging behavior" does not just mean changing the person's behavior. It also means changing the behavior of people around the person. It also means changing the person's environment. A person's **environment** is the different places the person lives, works, and plays in.

A person’s environment can have a big effect on their behavior. For example, if the lights in a person’s house are too bright, the person might be stressed and overwhelmed a lot. The person might have a lot more “challenging behavior” because they are stressed and overwhelmed.

- Even when someone’s behavior is dangerous, they are still a person with needs and rights. Some people can have behavior that is very dangerous to themselves or others.

  For example:

  - ◊ Someone who cuts their arms with a knife.
  - ◊ Someone who has so many dirty dishes that they start to have rats in their kitchen.
  - ◊ Someone who hits or kicks others when they get upset.

  But even people who have dangerous behavior still have rights. Even people who have dangerous behavior still have needs that need to be met. Having dangerous behavior does not make someone less human. It does not make someone less deserving of good services.

Not every service that can help with “challenging behavior” calls itself a behavior support service. Some things that can help with “challenging behavior” are not services at all!

People with IDD can need help with many different parts of life. Some things we can need help with are:

- Finding accessible housing.
- Activities of daily living, like eating, getting dressed, or going to the store.
- Getting health care (including mental health care).
- Finding and keeping a job.
- Self-advocacy skills.

We may need specific services to help with these things. We may also need more general help with these things. The goal of the services we get should be to let us make choices and live the lives we want. The goal of the services should not just be to make us have less "challenging behavior."

In a lot of cases, the goal for behavior support services should be changing the behavior of *other* people around the person. In a lot of cases, the goal for behavior support services should be changing the environment around the person. People who have "challenging behavior" are often responding normally to other people treating them badly.

Our goal with this appendix is to help people think about what causes "challenging behavior." Our goal with this appendix is to talk about what general goals are okay for behavior support services. Our goal with this appendix is to talk about what general goals are not okay for behavior support services.

In this appendix, we do not want to tell HCBS providers what specific goals each person with IDD should have for behavior support services. We know different people have different needs. We know different people will need different kinds of services. We know different people will have different goals for HCBS. We could not possibly write goals for every single person with IDD who needs behavior support services.

We want people with IDD and HCBS providers to use this appendix to work together. We want people with IDD and HCBS providers to use this appendix to create good goals for behavior support services.

ASAN broke up this appendix into five main sections. The sections are:

- People with IDD are people first.
- Meeting the needs that cause people with IDD's behavior.
- Supporting people with IDD's mental health.
- Helping people with IDD be part of our communities in the ways we want.
- Dealing with dangerous behavior.

We picked these ideas for sections because they are the big main causes of "challenging behavior" among people with IDD. We will talk about each of these ideas in more detail in this part.

All of the sections besides "People with IDD are people first" have a list of questions in them. These are questions people with IDD and service providers should think about. These questions can help people with IDD and service providers set good goals for behavior support services and other HCBS.

People with IDD are people first.

The first big idea we want service providers to know is that people with IDD are people first.

Often, service providers treat people with IDD like we are not human. Service providers often treat people with IDD like we cannot make our own choices. Service providers often treat people with IDD like we need to be protected from the world. Service providers often do not respect people with IDD. Service providers often act like people with IDD cannot take risks.

All of these things affect people with IDD. All of these things make people with IDD feel bad about ourselves. All of these things can cause people with IDD to have “challenging behavior.”

It is true that some people with IDD have behavior that gets in the way of us living the lives we want to live. This behavior might be difficult for us to control. This behavior might be dangerous for us or other people. It is true that it can be hard to support people with IDD who have this kind of behavior. It is true that it can be hard to figure out what causes someone to have this kind of behavior.

But none of this means that people with IDD are less human. None of this means that people with “challenging behavior” are less human. No matter our disability or behavior, we deserve respect and good treatment from service providers.

There is not one best way to get HCBS providers and support workers to see people with IDD as people first. But one thing that does seem to work is getting people without IDD to talk to people with IDD. Having people without IDD go to events run by people with IDD also seems to help. For example, self-advocacy groups.

It is very important that people without IDD talk to people with IDD as equals.

A lot of the time, people without IDD only talk to people with IDD when they are our:

- Doctors, nurses, or therapists.
- Teachers.
- Support workers.

Those are all roles where people without IDD have a lot of power over people with IDD. People without IDD need to meet and talk to people with IDD in ways where both groups have equal power. It is important that people without IDD listen to people with IDD like they do everyone else.

Meeting the needs that cause people with IDD's behavior.

The second big idea we want service providers to know is that meeting people with IDD's needs can help with "challenging behavior." A lot of "challenging behavior" happens because someone's needs are not being met.

If service providers meet the needs of people with "challenging behavior," a lot of that challenging behavior would go away.

For example:

> Itai has cerebral palsy. Itai uses a wheelchair. Itai lives in an apartment building. The apartment building's elevator is broken most of the time. That means Itai cannot leave the apartment building.
>
> Most of the time, Itai sits at home and is really bored. Itai feels really upset that the elevator is broken all the time. When Itai is bored and upset, he gets angry really easily. Itai ends up shouting at his support workers a lot.

Itai's support workers say Itai has "challenging behavior." But Itai would not get so angry if he could leave his apartment whenever he wanted. If the apartment building fixed the elevator, Itai would not be so angry all the time.

ASAN came up with a list of different needs that all people have. We think it is really important for service providers working with people with IDD to meet all of these needs. If a service provider cannot meet one of these needs, they need to figure out who can help meet the need. The needs we came up with are:

- Getting health care and not being in pain.
- Having a safe place to live and enough to eat.
- Communicating what we have to say.
- Meeting sensory needs.
- Being in control of our own lives.
- Respect from people around us.
- Having relationships that matter to us.

Health care and not being in pain

Earlier in this toolkit, we talked about how people might have "challenging behavior" because of health problems.

For example:

Amina has a developmental disability called Fragile X Syndrome. Amina cannot speak with her mouth. She mostly communicates by pointing. Amina went to a friend's house to jump on her friend's trampoline. While Amina was on the trampoline, she sprained her ankle really badly.

Amina's ankle really hurts. Amina lies in bed and cries. When her parents ask her what is wrong, she points to her ankle. Amina's parents are really worried about her. They are worried because she will not get out of bed. But they cannot figure out what is wrong. Amina's behavior is because she is in a lot of pain.

There are a few big reasons why people with IDD do not get good health care to treat our health problems.

These reasons are:

- Lack of access to good, regular health care.
- Diagnostic overshadowing. **Diagnostic overshadowing** is when doctors blame medical problems a person with IDD has on the person's disability.
- Doctors often do not take time to figure out what is wrong when someone with IDD has a health problem.

These reasons all mean that people with IDD can have a lot of health care problems that we cannot get care for. These reasons all mean that people with IDD often have worse health than people without IDD. We tend to get sick or injured more often. We tend to have more chronic illnesses (like diabetes or high blood pressure). We tend to not get as many kinds of health exams, such as tests that look for signs of cancer.

We will talk about each of these issues next.

Lack of access to good, regular health care.

People with IDD are less likely than people without IDD to access certain kinds of preventive health care. We are less likely to get care like:

- Dental exams.
- Tests for chronic illnesses.
- Sexual preventive health care, like birth control or HIV testing.

People with IDD are generally as likely as people without IDD to have a primary care doctor. A primary care doctor is a doctor you see for regular, general (preventive) health care. But people with IDD are still less likely to get good preventive health care.

This has bad effects on people with IDD. When we are less likely to get good preventive care, we are more likely to develop chronic illnesses. For example: cancer or diabetes. If we do develop chronic illnesses, we are less likely to get tested for them. If we are not tested for chronic illnesses, we will not know why we are sick. We might not even know that we are sick.

All of these things mean that people with IDD can end up having “challenging behavior” that could have been prevented with good health care.

Diagnostic overshadowing.

Diagnostic overshadowing is when doctors blame health problems a person with IDD has on the person’s disability. With diagnostic overshadowing, doctors usually do not take the time to figure out the actual cause of the health problem. Instead, the doctors just say that the person’s health problem is caused by the person’s disability. This happens even when the health problem is not a symptom of the person’s disability.

For example:

> Diego has an intellectual disability. Diego recently started taking a new medication. The medication causes Diego to have seizures. When Diego has a seizure, he “blacks out” and loses consciousness for a few seconds. When this happens, Diego has a blank, empty look on his face.

Diego's roommates are worried about Diego. They go with Diego to the doctor. Diego and his roommates tell the doctor he keeps blacking out. The doctor tells Diego's roommates, "There is nothing to worry about. People with intellectual disabilities look like that sometimes."

Diego and his roommates know that is not right. But the doctor just blames Diego's intellectual disability.

Diagnostic overshadowing can be really dangerous. If a doctor just blames a new symptom on someone's IDD, the person may not get the care they need. It can mean their symptoms get worse. In some cases, they could get really sick or even die.

Let's look at the example with Diego:

It is not good that Diego is having seizures. If he does not get help for his seizures, they could keep getting worse over time. Seizures can be really dangerous. People can get hurt if they have a seizure. There are tests doctors can do to look for seizures.

And, Diego only started having seizures after he started the new medication. If the doctor asked questions, they could have seen the medication is causing the seizures. But the doctor did not ask Diego or his roommates any questions to find out what was going on. The doctor just blamed the seizures on Diego's intellectual disability.

Doctors do not take time to figure out what is wrong.

Doctors often do not take time with people with IDD to figure out why a person has a health problem. This is related to diagnostic overshadowing. When a doctor does not take time with a person with IDD, the doctor:

- Is less likely to look for the cause of the person's health problem.
- Is more likely to just blame the person's disability.

This especially affects people with IDD who need extra time to communicate.

For example:

> Shelby has a developmental disability. Shelby's disability makes her speech really hard to understand for most people.
>
> Shelby starts having really bad stomach pain one night. Her pain is so bad she cannot eat or sleep. Shelby goes to the emergency room. She tries to tell the doctor there that she has bad stomach pain. The doctor cannot understand Shelby. Shelby tries to talk slowly enough that the doctor can understand her. Shelby offers to write down what she is saying.
>
> The doctor tells Shelby, "I do not have time for any of that." The doctor tells Shelby to go home and call her primary care doctor in the morning. Shelby goes home. She is still in a lot of pain. She is angry that the doctor did not listen to her.

There are a lot of reasons why doctors do not take time with people with IDD. Doctors often have to see a lot of patients every day. Doctors cannot take too long with each patient. If they take too long, they will not be able to see all the patients.

Doctors also usually only get paid a certain amount per patient. This is because of how health insurance works. Doctors can take extra time with a patient. But health insurance may not pay the doctor for the extra time. If a doctor spends a lot of extra time with a patient, they may not be able to get paid for it.

Health problems that are not getting treatment are a big cause of "challenging behavior." But a lot of the time, behavior support services do not look at whether people with IDD are having health problems. Instead, behavior support services just try to get rid of the behavior that the health problems are causing.

ASAN thinks that behavior support services and other HCBS need to change in 2 ways related to health care needs.

The first way is that behavior support services need to look at if health care needs are causing someone's "challenging behavior." Behavior support services need to make sure that people get checked for health problems. If someone is having a health problem, they need to get care for that health problem. The service provider needs to see if the "challenging behavior" stops happening as often when the person gets care for their health problem.

The second way is that support workers and other service providers need to help people with IDD get the kinds of health care we need. This includes health care for chronic illnesses. It also includes health care for illnesses that only last a little while, like the flu. This includes getting preventive care from a primary care doctor. It also includes getting health care from a doctor that does one kind of health care, such as:

- A neurologist (a doctor that helps with problems related to the brain).
- A cardiologist (a doctor that helps with problems related to the heart).

This also includes getting health care in our homes. For example, if someone needs a nurse to come to their home to give them a shot or vaccine.

Service providers need to help people with IDD get health care no matter where we live. Service providers must not say people with IDD have to live in a group home or an institution to get support with health care.

Service providers need to help people with IDD when we need help with activities around health care. For example, if someone needs help to take a daily medication. Also, service providers need to help if someone needs support with:

- Making doctor appointments.
- Getting to and from doctor appointments.
- Dealing with health insurance and paying for doctor appointments.

Service providers should help people with IDD make our own choices about our health care. Service providers should help us advocate for the health care we need. Service providers should help people with IDD talk to doctors about the health care we need. But service providers should not talk over people with IDD.

Questions about health care and not being in pain to help with writing goals for behavior support services

ASAN wrote some questions about health care and not being in pain. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say “this person,” we mean the person with IDD. The questions are:

- Does this person have any chronic illnesses or disabilities?
    - ◊ If the answer is yes, what are those chronic illnesses or disabilities?
    - ◊ If the answer is yes, are those chronic illnesses or disabilities under control?
- Does this person have access to health care when they need it?
    - ◊ Does this person have a primary care doctor?
    - ◊ Does this person have access to specialized health care if they need it?
- Does this person have the tools or devices they need to talk about their health care needs? For example, an AAC device.
- How does this person show or tell other people when they are sick or in pain?
    - ◊ If this person is in pain, can they easily let someone else know?
    - ◊ Can this person show or tell others where in their body their pain is?
    - ◊ How does this person show or tell others when they are not feeling well in other ways?

- Does this person have providers and people around them that they can communicate with about their health? This can include:
    - ◊ Doctors.
    - ◊ Service providers.
    - ◊ Support workers.
    - ◊ Case managers.
- Do this person's providers know a lot about this person's health care needs?
- Can this person get information about health care in ways they can understand, like Easy Read or plain language?
- Does this person need help scheduling and keeping track of health care appointments?
- Does this person have a way of getting to health care appointments? For example:
    - ◊ Taking the bus or train.
    - ◊ Driving or having someone else drive them.
    - ◊ Walking.
- Does this person need health care that they are not getting right now?
    - ◊ If the answer is yes, what services or supports does this person need to get that health care?

Safe places to live and enough to eat

All people need a safe place to live. All people need enough food to eat. But people with IDD are less likely than people without IDD to have safe places to live. People with IDD are less likely than people without IDD to have enough food to eat.

People with IDD are more likely than people without IDD to be homeless. When someone is **homeless**, they do not have a long-term place to live. People with IDD are also more likely than people without IDD to live in unsafe places. You can read more about homelessness and unsafe housing in ASAN's toolkit "Crisis in our Communities: Racial Disparities in Community Living."

People with IDD are also more likely than people without IDD to have food insecurity. **Food insecurity** is when someone does not have enough food to eat and does not have money to buy more food.

People with IDD are more likely than people without IDD to be homeless and to have food insecurity. A big reason for this is that people with IDD are less likely to have a lot of money. Housing can cost a lot of money. Food can cost a lot of money. People without a lot of money have a hard time paying for housing or food. When someone does not have a lot of money, it is hard for them to buy enough food to eat.

People with IDD need housing that we can live in safely. People with IDD need food that we can eat safely. These things can cost a lot of money.

For example:

> Beverly has a disability. She uses a wheelchair. Beverly is trying to find a place to live. She does not have a lot of money to pay for a place to live. Most places to live in Beverly's city have lots of stairs. Beverly cannot go up or down stairs in her wheelchair. There are very few places to live that do not have any stairs. And, most of those places tend to cost a lot of money. It is hard for Beverly to find somewhere she can afford to live that is safe for her.

Here is another example:

> Dana has a disability called gastroparesis. Gastroparesis means that Dana's stomach does not work well. Dana cannot eat a lot of solid foods. He has a feeding tube that helps him eat. Dana needs special formula for his feeding tube. The formula costs a lot of money. Dana does not have a lot of money. Dana is having trouble paying for his feeding tube formula.

People with IDD might get support from the government so we can pay for housing or food. But this support does not always help in the ways we need help. Let's take another look at our examples.

For example:

Beverly needs to find somewhere to live that:

- Does not have any stairs.
- Does not cost a lot of money.

> Beverly gets help from the government through a program called Section 8. Section 8 helps Beverly pay for housing. But there are very few apartment buildings in Beverly's city that will accept Section 8 payments. There are even fewer that do not have any stairs. Section 8 helps Beverly pay for housing. But she still cannot find a place to live.

Here is another example:

> Dana needs help paying for his feeding tube formula. Dana gets help from the government through a program called SNAP. SNAP helps Dana pay for groceries. But SNAP does not cover Dana’s feeding tube formula. SNAP says the formula is “a medical product.” Dana is still having trouble paying for the feeding tube formula.

IDD service providers need to make sure all people they support have safe places to live and enough food to eat. This means that IDD service providers need to work with other groups that help people get housing and food. IDD service providers can work with groups like:

- Groups that help people who are homeless pay for housing.
- Groups that help people who have food insecurity pay for food.
- Groups that help people with disabilities fix our homes to make them safer for us.
- The U.S., state, and local governments.

Some IDD service providers offer housing for people with IDD. This housing is usually provider-owned settings like:

- Group homes.
- Assisted living facilities.
- Apartment buildings just for people with disabilities.

IDD service providers who offer housing need to provide “housing first” services. “Housing first” is an idea. “Housing first” says that housing is the most important service that people who are homeless need.

“Housing first” says that groups that provide housing need to provide it to people who need it. It does not matter if those people:

- Are using drugs or alcohol.
- Have disabilities or chronic illnesses they should be getting health care for but are not.
- Have “challenging behavior.”

IDD service providers who offer housing must not say that someone cannot get housing from them because of “challenging behavior.” IDD service providers who offer housing need to find ways to work with people with IDD who need housing. It does not matter if the person has “challenging behavior.” It does not matter if the person is using drugs or alcohol. It does not matter if the person should be getting health care but is not.

People with IDD who need help finding housing still have the right to live in the **community**. People with IDD who need certain kinds of housing still have the right to live in the community. It is not okay to say someone must live in an institution because they are homeless and have IDD. It is not okay to say someone must live in an institution because they need a certain type of housing.
For example, a house that has no stairs. When we say “institution” here, we also mean places like group homes and assisted living facilities.

Making housing safe for people with IDD does not mean turning the housing into “an institution of one.” Most institutions are places where many people with disabilities live together. But a place can still be an institution even if only one person with a disability lives there. What matters is whether the person has control over their life. What matters is whether the person can make choices about their own life.

For example:

> Odessa has an intellectual disability. Odessa gets services from an IDD service provider called Caring Hearts, Inc.. Odessa wants to live in her own apartment in the community. So Caring Hearts, Inc. finds an apartment for Odessa.
>
> Caring Hearts, Inc. makes a bunch of changes to the apartment. They put a lock on the door so that Odessa cannot leave the apartment without a key. Odessa does not get a key to the apartment. Only Odessa's support workers get keys to the apartment.
>
> The apartment is not on a bus or train line. If Odessa wants to go out, she has to get a support worker to drive her. Odessa feels trapped in the apartment. The apartment belongs to Odessa. But Caring Hearts, Inc. has turned the apartment into "an institution of one."

IDD service providers also need to work with people with IDD to meet our needs around housing and food. People with IDD do not have to take the first kind of housing offered to us. People with IDD do not have to accept food that we do not like. It does not matter if we are homeless or might become homeless. It does not matter if we do not have enough food to eat. We are still allowed to say no to housing or food that does not meet our needs.

For example:

> Charlie is autistic. He has a very hard time cooking for himself. Charlie gets services from Caring Hearts, Inc.. Charlie asks Caring Hearts, Inc. if he can get help with cooking. So Caring Hearts, Inc. sets up that Charlie will get frozen meals delivered from another service provider every week. Then, when Charlie wants to eat the meals, he can just reheat them in the microwave.

Charlie does not like the frozen meals. He thinks they taste gross. And the texture of the meals is weird once Charlie reheats them. Charlie asks Caring Hearts, Inc. if he can get a support worker to come to his house and help him cook. But Caring Hearts, Inc. says no. Caring Hearts, Inc. says that Charlie just needs to eat the frozen meals.

This is not right! If Charlie needs help cooking, he should get help cooking. He should not have to eat gross reheated frozen meals.

Some people with IDD need help staying safe around the house or with eating. Service providers should help people stay safe while still letting the person have their rights. The **HCBS Settings Rule** says service providers can only take away someone's rights if:

- The service provider has tried other things that do not take away the person's rights.
- The other things the service provider tried have not worked.
- The person agrees the service provider can take away their rights.

For example:

Miguel lives in a group home. Miguel's disability makes him always hungry, no matter how much he eats. It would be bad if Miguel ate food whenever he is hungry. He would never be able to stop eating. He might get sick from eating so much.

Miguel has other things he wants to do besides eating. He likes going to work and the movies. At first Miguel tries to do other things. He makes his own rules to figure out when to eat. But those rules don't work for him. Miguel decides he needs help to stop eating so much.

So Miguel works with his service provider. Miguel and his service provider set times during the day when Miguel can eat. The rest of the time, Miguel's service provider can tell him that he can't eat.

This would usually go against Miguel's rights in the HCBS Settings Rule. But other things Miguel and the service provider tried did not work. And Miguel agreed that the service provider could set times when he can and cannot eat. So it is okay that the service provider made rules for Miguel that they usually would not be able to make.

Questions about safe places to live and enough to eat to help with writing goals for behavior support services

ASAN wrote some questions about safe places to live and enough to eat. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say "this person," we mean the person with IDD. The questions are:

- Does this person have a safe, long-term place to live?
    - ◊ If the answer is no, what can service providers do to help this person find safe, long-term housing?
    - ◊ Does this person feel comfortable in their home?
    - ◊ Does this person's home meet their needs? For example, a person who uses a wheelchair needs a home without stairs.
    - ◊ Can this person get to everything they need in their home?

- Does this person have enough food to eat? This includes being able to buy more food when they need to.
  - ◊ If the answer is no, what can service providers do to help the person get enough food to eat?
  - ◊ Does this person have access to food they enjoy?
  - ◊ Does this person have access to food that meets their health needs? For example, feeding tube formula for someone with a feeding tube.
- Does this person receive government support or benefits for food or housing? For example, SNAP or Section 8.
  - ◊ If the answer is no, would this person be able to get help from the government for food or housing?
  - ◊ Are there other resources or benefits the person might be able to get? For example: food from a food pantry.
- Does this person need support to stay safe around the house?
  - ◊ If the answer is yes, how can service providers support the person to stay safe while respecting the person's rights?
- Does this person need support to stay safe around food? For example: Someone whose disability makes them hungry all the time, no matter how much they eat.
  - ◊ If the answer is yes, how can service providers support the person to stay safe while respecting the person's rights?

Making sure other people do not hurt us

People with IDD are more likely to be abused than people without disabilities. This is especially true of people with IDD who live in institutions. **Abuse** is hurting someone or treating them badly as a way to control them. Some types of abuse are:

- Physical abuse, like hitting, kicking, or punching someone.
- Emotional abuse, like screaming at someone or threatening to hurt them. Emotional abuse can also look like telling someone they cannot spend time with their friends and family. It can also look like spreading lies about someone.
- Sexual abuse, like:
    - ◊ Touching a person's sexual body parts
    - ◊ Making a person do sexual things they do not want to do.

  Some types of sexual abuse are called rape.
- Financial (money) abuse, like taking someone's money and spending it without them saying you can.
- Neglect, or not taking care of a person who needs your help and support.

There are a lot of reasons why other people are more likely to abuse people with IDD. Some of these reasons are:

- People with IDD may need help with personal care, like showering and getting dressed. We may have very little control over the kind of help we get.
- People with IDD get taught that it is okay for others to touch us when we do not want them to. **ABA** and other behaviorist services especially teach this. But many different services for people with IDD teach this.

- People with IDD may have a harder time communicating with people around us. We may not be able to speak with our mouths.
- Other people do not teach people with IDD about abuse. This means that people with IDD may not know what abuse is. We may not know that something someone else did to us was abuse. We may not know who to tell if we are being abused.
- People with IDD may not spend a lot of time in the community. This is especially true when people with IDD live in provider-owned settings, like group homes. When we do not spend a lot of time in the community, there are fewer people we can tell about abuse.
- Other people might not believe people with IDD when we tell them about abuse. Other people might say that we are “unreliable” or “do not know what we are talking about.” This especially happens when someone who has power over us is the one abusing us. For example, a support worker or therapist.
- Other people may not see people with IDD as fully human. They may not think we have the right to stay safe from abuse. They may not even realize what happened to us was abuse.
- Services for people who have been abused may not be accessible to people with IDD. These services might use language that is hard for us to understand. Or these services might be in buildings that we cannot get into. For example, someone using a wheelchair cannot get into a building with stairs and no elevator.

Abuse is never the fault of the person being abused. It does not matter what that person did. It does not matter why the abuse happened. Abuse is always the fault of the person doing the abuse.

It can be really hard for *anyone* who is being abused to get help. It is not just hard for people with IDD to get help when we are abused. But it is often harder for people with IDD to get help than it is for other people. Many services for people who have been abused do not know how to work with us. And often, the person abusing us is someone who we depend on for support. We may not want to leave the person abusing us. We may not be able to leave the person abusing us.

We know that abuse can cause “challenging behavior” in adults with IDD. We also know that abuse can cause “challenging behavior” in children, whether or not they have an IDD. But many behavior support services do not ask about whether a person with IDD and “challenging behavior” has been abused. These services do not try to help people from IDD recover from abuse. These services try to fix the “challenging behavior” without looking at the abuse that causes it.

Abuse can cause a lot of trauma. **Trauma** is changes in how a person thinks, feels, and behaves. The changes are because of a scary situation the person went through.

There are different mental health therapies that can help with trauma. Many of these mental health therapies have adapted versions for people with IDD. “Adapted” means the therapy was changed to make it easier for people with IDD to take part in it. But people with IDD who have been abused rarely get mental health therapy to help with trauma.

Everyone has the right to be safe from abuse. This includes people with IDD. We should be able to get support for dealing with abuse. We should get to learn about what abuse is and how to respond to abuse.

There are different community groups that help people who are being abused. These groups do a lot of good work. But many of them do not know how to help people with IDD. So many of these do not help people with IDD who are being abused.

One specific way to stop abuse is to teach people sexual education. Sexual education is classes about things like:

- Sexual body parts.
- Changes to your body as you grow up.
- Having sex.
- Romantic and sexual relationships.
- Abuse (including sexual abuse) and what to do about it.

Many people without disabilities get sexual education when they are students in school. But many people with disabilities do not get sexual education in school. This includes many people with IDD. This is because other people think students with disabilities do not need sexual education. This is not true! But many people think it is true.

ASAN thinks IDD service providers need to work with community groups that help people who are being abused. ASAN thinks IDD service providers need to work with community groups that provide sexual education. All these groups need to work together to figure out how to help people with IDD who are being abused. All these groups need to work together to figure out how to teach people with IDD good sexual education.

IDD service providers need to figure out ways to help keep people with IDD safer from abuse. Some ways to keep people with IDD safer from abuse are:

- Training support workers and other staff in treating people with IDD with respect.
- Training support workers and other staff in recognizing when someone with IDD is being abused.
- Teaching people with IDD what abuse can look like.

- Teaching people with IDD what we should do if we are being abused.
- Making rules that can protect people with IDD from abuse. For example: rules about when a support worker can be alone with a person with IDD.

But IDD service providers also need to make sure their rules do not get in the way of people with IDD's rights.

For example:

Molly lives in an adult foster home. Molly's foster home is a provider-owned setting under the HCBS Settings Rule. That means Molly has the right to close and lock her bedroom door whenever she wants.

Molly has a boyfriend, Jacques. Molly likes to have Jacques come over. Molly and Jacques cuddle in bed and watch movies. Sometimes, they have sex.

Molly's foster parents make a new rule. The rule says Molly has to keep her bedroom door unlocked whenever Jacques is over. Molly's foster parents say this is so they can "make sure Jacques is not hurting" Molly.

This goes against the HCBS Settings Rule. There are other ways for Molly's foster parents to make sure she is safe. They do not need to make her keep her bedroom door unlocked.

Questions about making sure we are safe and other people do not hurt us to help with writing goals for behavior support services

ASAN wrote some questions about making sure other people do not hurt people with IDD. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say “this person,” we mean the person with IDD. The questions are:

- Has this person ever been abused?
    - ◊ If the answer is yes, who was the person who abused them? Was it a service provider?
    - ◊ If the answer is yes, how can service providers work with this person to make them feel safer?
- Does this person have other identities that make others more likely to abuse them? For example: being a woman or a person of color.
- Does this person have a way to communicate if they are being abused?
- Does this person have someone else they trust and can tell if they are being abused? For example, a family member or support worker.
- Has this person received sexual education in a way they can understand?
    - ◊ If the answer is yes, did this include talking about abuse?
- Does this person know people who can recognize if the person is being abused? For example: friends, coworkers, or teachers.

- Can this person get community resources to help prevent and respond to abuse?
    - ◊ Are these resources trained in working with people with IDD?
- Have support workers and other disability professionals working with this person been trained in …
    - ◊ Recognizing abuse?
    - ◊ Preventing abuse?
    - ◊ Addressing abuse?

Safety around the house and in the community

People with IDD often have more trouble staying safe at home and in the community than people without IDD. We face more hazards at home and in the community than people without IDD. A **hazard** is something that could hurt people. Some types of hazards around the house and in the community are:

- Household chemicals, like bleach. These can make a person very sick if they eat or drink the chemicals.
- Furniture and large appliances, like refrigerators.These can tip over and crush a person if they are not properly set up.
- Slippery surfaces, like a wet floor or an icy sidewalk. People can slip and fall on surfaces that are not dry.
- Traffic and cars on the road. If someone wanders into traffic without looking, they could get hit by a car.

There are ways for service providers to make all of these hazards less dangerous for people with IDD. Service providers can do things like:

- Label hazards as dangerous in ways people with IDD can understand.

For example: putting stickers with a “yuck!” face on bottles of household chemicals.

- Use bolts and screws to attach furniture and large appliances to the wall.

For example: screwing a bookshelf to the wall so it cannot fall over on someone.

- Teach people with IDD about different hazards around the house and in the community.

For example: teaching someone how to read a stoplight so they do not walk into traffic.

But a lot of the time, service providers do not try to make hazards less dangerous for people with IDD. Instead, service providers just try to take hazards away from people with IDD. Service providers do this even when the hazard has a real use in the person's home or in the community.

For example:

> Kyah has an intellectual disability. Kyah likes to paint her nails. Kyah uses acetone to remove her nail polish. Acetone is a household chemical. Kyah's support worker is worried Kyah will spill the acetone or accidentally drink it. Acetone is very dangerous to drink. It can make people very sick. And, acetone catches on fire very easily.
>
> So Kyah's support worker takes the acetone and locks it in a cabinet where Kyah cannot get to it. Kyah is only allowed to use the acetone when her support worker is over. This is not right! The support worker should have tried other ways of helping Kyah understand how the acetone can be dangerous. The support worker should not have just taken the acetone away from Kyah.

Service providers need to find ways to teach people with IDD how to be safe around hazards in our homes and in the community. Service providers need to work with other groups in the community to teach people with IDD about household safety. Service providers also need to work with other groups in the community to make hazards less dangerous for people with IDD.

For example:

Marvin has a developmental disability. Marvin's disability makes his balance really unsteady. He can slip and fall really easily. Marvin lives in a state where it snows a lot in the winter. He lives in an apartment building owned by an IDD services provider.

There is a lot of ice outside the building in the winter. The ice makes it unsafe for Marvin to walk outside the building. Marvin and his service provider work together. The service provider hires someone to come remove the snow from in front of the building after a snowstorm. That way, ice will not form on the ground. It is now safer for Marvin to go outside the building in the winter.

Here is another example:

Peggy has an intellectual disability. Peggy is pregnant. She is going to have a baby. Peggy lives in an old house. Many older houses have lead paint in them. Lead is a chemical. Lead is really dangerous to eat. It can cause brain damage, especially in children. Peggy's support worker is worried Peggy's house might have lead paint in it.

So Peggy's support worker talks to her about lead paint and how it could harm her baby. Peggy and her support worker talk to a local group that helps people get rid of lead paint in their houses. The local group does some tests to figure out if there is lead paint in Peggy's house. The local group works with Peggy and her support worker to remove all the lead paint from Peggy's house.

Service providers who run provider-owned settings should make changes in those places to keep people with IDD safer. But these changes cannot take away people with IDD's rights. This includes rights from the HCBS Settings Rule. Remember, the HCBS Settings Rule says service providers can only take away someone's rights if:

- The service provider has tried other things that do not take away the person's rights.
- The other things the service provider tried have not worked.
- The person agrees the service provider can take away their rights.

Here is an example of a service provider making changes in a way that does **not** follow the HCBS Settings Rule:

> Caring Hearts, Inc. is a service provider. Caring Hearts, Inc. runs a group home. Caring Hearts, Inc. notices a couple people living in the group home are using kitchen knives in unsafe ways. So Caring Hearts, Inc. makes a new rule. The new rule says that only support workers in the group home are allowed to use kitchen knives. People with IDD in the group home are not allowed to use kitchen knives.
>
> This rule does not follow the HCBS Settings Rule. The HCBS Settings Rule says that people need to have access to food at all times. If people cannot use kitchen knives at all, it means they cannot make certain food to eat.

Let's look at that example again.

> This time, Caring Hearts, Inc. makes sure their rules follow the HCBS Settings Rule. Caring Hearts, Inc. sees that a couple of people living in the group home are using kitchen knives in unsafe ways. So Caring Hearts, Inc. holds a training for all the support workers who work in the group home.
>
> The training is on kitchen safety, including knife safety. The training talks about how to teach people to use knives safely. The support workers take what they have learned back to the group home. The support workers help the people in the group home learn to use kitchen knives safely.

Questions about safety around the house and in the community to help with writing goals for behavior support services

ASAN wrote some questions about safety around the house and in the community. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say "this person," we mean the person with IDD. The questions are:

- What hazards does this person have to deal with in their home or living space? For example: household chemicals or kitchen knives.
    - ◊ How can service providers help this person stay safer around these hazards?
- What hazards does this person have to deal with when out in the community? For example: traffic or icy surfaces.
    - ◊ How can service providers help this person stay safer around these hazards?

Communication

Nobody knows exactly how many people with IDD cannot speak with their mouths. But we do know that many people with IDD do not have the support they need to communicate everything they want to say. This includes people with IDD who do not have a way to communicate other than behavior.

It is really upsetting to not be able to communicate everything you want to say. When people do not understand what you are trying to tell them, it is really hard to get what you need. When people do not have a good way to communicate everything they want to say, they might have more “challenging behavior.”

IDD service providers must make sure all people with IDD have ways to communicate everything they want to say. IDD service providers need to make sure all people with IDD who need AAC have access to good AAC. AAC stands for augmentative and alternative communication. **AAC** is ways of communicating other than speaking with your mouth or using a sign language. AAC can include:

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

IDD service providers need to make sure that the AAC system works for the person. For example, making sure someone who cannot read has an AAC system that uses pictures as well as words.

Some people with IDD could also learn to use a sign language. If someone with IDD wants to learn a sign language, their service provider should help them find classes to learn.

Support workers who help people with IDD learning to use AAC systems should do a few things. Support workers should:

- Assume that people with IDD can learn to use some kind of AAC.
- Assume that people with IDD can communicate what we have to say if we have the right kinds of AAC.
- Know that learning to use an AAC system takes a long time.
- Not give up on helping people with IDD learn to use AAC just because it takes a long time.
- Not force someone to use just one kind of AAC system. Many people who use AAC say they use multiple kinds of AAC.

Dave Hingsburger was a writer and support worker for people with IDD. He wrote a lot about supporting people with IDD. He helped train other support workers to give good help to people with IDD.

Dave wrote a book called “First Contact: Charting Inner Space: Thoughts About Establishing Contact With People Who Have Significant Developmental Disabilities.” The book is about working with people with IDD who need a lot of support. The book talks about how to help people find communication methods that work for them.

In the book, Dave talks about 5 steps for support workers to help people with IDD find ways to communicate. These steps are:

1. Talk to the person. Show that you care about them. Be interested in how they respond to what you say, even if you cannot understand them.
2. Watch the person. Look at what they do when you talk to them. Tell them that you notice their reactions.

3. Respect all the ways people communicate. Everyone can communicate. Even if someone’s communication is hard to understand, that person is still communicating. Write down how the person communicates different things. Make sure everyone who works with the person knows how the person communicates different things.

4. Have empathy for the person. Empathy means you understand how the person is feeling. You might have very different experiences from the person. But, you probably have experienced the same feelings as the person. Use your experiences to relate to how the person feels. Talk about how the person’s experiences are similar or different to yours.

5. When the person communicates with you, show and tell them that you know they are communicating. Tell and show the person that you know they are communicating. It is okay if you do not know what the person is trying to communicate. Talk to the person more. Ask them questions to try to figure out what they mean.

Dave also wrote about what support workers should do if a person is not communicating in a way they can understand. If a support worker cannot tell what a person is trying to communicate, they should let another support worker try to “make contact.” Dave talks about this by comparing it to making a phone call.

Dave says that someone not responding to a particular support worker “doesn’t mean no one’s home. It just means they are screening their calls.” The person is not unable to communicate. They might just not want to communicate with the specific support worker.

Questions about communication to help with writing goals for behavior support services

ASAN wrote some questions about communication. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say “this person,” we mean the person with IDD. The questions are:

- Can this person communicate everything they want to say through talking with their mouth?
- Can this person communicate everything they want to say through using a sign language?
- Does this person have access to AAC?
    - ◊ Does the type of AAC meet this person’s needs?
    - ◊ Has this person had the time and training to learn to use their AAC system?
    - ◊ Are support workers and other people around the person trained in how to use the AAC system?
- How does this person use behavior to communicate?
    - ◊ Does this person have many different people around them to communicate with?

Sensory needs

People with IDD often have different sensory needs than people without IDD. Sensory needs are needs related to human senses, such as:

- Hearing.
- Sight.
- Touch.
- Smell.
- Taste.
- Telling where your body is in space.
- Telling how your body is moving.

People with IDD may be less sensitive to certain things. For example: we may not be bothered by bright lights that bother other people.

People with IDD may be more sensitive to certain things. For example: we may find music too loud when other people are not bothered by it.

People with IDD may seek out certain sensations. For example: we may like to touch soft surfaces.

People with IDD may try to avoid certain sensations. For example: we may feel grossed out by how paint on a wall feels.

Some **mental health disabilities** can also cause sensory issues.

IDD service providers need to work to meet the sensory needs of people with IDD. This is especially true of IDD service providers who run provider-owned settings like group homes. IDD service providers can do this through making changes to the places where people with IDD live.

Some kinds of changes IDD service providers can make are:

- Changing the lighting in a house to make the lighting less harsh.
- Adding panels to rooms to make the rooms quieter.
- Using machines that make noise to “cancel out” other noises.
- Making rules that people cannot wear strong scents, like perfume or cologne, in the house.
- Making sure there are wide, clear paths between spaces in the house.
- Putting in furniture, like swings or rocking chairs, that people can move around in.

People with IDD who have “challenging behavior” might have sensory needs that are not being met. When someone’s sensory needs are not being met, they might be grumpier. They might be more likely to get upset.

IDD service providers need to make changes to people’s environments to help meet sensory needs. IDD service providers need to make sure that the changes they make need the person with IDD’s needs. But for spaces like group homes, where several people with IDD live, need to think about competing access needs. Competing access needs are when two people have different needs that get in the way of each other.

For example:

> Paula and Amanda both live in the same group home. Paula really likes loud music. She listens to loud music all the time. It helps her feel safe and in control. Amanda cannot stand loud noises. She needs quiet in order to think. She does not like it when other people play loud music. Paula and Amanda have conflicting access needs.

IDD service providers who run provider-owned settings need to think about conflicting access needs.

IDD service providers need to make sure everyone in the setting can get their sensory needs met.

For example:

> The service provider who runs Paula and Amanda's group home wants to help with their conflicting access needs. The service provider wants to make sure Paula can listen to her music without Amanda hearing it. So the service provider buys Paula a good pair of headphones. That way, she can listen to her music without other people hearing it. The service provider also puts panels up in Amanda's room. The panels block out a lot of noise. Then, Amanda's room is quieter.

Part of meeting conflicting access needs in provider-owned settings also means having enough support workers. That way, if someone needs to leave or take a break, they can get the support to do so.

For example:

> Paula and Amanda's group home hires a new support worker during the day. The support worker makes sure that Paula and Amanda can take a break if they need to. If Paula wants to go to the park so she can play her music, the new support worker can go with her. If Amanda needs to go on a quiet walk to calm down, the new support worker can go with her.

People with IDD who have “challenging behavior” should get to meet with an occupational therapist. Occupational therapists can help people learn and practice skills for everyday life. Occupational therapists can help people with IDD with sensory needs.

When people with IDD get **occupational therapy**, it should focus on addressing our needs. Occupational therapy should help us learn to be in control of our emotions. Occupational therapy should not just force us to do what other people want us to do. Occupational therapy should not just try to get rid of our behavior without figuring out what is causing the behavior.

Questions about sensory needs to help with writing goals for behavior support services

ASAN wrote some questions about sensory needs. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say “this person,” we mean the person with IDD. The questions are:

- How does this person respond to things they sense around them? (For example: bright lights, loud noises, or pain.)
    - ◊ Does this person seem to react much more than other people to some things they sense?
    - ◊ Does this person seem to react much less than other people to some things they sense?
    - ◊ Does this person seek out certain things they sense?
    - ◊ Does this person try to avoid certain things they sense?
- What changes could service providers make in this person’s home to help with their sensory needs?
- What changes could service providers make to help this person with their sensory needs in the community?
- Is this person able to access an environment that meets their sensory needs whenever they want? For example: having a room in their house that they can use to relax.
- Does this person have other disabilities or conditions that could change their sensory needs? For example: mental health disabilities.
- Does this person have access to occupational therapy?

Being in control of our own lives

Many people with IDD do not have a lot of control over their lives. They might live in a group home or other provider-owned setting that controls who they live with and can see. They might work in a sheltered workshop that chooses where they can work and what kind of work they do. They might be under guardianship and have someone else make choices for them.

A lot of provider-owned settings use block treatment. **Block treatment** is when a group of people all get the same services, even if they have different needs.

For example:

> In Part 5, we talked about Viola. Viola lives in a group home. Viola's group home does not have enough staff. So everyone living in the group home has to do the same activities. If one person in the group home wants to go somewhere, everyone in the group home has to go there. Viola and her housemates do not get to choose where they go most of the time. This is an example of block treatment.

The HCBS Settings Rule says that provider-owned settings are not supposed to use block treatment. Provider-owned settings are supposed to let every person living in the setting set their own schedule. But it is really hard for states to make sure all HCBS providers follow the HCBS Settings Rule.

Another problem is that support workers often do not let people with IDD make our own choices. A lot of the time, support workers do this because they are worried we will get hurt if we make the wrong choice. Most support workers who do this do not mean to hurt people with IDD. But it still hurts to not be able to make choices about your life. It hurts even if the person saying you cannot make choices means well.

Not having a lot of control over your life can cause “challenging behavior.” People who do not have control over their lives tend to “act out” in the ways they do have control over.

For example:

Nadya is autistic. She lives in a group home. Nadya does not have much control over her life. She does not get to choose where she lives. She does not get to choose what she does most days.

What Nadya does control is how she decorates her room. So she puts up posters all over her walls. She puts sheets of paper above her bed and doodles on them with markers. She buys stuffed animals and puts them all over her furniture.

The staff at Nadya’s group home do not like how she decorates her room. They say that Nadya has “challenging behavior.” But Nadya is just trying to express herself in the ways she can control.

Service providers need to train support workers in helping people make choices for themselves. Service providers need to make sure that support workers know how much power they have over people with IDD. Support workers have a lot of power over people with IDD. Support workers can use their power to make people with IDD make choices the support worker wants. But support workers should not do this. Support workers should use their power to help people with IDD make our own choices.

People with IDD should have control over choices that affect our lives. This includes big choices, like:

- Where we live.
- Where we work.
- Who we spend our time with.

It also includes small choices, like:

- What we eat at meals.
- What kind of clothes we wear.
- How we decorate our rooms.

We need to have real choices that matter to us about our lives. Service providers need to make sure we have real choices about our lives and services.

All people with IDD should have the choice to self-direct our own services. **Self-direction** is an option that some people who get HCBS through a **waiver** use. Self-direction lets a person design and run the HCBS they get. Right now, people who live in provider-owned settings usually cannot direct their own services. This needs to change.

Right now, people with IDD who need a lot of support mostly do not get to make their own choices. They get put under guardianship instead. Guardianship takes away someone’s right to make choices for themself. Guardianship hurts people with IDD.

People with IDD who need a lot of support do not need to be under guardianship. They can use supported decision-making instead. Supported decision-making is a way to help people make choices for themselves. A person can pick other people they want to help them make choices. These people are called supporters. A person can have as many supporters as they want.

Then, when the person needs help to make a choice, they can talk to their supporters. The supporters can give the person advice. The supporters can talk through different choices with the person. The supporters can suggest different choices the person could make. But the person is still the one making the final choice. Nobody else gets to choose for the person.

Service providers should help people with IDD set up supported decision-making. Service providers should not force people with IDD into guardianship.

It can take a lot of practice to learn to make choices for yourself. It can take a lot of practice to speak up and advocate for your choices and needs. Making choices and speaking up for your choices are both skills people can get better at. One way people with IDD can get better at this is by joining self-advocacy groups. Self-advocacy groups can help people with IDD get better at making and speaking up for choices. Service providers and support workers should help people with IDD get involved with self-advocacy groups.

Service providers and support workers should help people with IDD practice making choices in other ways. Service providers and support workers should do this even if a person cannot tell others what their choice is. Service providers and support workers should give people with IDD as many choices as possible about our lives.

Questions about being in control of our own lives to help with writing goals for behavior support services

ASAN wrote some questions about people with IDD being in control of our own lives. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say “this person,” we mean the person with IDD. The questions are:

- Is this person under guardianship?
- Does this person live somewhere that does not let them have choices about their life? For example, a provider-owned setting?
- Have this person’s support workers been trained on how to help this person make choices?
- Does this person have self-direction of their services?
    - ◊ Do they get to choose their support workers?
    - ◊ Do they get to choose where and when they get support?
    - ◊ Do they get to choose what they receive support with?
- Does this person get to control their everyday life?
    - ◊ Do they get to make big choices about their life?
    - ◊ Do they get to make small choices about their life?
    - ◊ Do they have the support they need to make choices?
- Does this person have support to improve their self-advocacy skills? For example, through working with a self-advocacy group.

Respect from people around us

People with IDD have the same right to respect from people around us as everyone else. We deserve to be treated well by other people. But often, people around us do not respect us. Often, people around us do not treat us well.

We do not know a lot about how other people treat people with IDD living in the community. But we do know that people with IDD who live in big institutions are treated very badly. People who work in the institutions treat the people with IDD living there very badly. So we think that people with IDD who live in smaller institutions, like group homes, are also treated badly.

People with IDD face a lot of ableism. Ableism is bad treatment of people with disabilities because we have disabilities. Ableism can have a lot of bad effects on people. Ableism can make people feel really bad about themselves. Ableism can have bad effects on a person's health.

For example:

> Alisha has an intellectual disability. Alisha hates going to the doctor. Alisha's doctor treats her like a child even though she is an adult. Alisha's doctor only talks to her support workers. They do not talk to Alisha directly. Alisha's doctor is being ableist towards her.
>
> One day, Alisha gets an ear infection. Alisha does not want to go to the doctor. She does not want the doctor to treat her badly. So Alisha does not go to the doctor. Alisha's ear infection gets worse. Alisha eventually loses the ability to hear out of the ear with the infection. The doctor's ableism had an effect on Alisha's health.

People with IDD are supposed to have the right to live in the community. But ableism often means we do not have the same right to community living as everyone else. Not being respected often means we do not have the same right to community living as everyone else. If other people in the community are ableist to us, we may not want to go out into the community. If other people in the community do not respect us, we may not get what we need in the community.

Service providers and support workers need to do 2 things as part of respecting people with IDD. Service providers and support workers need to treat people with IDD with respect. And, service providers and support workers need to help people with IDD advocate for ourselves when other people do not respect us.

Service providers and support workers need to learn what respect looks like for the people with IDD they support. Respect looks different for different people. For example: Respect for one person might look like a support worker always asking before touching that person's things. Another person might not mind if a support worker touches their things without asking.

Service providers and support workers should respect people with IDD. They should do this even if a person with IDD cannot tell others what respect looks like for them. Service providers and support workers should think about what respect looks like for themselves. Service providers and support workers should think about how they would want to be treated. Then, they should treat the person with IDD like they would want to be treated. This is sometimes called the "golden rule." The golden rule says that people should treat other people like they themselves would want to be treated.

Service providers and support workers should work with people with IDD to help people with IDD build self-advocacy skills. Service providers and support workers should help people with IDD figure out what we want to say if other people do not respect us. Service providers should talk to people with IDD about what respect looks like. Service providers should talk to people with IDD about what respect does not look like.

Service providers should also tell people with IDD that we have the right to respect from other people. Service providers can do this through:

- Showing people with IDD what self-advocacy skills can look like.
- Setting up chances for people with IDD to practice self-advocacy skills.
- Helping people with IDD find self-advocacy groups that can help with these skills.

Questions about respect from people around us to help with writing goals for behavior support services

ASAN wrote some questions about respect for people with IDD from people around us. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say “this person,” we mean the person with IDD. The questions are:

- Has this person not been respected in certain places or situations before?
  - ◊ If the answer is yes: How can service providers help this person feel respected in those places again?
- Do this person’s support workers treat the person with respect?
- Do support workers get training on how to treat people with IDD with respect?
- Does this person have a way to tell others if someone else does not respect them?
- Does this person have other people they trust to tell if someone does not respect them?
- Does this person have the support they need to practice responding when someone does not respect them?

Relationships that matter to us

Everyone deserves to have relationships with other people that matter to them. Some types of relationships are:

- Friendships.
- Professional relationships, like between a doctor and their patient.
- Family relationships.
- Relationships with people at work.
- Romantic or sexual relationships.

But a lot of the time, people with IDD do not get the same chances as everyone else to have relationships. We may not get to be around other people that we can form relationships with. This is especially true of people without disabilities. We may not get to choose relationships that matter to us. We may only get the “choice” to have relationships with other people with IDD or support workers.

For example:

> Bill has Down Syndrome. As a child, Bill went to school at a school only for students with IDD. Bill did not have any classmates or friends without disabilities. When Bill graduated high school, he moved out of his parents’ house. He moved into a group home. He started working at a sheltered workshop.
>
> All of Bill’s housemates are people with IDD. All of Bill’s coworkers are people with IDD. The only people without disabilities Bill knows are support workers and family members.

People with IDD often do not get the same chance as everyone else to form friendships or romantic or sexual relationships. When we do try to form friendships or romantic or sexual relationships, we are often punished for “inappropriate behavior.” This is not fair!

For example:

> Let’s take another look at Bill. Bill really likes watching car racing. He meets some other race car fans in his city on the internet. Bill makes friends with the other fans. He wants to meet up with them and go to a car race together.
>
> But the staff at Bill’s group say he is not allowed to go to the car race. They say it is too dangerous for him to meet people from the internet. They say he is not allowed to go, even if he takes a support worker with him.

Here is another example:

> Bill meets a woman at his job at the sheltered workshop. The woman’s name is Ellie. She works as a delivery driver that comes by the sheltered workshop often. Bill and Ellie start talking a lot. They really like each other. They want to start dating.
>
> But the staff at Bill’s group home say Bill and Ellie cannot date. The staff at the group home say it is “not appropriate” for Bill to be talking to Ellie at work. The staff at the group home tell Bill he is not allowed to talk to Ellie anymore.

Some people with IDD who have trouble making relationships get sent to social skills training. Social skills training is a type of service that tries to teach people with IDD skills like:

- How to make friends.
- How to talk to other people you meet.
- How to make boundaries and keep them. Boundaries are rules you set for how you want people to treat you.

Some social skills training programs are based in ABA and behaviorism. Other social skills training programs are not based in ABA and behaviorism. But most social skills training programs are still not good services. A big problem with social skills training is that it only focuses on changing the way people with IDD behave. Social skills training does not focus on changing how other people behave towards people with IDD.

For example:

> Bernice is autistic. She has a lot of trouble making friends at school. Bernice tries to show people she likes them by telling them about her favorite dinosaurs. The other kids at school think this is weird. They do not talk to Bernice.
>
> Bernice gets put in social skills training. The teacher leading the training tells Bernice that if she wants to make friends, she needs to stop talking about dinosaurs. The teacher tells Bernice that she needs to talk about "appropriate" topics. For example, the weather or classes at school. The teacher says Bernice will only make friends by talking about "appropriate" topics.
>
> But nobody tells the other kids to stop being mean to Bernice when she talks about dinosaurs. Nobody tells the other kids to try talking to Bernice about the dinosaurs she likes.

Another big problem with social skills training is it tries to get people with IDD to act like people without IDD. Often, social skills training focuses on things like:

- Making eye contact with other people.
- Using the right tone of voice for the conversation.
- Using body language that matches what you are trying to say.

Not everyone with IDD can do these things. Some people with IDD cannot make eye contact. Some people with IDD cannot control how their voice sounds. Some people with IDD have trouble matching their body language to what they are saying.

Even when people with IDD can do these things, it is often very hard and tiring. When people with IDD try to appear like we do not have IDD, it is called masking. Masking is hard work. It takes a lot of energy. It is very hard to appear like you do not have IDD every day. But a lot of social skills training teaches that people with IDD have to mask if we want to make friends.

Service providers should help people with IDD make friends in ways that work for us. Service providers should not make us go to social skills training if we need help making friends. Service providers should look for ways to help us make friends in the community. Some common places people go to meet new people are:

- Social spaces, like bars or bowling alleys.
- Educational spaces, like community college or community education classes.
- Spaces where everyone has a common interest, like hobby clubs.

For example:

Tyler has an intellectual disability. Tyler is lonely. He wants to make friends but does not know how. Tyler's support worker brings him the new community education catalog. Tyler's support worker suggests he could take classes through community education to meet new people.

So Tyler and his support worker make a list of classes Tyler wants to take. Tyler signs up for:

- A drawing class.
- A ping-pong class.
- A cooking class.

Tyler goes to the classes. He meets other people there. He makes friends with some of the people he meets.

Questions about relationships that matter to us to help with writing goals for behavior support services

ASAN wrote some questions about relationships that matter to people with IDD. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say “this person,” we mean the person with IDD. The questions are:

- Does this person have chances to start relationships that matter to them?
    - ◊ Does this person have access to places in the community where they can meet people?
    - ◊ Can this person make friends with people they meet at work or school?
    - ◊ Does this person have friends who are not paid support people?
- Could this person start a romantic or sexual relationship if they wanted to?
    - ◊ Has this person had good sexual education classes?
    - ◊ What support does this person need to keep having a romantic or sexual relationship?

Supporting people with IDD’s mental health.

People with IDD have many different feelings and emotions. People with IDD have many different thoughts and reactions to what is going on around us. This is true of people with IDD just like it is true of people without IDD.

Many people with IDD also have a mental health disability. Mental health disabilities are disabilities that affect how people think and feel. Mental health disabilities can make it hard for people to control their emotions. Some different mental health disabilities are:

- Depression.
- Anxiety.
- Schizophrenia.

In this toolkit, we call people who have both IDD and a mental health disability “people with **dual diagnosis**.” “Dual” means “two.”

Many people with IDD also have trauma. Trauma is changes in how a person thinks, feels, and behaves. Trauma is caused by a scary situation the person went through. Trauma can be caused by many different situations.

More services for people with IDD now know that people with IDD can also have mental health disabilities. But a lot of services for people with IDD still think that people with IDD cannot have mental health disabilities. Or, these services think that people with IDD’s thoughts and feelings do not matter. Some services specifically for people with dual diagnosis believe that people’s thoughts and feelings do not matter.

This is not right. This is not fair. People with IDD’s thoughts and feelings do matter. Our thoughts and feelings have a big impact on how we behave.

IDD service providers need to work with mental health service providers. IDD service providers and mental health service providers need to work on improving **mental health services** for people with IDD. People with IDD, especially people with dual diagnosis, need to be part of this process. Providers need to get feedback from people with IDD on what mental health services we need. Once providers have created mental health services for people with IDD, providers need to look at how to make those services better.

When ASAN wrote this section, we divided it into 7 main topics. Those topics are:

- Making sure people with IDD have good mental health in general.
- Preventing and responding to trauma.
- Helping people with IDD who also have mental health disabilities.
- Making sure people with IDD get good mental health therapy if we want.
- Making sure people with IDD do not take too many mental health medications.
- Helping people with IDD avoid and calm down from mental health crises.
- Helping people with IDD when we are in very bad mental health crises.

Each of these topics builds on the topic before it. The first topic talks about providing good mental health support for all people with IDD. The last topic talks about providing support for people with IDD in bad mental health crises.

ASAN wrote most of this appendix in December 2023 and January 2024. In March 2024, the state of Minnesota put out a resource called the Psychotropic Medication Manual. Psychotropic medication is another term for mental health medication. Minnesota's Psychotropic Medication Manual covers a lot of the same topics we cover in this section. The Psychotropic Medication Manual talks about things like:

- Mental health medication.
- Mental health therapy.
- Figuring out why a person with IDD is doing a "challenging behavior."
- How IDD service providers and mental health service providers can work together to help people with IDD.

ASAN really likes Minnesota's Psychotropic Medication Manual. We think more states should make resources like it.

Making sure we have good mental health in general

Good mental health means a lot of different things. For this toolkit, ASAN looked at how two different groups explain what mental health is. The two groups are the U.S. government's Substance Abuse and Mental Health Services Administration (SAMHSA) and the World Health Organization. Both of these groups know a lot about what mental health and wellness looks like. Both SAMHSA and the World Health Organization said that good mental health:

- Is more than just not having a mental health disability or not being in a mental health crisis.
- Has to do with how you feel about yourself and the world around you.
- Can affect your choices and actions in everyday life.
- Looks different from person to person.

IDD service providers can offer people with IDD different kinds of support with mental health. Some ways that IDD service providers can support good mental health for people with IDD are:

- Training support workers in how to talk about mental health with people with IDD.
- Providing lots of activities and choices for what people with IDD can do during the day.
- Making sure the providers meet people with IDD's needs, like the need for respect.
- Helping people with IDD choose what kinds of support we want with mental health.

It is important that IDD service providers meet people with IDD's needs. It is important that IDD service providers make sure people with IDD have choices about our lives. It is important that IDD service providers respect people with IDD. All these things are important for good mental health.

IDD service providers and support workers do not have to be experts in mental health care. Being an IDD service provider or support worker is different from being a mental health therapist. Being an IDD service provider or support worker is different from being a mental health doctor. But IDD service providers and support workers should be able to tell what bad mental health looks like in people with IDD. IDD service providers and support workers should know how to help people with IDD get mental health services if we want them.

Questions about making sure we have good mental health in general to help with writing goals for behavior support services

ASAN wrote some questions about making sure people with IDD have good mental health. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say “this person,” we mean the person with IDD. The questions are:

- What does this person’s mental health usually look like?
    - ◊ What does a “good day” look like for this person?
    - ◊ What does a “bad day” look like for this person?
- Who in this person’s life can check in with them regularly and ask how their mental health is? For example: a support worker or family member.
- Is someone keeping track of this person’s mental health to make sure it stays good? For example: a primary care doctor.

Trauma

Many people with IDD have trauma. Trauma is changes in how a person thinks, feels, and behaves. Trauma happens because of a scary situation the person went through. We do not know exactly how many people with IDD have trauma. But we think a lot of people with IDD have trauma.

People with IDD often go through a lot of events that can cause trauma. These can be “big” events, such as:

- Abuse or neglect.
- Being very sick.
- Being put in an institution.

These can also be “small” events that happen over and over, such as:

- Being left out of social events.
- Having to move between living situations a lot.
- Being bullied or picked on.

A specific type of trauma a lot of people with IDD have is called adverse childhood experiences, or ACEs. Adverse childhood experiences are bad things that happen to you when you are a child, such as:

- People in your family yelling and fighting with each other.
- Someone in your family going to jail.
- Someone in your family using drugs or alcohol in an unhealthy way.

ACEs can have big impacts on your health as an adult. People who had more ACEs as a child tend to have worse health as an adult.

Trauma can have a lot of bad effects on people's physical and mental health. These effects can last for a short or long time.

Some kinds of effects trauma can have are:

- Effects on how a person feels.

For example: feeling angry or nervous more often.

- Effects on a person's physical health.

For example: having a hard time sleeping or eating.

- Effects on how a person thinks.

For example: having a hard time remembering things.

- Effects on how a person behaves.

For example: avoiding things that remind them of the traumatic event.

- Effects on how a person feels about the world.

For example: feeling really bad about the future.

We know these effects can all happen in people with and without IDD. But we do not know much about how trauma looks different between people with IDD and without IDD. We know that trauma can be a big cause of "challenging behavior" in people with IDD. But a lot of IDD and mental health service providers are not taught how to recognize trauma in people with IDD. So when a person with IDD has "challenging behavior," nobody asks if the behavior might be because of trauma.

IDD service providers need to help people with IDD who have trauma. IDD services providers can do this in a few ways. IDD service providers can:

- Use trauma-informed care in their services.
- Train support workers and other staff in working with people with trauma.
- Help people with IDD who have trauma get mental health services.

We will talk about each of these ideas in this section.

Using trauma-informed care in services

Trauma-informed care is a way to provide services to people with trauma. Trauma-informed care focuses on not making people's trauma worse. Trauma-informed care helps people work through their trauma.

The U.S. government's Substance Abuse and Mental Health Services Administration (SAMHSA) says that trauma-informed care involves service providers:

- Realizing that trauma can have a big impact on someone.
- Understanding how people can recover from trauma.
- Knowing what the signs of trauma look like in people.
- Making sure everyone working for the provider knows what trauma looks like.
- Changing practices so they do not give people more trauma.

IDD service providers can do different things to make sure they are doing trauma-informed care. IDD service providers can do things like:

- Making changes to their buildings to make people with IDD feel safer. For example: making sure everyone in a group home can lock their doors when they want.
- Building trust with people with IDD. For example: support workers talking to people with IDD to get to know us and build relationships.
- Giving people with IDD real choices about our lives. For example: finding many different places someone could live in the community, not just one or two.
- Working with people with IDD to solve problems. For example: a support worker helping a person with IDD solve a problem they have with a roommate.
- Giving people with IDD the support and skills we need to make our own choices. For example: helping someone with IDD choose where in the community they want to work.

These ideas will look different depending on the provider and the people they work with. But the basic ideas of trauma-informed care should be very similar between different providers.

Training support workers and other staff in how to recognize trauma

IDD service providers need to train support workers and other staff in how to recognize trauma. This is part of trauma-informed care. Support workers do not have to be experts in helping people work through trauma. But support workers should know what trauma can look like in people with IDD.

Support workers should understand how trauma can affect people with IDD. Support workers should understand that trauma can cause “challenging behavior” in some people with IDD. Support workers should know how to help someone with IDD get mental health services for trauma. Support workers need training in all of this.

IDD service providers also need to understand support workers can have trauma, too. Being a support worker can be a hard job. Many support workers have secondary trauma from their work. **Secondary trauma** is when someone has trauma from seeing someone else go through a really stressful experience.

IDD service providers need to train support workers on how to recognize signs of trauma in themselves. IDD service providers need to give support workers the support they need to deal with trauma. This can include:

- Setting up ways for support workers to talk about how their jobs are going.
- Offering health insurance and other ways to pay for mental health therapy to support workers.
- Making sure support workers get paid time off work for vacations or sick days.

Helping people with IDD who have trauma get good mental health services

There are different kinds of mental health services for people who have trauma. Some of these mental health services have been adapted for people with IDD. “Adapted” means the service was changed to make it easier for people with IDD to understand and take part in it. People with IDD can get a lot of help from mental health services for trauma. These services can help us figure out ways to cope with trauma. These services can help us work through trauma.

IDD service providers need to know what trauma looks like in people with IDD. IDD service providers need to make sure people with IDD who have trauma get good mental health services. This means that IDD service providers need to work with mental health service providers. It means that IDD service providers need to refer people with IDD to mental health service providers.

Part of trauma-informed care is not causing people more trauma. IDD service providers need to recognize when their practices might cause people with IDD more trauma. IDD service providers need to get rid of practices that cause trauma. This does not just mean getting rid of practices like restraint and seclusion. It means getting rid of all practices that do not let people with IDD have control over our own lives.

For example:

Caring Hearts, Inc. is an IDD service provider. Caring, Hearts, Inc. runs a group home. Caring Hearts, Inc. says the group home is "trauma-informed." Caring Hearts, Inc. says this because they do not use restraint and seclusion in the group home.

But Caring Hearts, Inc. still uses other practices that can cause trauma. The group home still uses practices like:

- Behavior charts that make people earn normal activities like going out on the weekends.
- Saying people "lose privileges" like having dessert if they do not do their chores.
- Treating the adults who live in the group home like children.

All these things can cause trauma. The group home might not be using restraint and seclusion. But it is still using practices that cause trauma.

Questions about trauma to help with writing goals for behavior support services

ASAN wrote some questions about trauma. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say “this person,” we mean the person with IDD. The questions are:

- Has this person had any kind of trauma?
    - If the answer is yes, what kind of trauma has the person been through?
    - If the answer is yes, what signs of trauma does this person show?
    - If the answer is yes, where did the person experience the trauma?
- Has the person been through any kind of mental health services for trauma?
- Are this person’s support staff trained in providing trauma-informed care?
- How do this person’s services make sure they are not adding to this person’s trauma?

Health care for mental health disabilities

Many people with IDD also have a mental health disability. The NADD is a group that advocates for people who have both an IDD and a mental health disability. The NADD says that between 3 in 10 and 4 in 10 people with IDD also have a mental health disability. About 2 in 10 people without IDD have a mental health disability. (In this toolkit, we call people with both IDD and mental health disabilities “people with dual diagnosis.” “Dual” means “two.”)

But a lot of the time, people with dual diagnosis do not get care for their mental health disability. This is for a few reasons. These reasons are:

- Diagnostic overshadowing.
- Mental health testing asking questions that can be hard for us to answer.
- Not enough doctors and therapists are trained in working with people with IDD.

We will talk about each of these issues in this section.

Diagnostic overshadowing

Diagnostic overshadowing is when doctors blame health problems a person with IDD has on the person’s disability. With diagnostic overshadowing, doctors usually do not take time to figure out the cause of the health problems. Instead, the doctors just say that the person’s medical problem is caused by the person’s disability.

Diagnostic overshadowing can happen with any health problem a person with IDD has. We talked earlier in this part how diagnostic overshadowing happens with physical health issues. But diagnostic overshadowing is especially common when people with IDD have mental health disabilities.

Part of this is that some symptoms of mental health disabilities look like symptoms of the person's IDD. It can be hard for doctors or therapists to tell what is caused by the person's IDD or mental health disability.

For example:

> Mariah has an IDD called ADHD. Mariah also has a mental health disability called anxiety. Both ADHD and anxiety make it hard for Mariah to sit still. Both ADHD and anxiety make it hard for Mariah to focus on one thing at a time. Both ADHD and anxiety make Mariah more likely to lose track of what she is doing.
>
> Mariah sees a therapist. But Mariah's therapist is not sure which of Mariah's disabilities cause which symptoms.

Another part of this is a lot of doctors and therapists think people with IDD cannot have mental health disabilities. A lot of doctors and therapists think people with IDD "cannot think" well enough to have mental health disabilities. This is not true. Mental health disabilities do not depend on how "well" someone can think. And, people with IDD can have mental health disabilities no matter what kinds of IDD we have. But a lot of doctors and therapists still think this.

For example:

> Luis has an intellectual disability. Luis also has a mental health disability called depression. Luis's depression makes him sad and tired all the time. It makes him not want to do anything all day.
>
> Luis's mother takes him to a mental health doctor. Luis tells the doctor he feels sad and tired all the time. Luis's mother tells the doctor that Luis will not get out of bed all day. The doctor says, "Of course he won't get out of bed. He is not smart enough to do anything."

The doctor says it is “natural” for Luis to be depressed.” The doctor says people with intellectual disabilities “cannot think well enough” to do activities that interest them.

This is wrong! Luis is not sad because all people with intellectual disabilities are sad. Luis is sad because he has depression.

Diagnostic overshadowing affects a lot of people with dual diagnosis. Diagnostic overshadowing especially affects:

- People with intellectual disabilities.
- People who do not communicate through talking with their mouths.
- People who need a lot of support in their everyday lives.

These three groups often have more trouble telling people around them what they are feeling. Other people tend not to listen as much to people in these three groups. Other people tend not to take what people in these three groups say seriously. Other people tend to think that people in these three groups “cannot think well enough” to have mental health disabilities.

Mental health testing asks a lot of questions that can be hard for people with IDD to answer

Doctors and therapists diagnose mental health disabilities differently from most other disabilities. Doctors and therapists cannot usually diagnose mental health disabilities from blood tests or x-rays. Doctors and therapists diagnose mental health disabilities by asking people questions about their feelings and thoughts. These questions can be hard for people with IDD to answer.

Many people with IDD have trouble figuring out what feelings we have. We may know something is wrong but not understand what. We may have trouble knowing what things we feel in our bodies could mean.

For example:

> Bella is autistic. She is in a bad mood. Bella knows something is wrong but cannot tell what. Bella spends all morning in a bad mood. Then, she goes out in the afternoon to meet a friend. Bella's friend asks her, "Bella, did you eat breakfast this morning?"
>
> Bella says, "No, I forgot." Bella realizes she has been in a bad mood because she is hungry.

Not knowing how you feel can make it hard to answer questions about your mental health. Not knowing why you feel bad can make it hard to answer questions about your mental health. This can make it hard for people with IDD to do mental health testing.

For example:

> Frank has Down Syndrome. Frank is taking a mental health test with a therapist.
>
> The therapist asks Frank, "Over the past 2 weeks, how many days have you felt down, depressed, or hopeless?"
>
> Frank thinks for a while. He knows he has felt bad over the past 2 weeks. He has felt sad and tired. But he does not know if he has felt "down, depressed, or hopeless." So Frank tells the therapist that he has not felt "down, depressed, or hopeless" over the past 2 weeks.

Another problem with mental health testing for people with IDD is that we might take the questions literally. Taking something literally means you think someone is saying exactly what their words mean. But the person actually means something different.

For example:

> Renee is talking to her friend. Renee's friend recently went on a trip to a nearby big city. Renee asks her friend how the trip was. Renee's friend says, "It was great! There were so many buildings towering over me like mountains."
>
> Renee thinks about this for a bit. She thinks her friend meant that the buildings were shaped like mountains. But her friend really meant that the buildings were very tall.

Taking questions literally can be an issue when people with IDD get mental health testing. Mental health tests often ask questions about specific experiences. But those questions sometimes use language that can mean multiple things.

For example:

> Lianna is autistic. Lianna is doing mental health testing with her therapist. Lianna's therapist asks her, "Have you ever heard voices when nobody else was in the room."
>
> Lianna thinks about the question. She remembers how she talked on the phone to her friend yesterday. Lianna could hear her friend's voice even though her friend was not in the room. So Lianna says, "Yes, yesterday I heard my friend speaking to me."
>
> But the therapist was not asking about telephone calls. The therapist was asking about auditory hallucinations. Auditory hallucinations are when a person can hear noises that nobody else can hear. Auditory hallucinations are a symptom of some mental health disabilities.

Not enough doctors and therapists are trained in working with people with IDD

Very few mental health doctors and therapists get training in how to work with people with IDD. Most schools that teach people how to be mental health doctors and therapists do not talk about IDD. Most mental health doctors and therapists do not learn about working with people with IDD after they finish school.

The mental health service system and the IDD service system are very separate. Providers who work in one system do not often talk to providers who work in the other system. This makes it very hard for people with IDD to get good mental health services.

The Mental Health and Developmental Disabilities National Training Center is a group of **researchers**. They study how to improve mental health services for people with IDD. They wrote a report talking about how difficult it is for people with IDD to find good mental health services. The report found that:

- There are not enough mental health service providers to meet the needs of people with IDD.
- Mental health service providers often say they cannot help people with IDD.
- Mental health service providers do not know how best to care for people with IDD.
- People with IDD often wait months for an appointment with a mental health service provider.
- All of these problems are worse for people with IDD who need a lot of support.
- All of these problems are worse for people with IDD who do not speak English well.

These are all big problems with mental health services for people with IDD. But it is still very important that people with IDD can get testing for mental health disabilities. Without a mental health diagnosis, a person may not be able to get mental health services at all. And if a person gets diagnosed with a mental health disability they do not have, they can get the wrong kind of care. A wrong diagnosis can mean a person gets put on medication that does not help them. A wrong diagnosis can mean a person gets put in therapy that does not help them.

All of these things can make a person's actual mental health disability worse. All of these things can make a person's "challenging behavior" worse.

IDD service providers and support workers need to help people with IDD access good mental health services. This includes testing for mental health disabilities. IDD service providers and support workers need to find mental health service providers who work with people with IDD. IDD service providers and support workers can also help people with IDD who are going through mental health testing. IDD service providers and support workers can help by:

- Putting the doctor or therapist's questions in simpler language that the person can understand.
- Adding more information to help the doctor or therapist understand the person's answers.
- Telling the doctor or therapist information that the person might not remember. For example: what medications the person already takes.
- Bringing health care or mental health records from other providers the person has already seen.

Questions about health care for mental health disabilities to help with writing goals for behavior support services

ASAN wrote some questions about health care for mental health disabilities. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say “this person,” we mean the person with IDD. The questions are:

- Does this person have mental health disabilities as well as IDD?
    - ◊ If the answer is yes, what mental health disabilities does the person have?
- Has this person been tested before for mental health disabilities?
    - ◊ What testing did this person do?
    - ◊ Was the testing adapted to make it more accessible to this person?
    - ◊ Was the testing done by a provider who knows how to work with people with IDD?

Mental health therapy

Mental health therapy is when you talk to a mental health doctor about your emotions and feelings. Mental health therapy can be really helpful for people with IDD. This includes people with dual diagnosis. This includes people with “challenging behavior.”

There are many different kinds of mental health therapy. Many kinds of mental health therapy have been adapted for people with IDD. “Adapted” means a therapy was changed to make it easier for people with IDD to understand and take part in it. Some types of mental health therapy that have been adapted for people with IDD are:

- Cognitive behavioral therapy.
- Dialectical behavioral therapy.
- Acceptance and commitment therapy.
- Eye movement desensitization and reprocessing therapy.

These are not the only types of mental health therapy that have been adapted for people with IDD.

Different people find different kinds of mental health therapy more or less helpful. There is no one “best” mental health therapy for people with IDD. But people with IDD get the most out of mental health therapy when it focuses on what we need.

People with IDD get the most out of mental health therapy when we have the right accommodations. **Accommodations** are changes that help people with disabilities get the same service as anyone else. Some types of accommodations that might help people with IDD in mental health therapy are:

- Information in plain language instead of difficult language.
- Having information in pictures as well as words.
- Having appointments more often, like having therapy twice a week instead of once a week.

There are also different ways mental health therapy can happen. Some people go to individual mental health therapy. Individual mental health therapy is where you work one-on-one with a therapist.

Some people go to group mental health therapy. Group mental health therapy is where a therapist works with a small group of people at the same time.

Some people go to mental health skills groups. Mental health skills groups are groups that teach skills for dealing with mental health disabilities.

Some people go to **peer mental health support**. Peer mental health support can be like mental health therapy. But in peer mental health support, you do not work with a mental health doctor or therapist. Instead, you work with a **peer worker**. A peer worker is another person with IDD or mental health disabilities. Peer workers get special training in helping other people with IDD or mental health disabilities.

Some people with IDD or mental health disabilities find peer mental health support more useful than mental health therapy. Some people with IDD or mental health disabilities find it easier to work with a peer than a doctor or therapist.

IDD service providers and support workers should help people with IDD find mental health therapies that work for us. IDD service providers and support workers can do this by:

- Helping us come up with goals we want to work on in mental health therapy.
- Helping us figure out what kind of a mental health therapist we do or don't want.
- Making a list of mental health therapies or services we have tried before and whether they helped.
- Helping us make appointments for mental health therapy.
- Coming with us to help us "interview" potential mental health therapists.

IDD service providers and support workers can help people with IDD find kinds of mental health therapies that work for us. But IDD service providers and support workers need to make sure people with IDD are in charge of our own therapy. IDD service providers should not use therapy as a way to get people with IDD to do what the service provider wants.

Using therapy to force someone to do something does not help the person. It does not make the person more likely to do what other people want them to do. It just makes the person hate therapy. It just makes the person less likely to do what other people want them to do.

Questions about mental health therapy to help with writing goals for behavior support services

ASAN wrote some questions about mental health therapy. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say “this person,” we mean the person with IDD. The questions are:

- Has this person had mental health therapy in the past?
    - ◊ If the answer is yes, what kind of mental health therapy did the person have?
    - ◊ If the answer is yes, did the person find the mental health therapy useful?
- Does this person want to get mental health therapy?
    - ◊ If the answer is yes, can they?
    - ◊ If the answer is yes, what kind of mental health therapy would this person find most helpful?
    - ◊ If the answer is yes, does this person have a choice over what kind of mental health therapy they get?
    - ◊ If the answer is yes, does this person get to choose their therapist?
    - ◊ If the answer is yes, does this person get to choose whether they get therapy that is adapted for people with IDD?
- If this person gets mental health therapy, is the therapy focused on their own needs?
- Can this person choose to not get mental health therapy?
- Can this person choose the type of mental health therapy they get (individual versus group therapy, therapy versus peer support)?

Medications for mental health

Some people with IDD take medications that treat mental health disabilities. Sometimes this is because the person has IDD and a mental health disability (dual diagnosis). Sometimes this is because the person gets mental health medications for their “challenging behavior.”

People have a lot of arguments about if and when people with IDD should take mental health medications. This is especially true when doctors give people with IDD mental health medications for “challenging behavior.”

Mental health medications can really help people. People with dual diagnosis often need a lot of help with their mental health disability. Mental health medications can help with symptoms like:

- Feeling sad or tired all the time.
- Feeling nervous or “wired up” when there is nothing to worry about.
- Having scary or gross thoughts that you cannot stop thinking about.

Mental health medications can help people who have a lot of mental health symptoms deal with those symptoms.

For example:

> Ron has an intellectual disability. He also has a fear of needles. Ron’s fear of needles is so bad that he has not gotten any vaccines (shots) in years. Ron knows he needs to get his flu and **COVID-19** vaccines this year. But he is scared of getting stuck with a needle.

So Ron talks to his doctor. Ron's doctor gives Ron a mental health medication. The medication will help Ron relax. It will help him stay calm if he needs to be around a needle.

Ron takes the medication before he gets his vaccines. Then, Ron is not as scared of getting stuck with a needle. The mental health medication helped Ron with his fear of needles. The mental health medications meant that Ron could get vaccinated this year.

Mental health medications can also help people who do "challenging behavior." Mental health medications are most helpful if the "challenging behavior" is caused by a mental health disability.

For example:

Niamh is autistic. She also has depression. Niamh's depression causes her to be extremely grumpy. She yells at anyone who gets in her way. If someone tries to make Niamh do something, she will push them out of her way. The staff at Niamh's group home say she has "challenging behavior." Niamh is about to get kicked out of the group home.

Then, Niamh starts taking mental health medication for her depression. The medication helps her feel better. She stops feeling so grumpy. She starts talking through problems she has with other people. Then, Niamh does not get kicked out of the group home.

Mental health medications can help people. But there are still risks with mental health medications.

Mental health medications can have a lot of side effects. Some of these side effects can still happen even after a person stops taking the medication. Some of these side effects can make people very sick. Some of these side effects can kill people if the side effects are bad enough.

And, people can have more side effects if they take more than 1 mental health medication. Sometimes these side effects are from the individual medications. Sometimes these side effects are because the medications interact with each other. Medication interactions can cause side effects that neither medication on their own would cause.

A lot of people with IDD take antipsychotics. **Antipsychotics** are a type of mental health medication that treat psychosis. **Psychosis** is a **symptom** of some mental health disabilities. People with psychosis think and experience things that most people do not. Some types of psychosis are:

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

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

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

Most people with IDD who get antipsychotics do not have psychosis. The antipsychotics are supposed to treat “challenging behavior.” But if a person does not actually have psychosis, antipsychotics are not going to treat psychosis.

In a lot of cases, antipsychotics “fix” “challenging behavior” by making people too tired to move. Using medication to make someone too tired to move is a kind of restraint. Restraint is bad. Restraint can hurt people badly. Restraint can kill people.

The HCBS Settings Rule says service providers are not allowed to use medication to restrain someone. But many service providers still use medication to restrain people.

A big question with mental health medication for “challenging behavior” is who is actually asking for the medications. Is the person with the “challenging behavior” asking for the medications themselves? Or is someone else, like a support worker or family member, asking?

If someone else is asking, why are they asking? Is it because they think the person might have a mental health disability? Or is it because they just want the “challenging behavior” to stop?

These are all questions that IDD service providers, support workers, and mental health doctors all need to think about.

IDD service providers need to look at “challenging behavior” as part of the person’s whole life.

IDD service providers need to ask questions like:

- What is going on around this person that might cause their behavior?

For example: Someone runs out of their house when it is very noisy. They are probably trying to get some quiet.

- When and where does the behavior happen? Does it only occur during certain times or around certain people?

For example: Someone who refuses to work on chores with a specific staff member. They might not like that staff member.

- What emotions or feelings might cause this person to do this behavior?

For example: If the person is shouting and throwing things, they may be angry. Then, the IDD service provider can figure out what might have made the person angry.

IDD service providers need to try many different things before they use mental health medications for someone with “challenging behavior.” IDD service providers need to work with the person doing the “challenging behavior.” IDD service providers need to look at what is going on around the person. IDD service providers need to make sure the person does not have basic needs that are not being met. IDD service providers need to work with the person to meet the person’s needs.

IDD service providers should only try mental health medications for “challenging behavior” if:

- They have tried many other methods of helping the person and none of them have worked.

For example:

◊ Meeting the needs causing a person’s behavior.

◊ Getting the person **physical therapy**, occupational therapy, or **speech therapy**.

◊ Getting the person mental health therapy.

- The person’s behavior is dangerous to themself or someone else.

For more information about what dangerous behavior is, you can read the section “Dealing with dangerous behavior” later in this part.

Mental health doctors who prescribe medication to people with IDD should follow rules. These rules help keep people with IDD who take mental health medication safer. These rules are:

- Mental health medications are only one part of helping someone with their mental health. Other parts of helping someone with their mental health could be:
    - ◊ Mental health therapy.
    - ◊ Support or skills groups.
    - ◊ HCBS.

  Mental health doctors should make sure people with dual diagnosis are not *just* getting mental health medication.
- Mental health doctors should work with other providers to make sure someone's symptoms are not caused by other issues. For example: "challenging behavior" in people with IDD can sometimes be caused by seizures. It is important to make sure medication will treat the cause of someone's behavior or symptoms.
- The person with IDD should take the smallest dose of the mental health medication they need to help with their symptoms.
- The person with IDD should take the smallest number of mental health medications they need to help with their symptoms.
- Mental health doctors should regularly ask people with IDD taking mental health medication about side effects.
- Mental health doctors should know that symptoms of mental health disabilities can look different in people with IDD.
- Mental health doctors should know that side effects of mental health medications can look different in people with IDD.
- People with IDD should not take mental health medications for longer than they need the medications. If someone no longer needs to take a medication, their doctor should help them stop taking it.

- People with IDD and people who support us need information about medication in ways we can understand. This could look like:
    - ◊ Getting Easy Read or plain language materials.
    - ◊ Having visual schedules or reminders to take medication.
    - ◊ Talking with mental health doctors about the good and bad things about different medications.

Questions about medications for mental health to help with writing goals for behavior support services

ASAN wrote some questions about medications for mental health. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say “this person,” we mean the person with IDD. The questions are:

- Is this person taking mental health medication right now?
- Does this person want to take mental health medication?
- Have other people said that this person should take mental health medication?
    - ◊ If the answer is yes, why have people said this person should take mental health medication?
    - ◊ If the answer is yes, does this person have a mental health disability?
- Is this person being given medication for “challenging behavior”?
    - ◊ If the answer is yes, what is the behavior?
    - ◊ If the answer is yes, what other, non-medication things have been tried? Explain why each intervention or service did not work.
    - ◊ If the answer is yes, has the person had testing to look for the causes of the behavior?
    - ◊ If the answer is yes, is this person’s behavior dangerous to themself or others?
- Does this person have information about the mental health medication in ways they can understand? For example, plain language or Easy Read information.

- Are this person’s support workers trained about the medication?
- Is a doctor or other provider checking this person’s medications regularly?
- Do this person’s medication types and doses make sense?

Supporting us to prevent and calm down from mental health crises

A **mental health crisis** is when a person is having thoughts or feelings that hurt them that they cannot control. During a mental health crisis, a person might try to hurt themselves or others. Mental health crises can often cause “challenging behavior” in people with IDD.

There are many things IDD service providers and support workers can do to make mental health crises less likely. We have already talked about many of these things. Some of these things are:

- Meeting underlying needs.
- Providing support for mental health disabilities.
- Making sure the person has access to the community.

These things can all help someone avoid a mental health crisis. But, they do not completely get rid of the risk of a mental health crisis.

IDD service providers and support workers need to figure out how to prevent and de-escalate mental health crises. When you prevent something, you stop it from happening in the first place. When you de-escalate something, you make it less dangerous. IDD service providers and support workers need to work with people with IDD to do this. Remember, nothing about us, without us!

IDD service providers and support workers need to know what mental health crises look like for each person they support. Mental health crises can look very different from person to person. If IDD service providers and support workers do not know what a mental health crisis looks like, they will not be able to prevent it.

People with IDD can work with IDD service providers and support workers to make a crisis support plan. A **crisis support plan** is a document. A crisis support plan talks about:

- What the person does when they are calm and happy.
- What the person does when they start to get upset.
- What the person does when they are in a mental health crisis.
- What things a person might do that look like a mental health crisis but are really not.

For example, if a person takes apart furniture when they are bored but not in crisis.

- What service providers and support workers can do to make mental health crises less likely.
- What service providers and support workers can do to help the person when they get upset.
- What kinds of things cause the person to get upset.
- How service providers and support workers can help the person stay safe during a mental health crisis.
- What people or groups in the community can help the person during a crisis.

People with IDD should lead the meetings to put together our own crisis support plans. We should be able to invite anyone we want to these meetings. We should be able to invite people like:

- IDD service providers.
- Support workers.
- Mental health service providers.
- Friends and family.
- Other people who know us well.

Crisis support planning only works when service providers and support workers see people with IDD as people first. People with IDD have thoughts. We have feelings. We do the things we do for reasons. We are not just bundles of “behaviors” to be fixed. We behave how we do for lots of reasons. We do not behave just to get attention or get out of situations.

When we have mental health crises, we need support and care. Even if nobody else can tell what is causing the mental health crisis, we still need support and care. Even if nobody else can tell what is causing the mental health crisis, people around us still need to help us.

IDD service providers and support workers should try to help people with IDD avoid situations that could cause a mental health crisis. This does not mean that people with IDD have to be protected from every little risk. We should get help to avoid situations that can cause mental health crises while still getting to take risks.

For example:

Jarrod has an intellectual disability. He also has a mental health disability called alcohol use disorder. Jarrod used to drink too much alcohol. He would keep drinking alcohol all the time. Drinking too much alcohol caused Jarrod a lot of physical and mental health issues.

Now, Jarrod no longer drinks alcohol. Jarrod’s support worker wants to help make sure that Jarrod will not drink alcohol. So Jarrod’s support worker says that Jarrod is never allowed to be anywhere where there is alcohol. This includes:

- Bars and restaurants that serve alcohol.
- Stores that sell alcohol.
- Friends’ houses that have alcohol in them.

Jarrod's support worker is trying to help Jarrod. But they are not letting Jarrod have all his rights. Jarrod has the right to go places in the community that serve alcohol. Just because the situation is risky for Jarrod does not mean he cannot take the risk.

Sometimes, it is impossible to avoid situations that might cause a mental health crisis. In these situations, IDD service providers and support workers should work with the person with IDD to build coping skills. Coping skills are skills that help someone manage their feelings and thoughts in a stressful situation.

For example:

Marjorie has cerebral palsy. Marjorie needs help showering and using the bathroom in the mornings. Marjorie has been abused by men before. So she is really uncomfortable with men seeing her naked.

Both of Marjorie's regular support workers are women. But Marjorie is worried about what would happen if both her regular support workers were out sick. She is worried that her HCBS provider agency would send a fill-in support worker who is a man.

So Marjorie gets together with others to write a support plan for fill-in support workers. Marjorie also works with a mental health therapist on coping skills for dealing with a male fill-in support worker.

Crisis support plans will look different for every person who makes one. Mental health crises look different for different people. The kind of support a person needs during a mental health crisis is different from person to person. So different people might use different strategies and ideas for support during a mental health crisis.

But support workers and service providers need to remember one thing for all crisis support planning. People with IDD are still people first. Our mental health crises may look different from those of people without IDD.

We may need different, or more, support during mental health crises. But we still deserve support and care during mental health crises. We still deserve respect during mental health crises.

There are different ways of thinking about helping people in mental health crises. One way of thinking about helping people in mental health crises is the SCARED method. The SCARED method was created to help autistic people having meltdowns. But it works for helping people in mental health crises, too. SCARED stands for:

- **S**afe: Support workers should make sure the person having the mental health crisis is safe.
- **C**alm: Support workers should keep calm. They should let the person know that it is okay to have a crisis and that they are safe.
- **A**ffirmation: Affirmations are words of support. Support workers should remember that the person is doing their best in the situation. Support workers should tell the person that they know the person is doing their best.
- **R**outine: Routines are sets of steps you do over and over again. Many people with IDD have routines that help us calm down. Support workers should let us do the routines we have to help us calm down. Support workers should help us find things we need to engage in routines to calm down. For example: fidget toys.
- **E**mpathy: Empathy is trying to understand how the person is feeling. Support workers should have empathy for people with IDD who are in crisis. Support workers should not tell people with IDD that we are bad or wrong for having mental health crises.
- **D**evelop a crisis support plan: Support workers should help the person make or add to their crisis support plan. Support workers should do this once the mental health crisis is over.

The SCARED model is not perfect. It will not work for every person with IDD. But it is a good place to start.

Questions about supporting us to prevent and calm down from mental health crises to help with writing goals for behavior support services

ASAN wrote some questions about supporting people with IDD to avoid and calm down from crises. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say “this person,” we mean the person with IDD. The questions are:

- What does this person do or look like when they are calm and happy?
- What does this person do or look like when they are upset but not in a mental health crisis?
- What does this person do or look like when they are in a mental health crisis?
- What situations or events can cause this person to have a mental health crisis?
    - ◊ What can be done to avoid these situations or events?
    - ◊ How can this person use coping skills when these situations or events do happen?
- What can people around this person do to help the person prevent crises?
- What can people around this person do to help this person calm down from crises?
- Does this person have a crisis support plan?
    - ◊ If the answer is no, what help does this person need to create a crisis support plan?

- What support does this person need to avoid mental health crises in their daily life?
    - ◊ How can service providers and support workers offer this support without taking away the person’s rights?

Supporting us when we are in crisis

We have already talked about what IDD service providers and support workers can do to prevent mental health crises. We have already talked about how IDD service providers and support workers can help people with IDD calm down from mental health crises. But mental health crises still sometimes happen. And people can still get very upset during mental health crises.

IDD service providers and support workers need to help people with IDD when we have mental health crises. IDD service providers and support workers need to make sure the help meets the person’s needs. The help one person needs during a mental health crisis might be different from what another person needs. But there are still some big ideas we think IDD service providers and support workers can use for every person. These ideas are:

- Help the person create a crisis support plan before the crisis happens.
- Find **mental health crisis services** that work with people with IDD before the crisis happens.
- Use mental health crisis services that come to where the person lives.
- Do not call the police.
- Help the person stay in the community, not an institution.

We will talk about each of these ideas in this section.

Help the person create a crisis support plan before the crisis happens.

We talked in the last section about making crisis support plans. You can read that section for more information about crisis support plans. Once the person has a crisis support plan, IDD service providers and support workers need to practice using the support plan. IDD service providers and support workers need to make sure they know what to do when the person has a mental health crisis. IDD service providers and support workers need to make sure they can do what the plan says, even when the person is in crisis.

Find mental health crisis services that work with people with IDD before the crisis happens.

IDD service providers need to work with mental health crisis services to help people with IDD who are having mental health crises. This means IDD service providers need to find mental health crisis service providers who know how to work with people with IDD. Not all mental health crisis service providers are good at working with people with IDD. So IDD service providers need to find mental health crisis service providers who are good at working with people with IDD.

Some mental health crisis service providers work specifically with people with dual diagnosis. Not every person with IDD who has a mental health crisis will need support from this kind of provider. But some people with IDD will. IDD service providers need to make sure the mental health crisis service providers they work with know how to work with people with IDD.

Use mental health crisis services that come to where the person lives.

There are two different kinds of mental health crisis services. These are:

- Mental health crisis services that meet the person where the person is. This could be at the person's house. It could be where the person works or goes to school. It could be somewhere else in the community. These services are sometimes called "push-in services."
- Mental health crisis services people have to go to. These services could be in a clinic in the community. These services could be in a house or building in the community, like a **crisis respite**. These services could be in a small institution, like a group home. These services could be in a big institution, like a hospital. These services are sometimes called "pull-out services."

IDD service providers need to work with crisis services that meet the person where the person is. These services make it easier for the person to stay where they are living. These services make it easier for the person to stay in the community. These services make it less likely the person will be put in an institution.

IDD service providers need to also make changes to help the person stay in the community until the mental health crisis is over. These changes could look like:

- Making sure the person has a support worker at their house all the time.
- Letting the person stay home from work or school for a few days.
- Helping the person make an emergency appointment with their mental health therapist or doctor.

IDD service providers cannot always use mental health crisis services that meet the person where the person is. Sometimes these services do not exist where the IDD service provider is. Sometimes these services will not work with people with IDD. So the IDD service provider has to work with a mental health crisis service that the person has to go to.

When this happens, IDD service providers should do a few things:

- Make sure the mental health crisis service is based in the community. People with IDD should not have to go to an institution because we have a mental health crisis.
- Make sure the person is not stuck in the mental health crisis service longer than they need to be. This is especially true of mental health crisis services in smaller institutions, like group homes.
- Make sure the person has the support they need to take care of themselves. Many mental health crisis services do not have support workers in the same way IDD services do. Many mental health crisis services do not help people in the services with activities like eating or getting dressed. IDD service providers need to work with mental health crisis service providers to get people with IDD the right help and support.

Do not call the police.

We talked in part 5 about how in many places, 911 will send police when someone is having a mental health crisis. The police are not trained to respond to mental health crises. The police carry guns. The police are trained to shoot people they think might hurt them. This is very dangerous for people in mental health crises.

Across the United States, police have shot and killed many people with IDD and people in mental health crises. The police especially shoot and kill Black people, Indigenous people, and other people of color. Even when the police do not hurt the person in a mental health crisis, the person often ends up in jail or in an institution. This can cause a lot of trauma for the person.

Calling the police on someone in a mental health crisis is dangerous. Calling the police on someone in a mental health crisis will not make the situation better. IDD service providers should not call the police when a person with IDD is having a mental health crisis.

There are other ways to get mental health crisis services within someone's community. One of these ways is the **988 Lifeline**. People can call or text the 988 Lifeline when they or someone else is having a mental health crisis. The 988 Lifeline will send the call or text to a local mental health crisis service provider who can help the person.

Some of the 988 Lifeline service providers work with police. Some do not. And there are cases when the 988 Lifeline says mental health crisis service providers must call the police. It does not matter whether the mental health crisis service provider thinks the police will help the person. In these cases, the rules say that the mental health service provider must call the police.

Because of this, IDD service providers should learn more about the mental health crisis service providers in their community. IDD service providers should find mental health crisis service providers that do not work with the police. IDD service providers should learn about the 988 Lifeline's rules for when mental health crisis service providers must call the police. IDD service providers should work with mental health crisis service providers that do not work with the police.

Help the person stay in the community, not an institution.

IDD service providers need to help people with IDD who are having mental health crises stay in the community. This means helping people with IDD stay out of big institutions, like:

- Hospitals, including psychiatric hospitals. Psychiatric hospitals are hospitals that take care of people in mental health crises.
- Psychiatric wards in hospitals. Psychiatric wards are units that take care of people in mental health crises inside larger hospitals.
- Intermediate care facilities (ICFs). ICFs are a kind of institution that is “in between” a hospital and a group home.
- Nursing homes.

It means helping people with IDD stay out of smaller institutions, like:

- Residential treatment facilities. Residential treatment facilities are kind of like a cross between a psychiatric hospital and a group home.
- Group homes.

Being put in an institution is scary. Being put in an institution causes a lot of trauma. It does not matter how “nice” the institution looks. It does not matter how “helpful” the institution is. Institutions are always bad.

There are some special psychiatric wards that only take in people with IDD. Sometimes these psychiatric wards only take in autistic people. Sometimes these psychiatric wards take in anyone with IDD. These psychiatric wards like to say they are “better” for people with IDD than other psychiatric wards.

But these psychiatric wards are still institutions. These psychiatric wards still hurt people. And, these psychiatric wards tend to use a lot of ABA and other kinds of behaviorism. ABA and behaviorism hurt people with IDD.

IDD service providers need to help people with IDD having mental health crises stay in the community. IDD service providers should never use institutionalization as a threat. IDD service providers should never use institutionalization to control someone's behavior. It is not okay for IDD service providers to say things like: "You better behave correctly or I will take you to the hospital and have them lock you up."

Questions about supporting us when we are in crisis to help with writing goals for behavior support services

ASAN wrote some questions about supporting people with IDD when we are in crisis. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say "this person," we mean the person with IDD. The questions are:

- Does this person have a crisis support plan?
    - ◊ If the answer is yes, are this person's support workers trained in how to use the crisis support plan?
- Can this person get mental health crisis services that know how to work with people with IDD?
- Can this person get mental health crisis services that will meet them where they are?
- If this person has to go somewhere else (such as a crisis respite) to get mental health crisis services ...
    - ◊ Do the services let this person access the community?
    - ◊ Do the services let this person have control over their life?
    - ◊ Are the services close to where this person lives normally?
    - ◊ Can this person get the level of daily support they need while at the service?

- Do this person’s support workers and providers know how to access mental health services in the community?
- Do this person’s support workers and providers know how to access mental health services that do not work with the police?

Helping people with IDD be part of our communities in the ways we want.

People with IDD have the same right to be part of the community as anyone else. We have the same right to:

- Live in the community.
- Work in the community.
- Go to school in the community.
- Be social and do fun things in the community.
- Get help when we need it in the community.

Our service providers and support workers should not make us do things in the community that we do not want to do. This is true even if lots of other people are doing that thing in the community. This is true even for people with IDD who live in provider-owned settings.

For example:

> Jasmine lives in a supported apartment building. Jasmine's building is a provider-owned setting. The building offers buses to different places in the community on the weekends.
>
> One Saturday, a lot of people from the apartment building are going bowling. Jasmine does not want to go bowling. She wants to stay home and watch a hockey game on TV. Jasmine's support worker tells Jasmine she should go bowling.
>
> Jasmine's support worker says Jasmine might have more fun if she went bowling. Jasmine still does not want to go bowling. So Jasmine's support worker does not make her go bowling.

Our service providers and support workers should stop not us from doing things in the community that we want to do. This is true even if most people are not doing that thing in the community. This is true even for people with IDD who live in provider-owned settings.

For example:

> Michael lives in a group home. The group home is a provider-owned setting. Michael wants to go to a local park and take pictures of the plants there. Nobody else in the group home wants to go to the park. They all want to stay home and play a board game. But Michael still wants to go to the park. So a support worker at the group home takes Michael to the park.

IDD service providers and support workers should not be asking “Should this person with IDD be part of their community?” The answer will always be yes! All people with IDD should be part of our communities. The questions IDD service providers and support workers should be asking are:

- What does this person with IDD want to do as part of their community?
- How can we support them to do it?

Many people with IDD may not know what to do in their communities. This is especially true for people who have been in institutions and other separate places for a lot of their lives.

For example:

> Kima is autistic and has an intellectual disability. When Kima was a child, she went to school in a separate classroom just for students with intellectual disabilities. She did not get to learn or play with students without disabilities.
>
> When Kima graduated high school, she moved into an institution. She lived there for many years. She did not get to go out in the community. Later, Kima lived in a group home. In the group home, she only went into the community for church and doctor appointments.
>
> Now, Kima is 60 years old. She lives in her own apartment. But Kima does not know what she can do in the community. She only leaves her apartment to run errands and go to church. Kima wants to do more things in the community. But she does not know what to do.

Many people with IDD also feel like we are not able to make our own choices. We often feel this way because other people tell us we are not able to make our own choices. This can make it hard for us to choose what we want to do in the community. It can make us more likely to just go along with what other people are doing.

A big thing IDD service providers and support workers can do to help people with IDD is just take us different places in the community. That way, we can learn what kinds of things we like to do. We can learn what places we like to go. This can also help us with other things, like:

- Figuring out what we might want to do for work.
- Figuring out what we might want to study in school.
- Making new relationships with people based on what we like to do.

Let’s look at Kima’s example again:

Kima’s support worker wants to help Kima find new places and things to do in the community. So Kima’s support worker takes Kima to different places in the community. Kima and her support worker go to:

- An art museum.
- A zoo.
- A community garden.

Kima likes the community garden. She likes working with her hands and planting flowers. So Kima and her support worker start going to the community garden once a week.

Kima also likes the art museum. Kima’s support worker thinks about Kima’s interests. Kima’s support worker thinks that Kima might like doing art with plants and flowers. So Kima and her support worker sign up for a flower arranging class at the community center. Kima likes taking the class. It makes her feel like she is a part of her community.

Many people with IDD want to work but do not have jobs. We should get the support we need to find and keep jobs. We should be able to get jobs that we want to do and that matter to us.

A lot of the time, people with IDD end up working jobs in what people call the 6 F's:

- Food (working in fast food restaurants and kitchens)
- Filth (working as janitors and cleaning up other people's messes)
- Flowers (working at flower shops and in landscaping or gardening)
- Factories (doing work like putting products in boxes in a sheltered workshop)
- Filing (working in an office delivering mail or putting paperwork in folders)
- Friendly (working as a greeter at a store or restaurant)

There is nothing wrong with these types of jobs! If someone with IDD wants to do one of these jobs, they should be able to. But these are not the only types of jobs people with IDD can do. If we want to do other types of jobs, we should be able to.

For example:

> Malik has Down Syndrome. He is about to graduate high school. Malik really likes working in his high school's woodshop. He likes building things out of wood and painting them.
>
> Malik is working with a job coach to find a job. The job coach thinks of places Malik could work, like:
>
> - As a janitor in a furniture store.
> - On the assembly line in a factory that makes chairs.
> - In the mailroom of a construction company.

Malik tries these jobs. But he does not like any of them. So Malik and the job coach keep looking. Then, the job coach finds a job at an architecture company. Architecture is the design of buildings and structures. The job is making small models of the buildings the architects design.

Malik tries this job. He really likes it. He is really good at figuring out how to turn the architects' drawings into models. The job coach helped Malik get a job he likes doing and is really good at.

If people with IDD need help finding or keeping a job, we should be able to get it. This includes help like:

- Figuring out what kind of jobs we want to do.
- Trying out different jobs and workplaces.
- Support with applying for jobs, like with writing a cover letter or having an interview.
- Transportation to and from work.
- Support on the job, like from a job coach.

We should get as much help as we need for as long as we need it.

Some people with disabilities get help from Vocational Rehabilitation. Vocational Rehabilitation is a service that helps people with disabilities get and keep jobs. Vocational Rehabilitation serves all different types of people with disabilities. You do not have to be on a waiver or receiving HCBS to get Vocational Rehabilitation services.

For example:

Bethany is autistic and has a mental health disability. She works in a factory that makes medical tools for doctors. Bethany finds the tools she makes really interesting. But she hates working at the factory. She only keeps working at the factory because she can take the bus right to work every day.

Bethany goes to Vocational Rehabilitation and asks them to help her find a new job. Bethany loves helping other people. She is really good at figuring out what support someone might need. She knows a lot about how the health care system works because of her job making medical tools.

Vocational Rehabilitation helps Bethany get a job as a receptionist in a hospital. The hospital is right on a bus line, so Bethany can get to work easily. Bethany loves her new job. She gets to help people every day.

No matter where we work, people with disabilities should work in jobs where we:

- Work in the community alongside people without disabilities.
- Get paid the same as our coworkers without disabilities.
- Get the same benefits as our coworkers without disabilities. Benefits can be things like health insurance or paid time off.
- Have the same chances as our coworkers without disabilities to make more money or get better jobs.

Jobs that have all of these things are sometimes called “competitive integrated employment.”

For more information about working in the community, you can read ASAN’s toolkit, “Real Work For Real Pay: A Self-Advocate’s Guide to Employment Policy.”

Not every person with IDD wants to work at a job for pay. Some people with IDD want to volunteer. Volunteering means doing work for free, usually for a group that helps people. Some common types of volunteer work are:

- Helping out at a daycare or school.
- Giving out resources like food or clothing to people who do not have much money.
- Going to nursing homes and homes for older adults and spending time with the people who live there.

IDD service providers and support workers should help people with IDD who volunteer to do that.

For example:

> Samantha has a developmental disability. Samantha wants to volunteer at a local bookstore. The bookstore sends free books to people in jail. Samantha asks her support worker to come with her to volunteer. The support worker says, "okay!"
>
> So Samantha and her support worker go to volunteer at the bookstore. Samantha's support worker reads the letters from people in jail out loud to Samantha. Then, Samantha picks out books to send the people. Samantha's support worker helps her wrap and address the books. Samantha feels good that she volunteers.

Some people with IDD may not want to work a job or volunteer. Instead, they might want to:

- Go to a day program for people with disabilities.
- Go to school or college.
- Spend time doing fun things in the community.
- Do projects, like making art or building things.

For example:

> Tanner has an intellectual disability. He is 24. Tanner goes to community college. He takes classes on topics that interest him. He really likes learning about animals. Tanner wants to graduate college so he can work in a zoo and help sick animals. Tanner's support workers help him go to class. They make sure he gets to campus on time. They help Tanner keep all his assignments organized.

No matter what a person with IDD wants to do, their service providers and support workers should help them do it. Service providers and support workers should not stop people from IDD from doing things we want to do.

People with IDD also have the right to be part of our communities in other ways. We have the right to do civic participation. Civic participation means helping choose how the community runs itself and who will be in government. Civic participation can look like:

- Voting in an election.
- Joining a political party.
- Talking to members of the government about an issue.
- Going to a protest or rally.

Service providers and support workers should help people with IDD do these things. It does not matter if the service provider or support worker thinks different things about the government than the person they support. The service provider or support worker still needs to help the person do civic participation.

For example:

David has a developmental disability. David is really interested in his city’s government. He thinks that the city government needs to spend more money on keeping the parks clean. David wants to go to a rally to tell the city government to spend more money on the parks.

David’s support worker does not agree with David. The support worker thinks the city government is doing a good job keeping the parks clean. But the support worker still goes to the rally with David. The support worker still helps David take part at the rally. The support worker does not tell David that they think he is wrong about the city government.

It is important for IDD service providers and support workers to remember that people with IDD have the right to take risks. We might do something that ends badly for us. But we still have the right to do that thing. We have the right to make mistakes. We can learn from our mistakes.

We should have dignity of risk. **Dignity of risk** is the idea that people have the right to make choices, even if those choices might have risks or end badly. IDD service providers and support workers should not stop us from making choices just because there might be a risk.

For example:

> Xochi is autistic. She also has a disability that makes her have random body movements. Xochi wants to learn how to ride a skateboard. There is a “skateboarding for beginners” class at her local community center.
>
> Xochi’s support worker is worried about Xochi. They are worried that Xochi might get hurt skateboarding. Xochi’s support worker talks to Xochi about the risks. They talk to Xochi about ways she could make herself safer, like wearing pads and a helmet. But Xochi’s support worker still lets Xochi choose if she wants to go to the class.
>
> Xochi goes to the class. She learns how to ride a skateboard. She falls off a few times but has a lot of fun.

Questions about helping people with IDD be part of our communities in the ways we want to help with writing goals for behavior support services

ASAN wrote some questions about helping people with IDD be part of our communities in the ways we want. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say “this person,” we mean the person with IDD. The questions are:

- Where does the person live right now? Are they living where they want?
    - ◊ If the person is not living where they want, what is getting in the way of them living where they want?
- Can this person go out in the community whenever they want to?
- Can this person stay home while other people in their home go out in the community if they want?
- What does this person like to do in the community?
- What hobbies or interests does this person have?
    - ◊ How could this person use their hobbies or interests to get more involved in the community?
- Does this person have other people in the community that they can spend time with? For example: friends, family, or romantic partners.
    - ◊ If this person does not have other people in the community to spend time with, how can they meet new people?

- If this person was going to work a job or volunteer in the community, what would they want to do?
    - What kind of jobs or volunteer work has this person done in the past?
    - What has this person liked or not liked about past jobs or volunteer work?
- Is this person interested in going to school or college?
    - If the answer is yes, what would they be interested in studying?
    - How could going to school or college help them get more involved in their community?

Dealing with dangerous behavior.

Good behavior support services help people who do behaviors that really hurt them or other people. Good behavior support services help people who do behaviors that could get them in trouble with the police. These types of behaviors can be really dangerous for people who do them. These types of behaviors can really get in the way of people living the lives they want.

ASAN thinks it is okay for people to have goals around not doing these behaviors so much. But, we also know that these behaviors are often caused by things we already talked about. These behaviors are often caused by:

- Someone not getting their needs met.

  For example:

  > Amanda has a bad headache. Amanda does not use words to communicate. She mostly communicates through her behavior. Amanda tries hitting her head to tell people around her that her head hurts.
  >
  > Hitting her head could really hurt Amanda. She needs medical care. She needs better ways to communicate that she is in pain. If Amanda had those things, she would not hit her head.

- Someone having a mental health disability or trauma.

For example:

Sasha used to live in a big institution. When Sasha lived at the institution, other people would get up in his personal space. Other people would try to touch him when he did not want to be touched. Sasha has a lot of trauma from being in the institution.

Now, when anyone gets too close to Sasha, he pushes them away. Sasha has hurt people by pushing them too hard before. Sasha needs mental health therapy to help with his trauma. He needs other people to respect his personal space and not touch him. If Sasha had those things, he would not push other people.

- Someone not having other people in their community that they can form relationships with.

For example:

Yvonne lives in a group home. She only gets to go out into the community a couple times a month. Yvonne is really lonely. So she goes on the computer to try to meet people. Yvonne has gotten in trouble on the computer before. She keeps sending money to strangers on the computer she does not know. And she has sent naked photos of herself to strangers on the computer before.

Yvonne does these things because the strangers tell her that they will be friends with her if she does them. But the strangers on the computer are not really her friends. They are trying to hurt Yvonne. If Yvonne could make friends in her community, she would not spend so much time on the computer. She would not end up sending money or photos to strangers.

What ASAN thinks “dangerous behavior” is.

ASAN thinks behavior support services should help people who do dangerous behavior. **Dangerous behavior** is behavior that:

- Hurts the person doing the behavior badly.
- Hurts someone else around the person badly.
- Could really hurt the person doing the behavior or someone else if the behavior does not stop.
- Could get the person in trouble with the police if the behavior does not stop.

In this section, we talk about 5 types of dangerous behavior.

The 5 types are:

- Serious self-injury. Serious self-injury is when a person tries to hurt themself very badly.
- Physical aggression. Physical aggression is when a person tries to hurt someone else very badly. Physical aggression is also when a person behaves in a way that could really hurt someone else by accident.
- Pica. Pica is when someone eats a lot of something that is not food. For example, dirt or metal.
- Self-neglect. Self-neglect is when a person does not take care of themself to the point where they are in danger.
- Behavior that could get someone in trouble with the police.

We will talk about each of these types of behavior in more detail in this section.

Serious self-injury

Serious self-injury is when a person tries to hurt themself very badly. This can be a person trying to kill themself. It can also be a person hitting their head very hard. Or it can be someone cutting their skin with a knife.

Not all behavior that could possibly hurt the person is serious self-injury. To be serious self-injury, the behavior has to be able to really hurt the person badly. Someone lightly tapping a pencil against their head is not serious self-injury. A person biting their hand and leaving a mark, but not breaking the skin, is not serious self-injury.

To be serious self-injury, a behavior also has to not be typical in the community a person lives in. There are a lot of behaviors that could hurt someone but are typical within a community.

For example:

> Getting a tattoo. Getting a tattoo involves getting ink put in your skin with a needle. Getting a tattoo can really hurt. But lots of people get tattoos.Getting a tattoo is a typical behavior in lots of communities. Getting a tattoo is not serious self-injury.

Physical aggression

Physical aggression is when a person tries to hurt someone else very badly. Physical aggression is also when a person behaves in a way that could really hurt someone else by accident. Some types of physical aggression could be:

- Hitting someone.
- Kicking someone.
- Biting someone.
- Using a weapon to hurt someone.
- Breaking things someone else owns.

Behavior does not need to be on-purpose to be physical aggression. But behavior does need to have a serious chance of hurting someone to be physical aggression.

For example:

> Earlier in this part, we talked about Sasha. Sasha has a lot of trauma from living in an institution. When other people get close to Sasha, he pushes them away. Sasha can be really strong when he pushes other people away. He can hurt people by pushing them. Sasha does not mean to hurt other people. But he still can really hurt people by pushing them away.

Here is another example:

> Lindsey and Sue are having a pillow fight. They are gently hitting each other with pillows. When Lindsey or Sue get hit, they pretend to fall over. But they are not really hurt. Lindsey and Sue are not being physically aggressive. Just because they are having a pillow fight does not make it physical aggression.

IDD service providers also need to look at what happened before a person did a physically aggressive behavior. This is especially true in situations where providers use restraint and seclusion. People being restrained or secluded often react with physical aggression. This is because restraint and seclusion hurt the person. The person being restrained or secluded might hurt the person restraining or secluding them. The way to fix this is to get rid of restraint and seclusion.

Pica

Pica is when someone eats a lot of something that is not food. For example: dirt or metal. Pica is often caused by someone not getting enough vitamins and minerals they need from the food they eat.

For example:

> Mindy has pica. Mindy's pica makes her eat dirt from her front yard. Mindy has pica because she is not getting enough iron. Iron is a mineral people get from food. People need to eat iron in food in order to survive. If Mindy ate more foods with iron in them, her pica would go away.

Not all pica is dangerous behavior. Pica is only dangerous behavior when it causes a big risk to someone's safety. This could be like:

- Eating a lot of dirt. The dirt could get stuck in the person's stomach and block up the stomach.
- Eating sharp things that could pierce the person's stomach, like a sewing needle.
- Eating or drinking household chemicals that could hurt the person. For example, bleach or acetone.

Not all kinds of pica can really hurt someone. For example, some kinds of pica cause people to eat a lot of ice. Ice is just frozen water. Eating a lot of ice will probably not hurt a person. So, not all kinds of pica are dangerous behavior.

Self-neglect

Self-neglect is when a person does not take care of themself to the point where they are in danger. This can include:

- Not keeping themself or their living space clean.
- Saying no to services they need to live and stay safe, like health care or HCBS.
- Creating situations that could really hurt them. For example: leaving a bunch of paper that could catch fire next to the stove.

Self-neglect can be dangerous behavior if it puts the person at risk of getting hurt really badly. But not all self-neglect is dangerous behavior. And not every situation where a person does not take care of themself is self-neglect.

For example:

> Filip has depression. Filip finds it really hard to get out of bed and shower. Filip only takes a shower every other day. Filip's support worker does not like this. The support worker thinks Filip should shower every day. The support worker says that Filip is "doing dangerous self-neglect."
>
> But showering every other day is not putting Filip at risk of getting hurt really badly. He might be a little stinky. But that is not the same as getting hurt really badly.

People can do self-neglect for different reasons, like:

- Having a disability that makes it hard to do something.

  For example:

  Carl uses a wheelchair. Carl cannot stand up without help. Carl's house does not have a bathtub. It only has a shower. This makes it really hard for Carl to wash himself. He cannot stand up long enough to take a shower. Carl has not washed himself in weeks. He feels really dirty and gross. Carl's self-neglect is because the shower is not accessible to him.

- Being really lonely.

  For example:

  Jeanie lives alone. She rarely leaves her apartment. The only person she sees regularly is her neighbor. Jeanie has trouble keeping her apartment clean. She does not see a reason to keep her apartment clean. She never has anyone over. Jeanie's self-neglect is because she is lonely.

- Not knowing how to do something.

  For example:

  Bert has a disability called diabetes. Bert needs to check his blood sugar and give himself insulin shots. But Bert does not know how to do this. He does not understand the instructions his doctor gave him. Bert needs someone to show him how to check his blood sugar. He needs someone to show him how to give himself insulin shots.

- Big events that make someone sad or are traumatic.

  For example:

  Leonora has lived with her dad her entire life. Her dad dies of cancer. Leonora is sad and upset all the time. She just wants to lie in bed all day. She does not want to do the dishes or clean her apartment. Leonora is getting mice and cockroaches in her apartment. But she is too sad to get out of bed.

People need help with the things that cause their self-neglect.

Let's look at our examples:

- Carl needs a house with a bathtub or a wheelchair-accessible shower.
- Jeanie needs people to come over and help her clean her house.
- Bert needs someone to show him how to check his blood sugar and give himself insulin shots.
- Leonora needs someone to talk to about her dad dying.

Telling people who are doing self-neglect that they are gross will not help them. Telling people who are doing self-neglect that they need to take better care of themselves will not help them.

Behavior that could get someone in trouble with the police.

The last kind of dangerous behavior is behavior that could get someone in trouble with the police. This can include:

- Sexual assault. Sexual assault is doing sexual things with someone who has not said yes to those things. To learn more about sexual assault, you can read ASAN’s resource about sexual assault.
- Setting fires on purpose.
- Stealing things.
- Hurting people on purpose.
- Using some kinds of drugs.
- Telling someone you are going to something that breaks the law.

Not every behavior that breaks the law is dangerous behavior.

For example:

Jaywalking is crossing the street where there is not a crosswalk. In many places, jaywalking is against the law. But people rarely get in trouble with the police for jaywalking. Jaywalking might be dangerous for other reasons. Someone who jaywalks on a busy street could get hit by a car. But jaywalking is not dangerous behavior just because it is against the law.

“Dangerous behavior” means very specific things.

Not every behavior that could possibly hurt someone is dangerous behavior. Dangerous behavior means very specific things.

When someone’s behavior gets labeled “dangerous,” other people use that to force the person to change their behavior. Saying a behavior is “dangerous” often gets used to say someone needs to be restrained or secluded. Saying a behavior is “dangerous” often gets used to say someone needs to be in ABA or other behaviorist services.

“Dangerous behavior” is like the term “challenging behavior.” Both terms can be used to mean something very specific. But both terms can also be used to mean whatever the person using them wants them to mean.

Limiting what “dangerous behavior” means matters. If people call any behavior they do not like “dangerous,” “dangerous behavior” will mean nothing. Not all behavior that could possibly hurt someone is “dangerous behavior.” But a behavior does not have to be dangerous for a person to deal with the effects of doing a behavior.

For example:

> Jonas lives in a group home. Jonas gets mad at his housemate, Sandra. Jonas goes into Sandra’s room and rips all her posters off the walls. The group home staff tell Jonas he has to fix Sandra’s posters. He can use tape to tape the posters back together. Or he can buy Sandra new posters. Jonas is dealing with the effects of his behavior.

People can deal with the effects of their behavior.

In many cases, people should have to deal with the effects of their behavior.

But IDD service providers and support workers should not punish people with IDD extra for our behaviors.

For example:

Say Jonas and Sandra were housemates without IDD in a typical apartment. Jonas would still have to fix Sandra's posters. Sandra would have the right to be mad at Jonas. Jonas would still have to deal with the effects of his behavior. But nobody would say that Jonas would lose getting to eat dessert for a week.

If the group home staff said Jonas could not have dessert for a week, that would be an extra punishment. That would be unfair. Jonas can deal with the effects of his behavior without being punished extra.

What to do when someone is doing dangerous behavior.

IDD service providers need to think about what makes people with IDD have dangerous behavior. Dangerous behavior can have all the same causes as other types of "challenging behavior." Dangerous behavior can be because of:

- Needs that are not being met.
- Mental health disabilities or trauma.
- Not being part of the community.

IDD service providers must figure out *why* a person is doing a dangerous behavior. IDD service providers must figure out how to help the person with the needs that cause their dangerous behavior.

All behavior has a cause. All behavior happens for a reason. Sometimes, a person might not be able to control the reason for their behavior. Even if the person cannot control the reason for their behavior, service providers can still help them cope with their behavior. Service providers can still help the person find other ways to deal with what is causing the behavior. Service providers should still help the person find ways to deal with what causes their behavior. Service providers should not just try to get the person to stop the behavior.

For example:

> Darius has a mental health disability called obsessive compulsive disorder (OCD). OCD makes Darius feel like he has to count every object in the room he is in. If Darius cannot count all the objects in the room, he gets upset and hits his head. Darius does not have control over his OCD. He cannot make himself stop feeling like he has to count things.
>
> Darius talks to a mental health therapist. Darius and the therapist think of other ways he can deal with his need to count things. Darius decides to try a new strategy. When he cannot count the objects in a room, he will imagine some objects in his head. Then, he will count the objects in his head. Darius still cannot make his OCD go away. But he can find ways to cope with his OCD besides hitting his head.

Service providers need to work with people with “challenging behavior” or dangerous behavior to find what causes the behavior. This needs to happen if the person is going to stop doing the behavior permanently. Just telling the person to stop doing their behavior will not get them to stop for very long. Putting the person in services that try to get rid of their behavior without understanding it will not help for very long.

People do their best when they feel like other people respect them. People do their best when they feel like other people understand their needs. This is true of people with IDD, just like it is true of everyone else.

People with IDD who do dangerous behavior still have thoughts and feelings. We still have thoughts and feelings even if we cannot communicate them very clearly. We still deserve respect and care from others. Just ignoring us will not make our behavior go away. Telling us to stop our behavior will not make our behavior go away. Service providers need to figure out why we are doing a behavior. Service providers need to work with us to figure out other ways we can communicate what we need.

People with IDD who do “challenging behavior” or dangerous behavior still have dignity of risk. Dignity of risk is the idea that people have the right to make choices, even if those choices might have risks or end badly. We still have the right to harm reduction. Harm reduction is the idea that people can take steps to make a behavior less dangerous while still doing that behavior. For example, wearing a helmet when you ride a bike to protect your head if you fall.

Adults with IDD should have the same right to take risks as adults without disabilities. Children with IDD should have the same right to take risks as other children their age without disabilities.

IDD service providers and support workers should help people with IDD figure out if our behavior might be risky. IDD service providers and support workers should let people with IDD have choices about our behavior.

But IDD service providers and support workers should not say people with IDD cannot do something at all because it is risky. IDD service providers and support workers should help people with IDD figure out what risks we want to take. IDD service providers and support workers should help people with IDD find ways to make risky behaviors less risky.

People with IDD can have behavior that is:

- Challenging to us or people around us.
- Risky.
- Dangerous to us or people around us.

ASAN agrees that this happens. But ASAN does think that behavior support services will not get rid of behaviors without understanding what causes those behaviors. We think that trying to get rid of a behavior without understanding it will just end badly for the person with IDD. We think that trying to get rid of behavior without understanding it does not show respect for the person doing the behavior.

People with IDD have the right to:

- Respect from others.
- Care from others.
- Support from others.

We have this right even when our behavior is “challenging” or dangerous.

Behavior support services should not just try to get rid of “challenging” or dangerous behavior. Behavior support services should help people with IDD live the lives we want to live. Behavior support services should help people with IDD stay in the community. Behavior support services should help people with IDD meet the goals we set for ourselves.

Questions about dealing with dangerous behavior to help with writing goals for behavior support services

ASAN wrote some questions about dealing with dangerous behavior. The questions are for people with IDD and service providers to talk about. The answers to these questions can help people with IDD and service providers write good behavior support services goals.

In these questions, when we say “this person,” we mean the person with IDD. The questions are:

- Does this person do any dangerous behaviors?
    - ◊ If the answer is yes, what are the behaviors?
    - ◊ If the answer is yes, what makes the behaviors dangerous?
- How is this person treated by other people if they do dangerous behavior?
    - ◊ Do other people try to punish this person for their behavior more than a person without IDD would be punished?
- Why might this person do a dangerous behavior?
    - ◊ How can service providers and support workers help this person figure out the cause of the behavior?
    - ◊ How can service providers and support workers change how they help the person to work on the behavior?
- What changes to this person’s life might help them stop the dangerous behavior?
    - ◊ What services might help this person work on their dangerous behavior?
- Does this person have chances to take risks?
    - ◊ Has this person been told about harm reduction?
- Have this person’s support workers been trained on dignity of risk and harm reduction?

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

Part 9: Appendix B:
Tools to Help People With IDD and Our Supporters Know What to Do in a Crisis

Words to Know in Part 9

Appendix

An extra part of a toolkit that gives more information.

Communication

The different ways people tell each other information and ideas.

Community

A place where you can make choices about your own life. Communities can be places like neighborhoods, towns, or cities.

Crisis support plan

A document that helps people know what to do when someone has a mental health crisis. A crisis support plan talks about:

- What the person does when they are calm and happy.
- What the person does when they start to get upset.
- What the person does when they are in a mental health crisis.
- What things a person might do that look like a mental health crisis but are really not.
- What service providers and support workers can do to make mental health crises less likely.
- What service providers and support workers can do to help the person when they get upset.

- What kinds of things cause the person to get upset.
- How service providers and support workers can help the person stay safe during a mental health crisis.
- What people or groups in the community can help the person during a crisis.

Health care passport

A document that lists out information about someone's health care, such as the medications they take or how to contact their doctors.

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.

Mental health crisis

When a person is having thoughts or feelings that hurt them that they cannot control. During a mental health crisis, a person might try to hurt themselves or others.

Mental health 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.

Psychiatric advance directives

A way to plan for a mental health crisis that lets someone write down what they would or would not like to happen if they were in a mental health crisis.

Appendix B: Tools to Help People With IDD and Our Supporters Know What to Do in a Crisis

A **mental health crisis** is when someone has thoughts or feelings that hurt them. They might not be able to control these thoughts or feelings, and may try to hurt themselves or others. It can be hard for someone to **communicate** what they want and need during a mental health crisis.

People need help during a mental health crisis. Having a plan helps people stay safer during a mental health crisis. It helps people know what to do to support someone through a crisis.

This **appendix** is about tools to help people with IDD and our supporters plan for a mental health crisis. We found tools to help people plan for a mental health crisis. We have listed them here, and split them into 5 categories:

- Psychiatric advance directives.
- Tools to help plan for a mental health crisis.
- More tools to help plan for a mental health crisis. These tools are just for people with IDD and our supporters.
- Health care passports.
- Other tools.

Some of these tools were made by people with IDD and/or mental health disabilities. We marked these tools with an asterisk (*).

Psychiatric Advance Directives

Psychiatric advance directives are a way to plan for a mental health crisis. They let someone write down what they want and need, before a mental health crisis happens. That way, other people know what to do if a mental health crisis happens.

Someone can write things down like:

- Where they want to go for help.
- Who they want to help them.
- What kind of medical care they want or don’t want.
- When they want someone else to make choices for them.

Psychiatric advance directives are a legal document. That means, in most cases, doctors and mental health workers have to follow what a psychiatric advance directive says. Psychiatric advance directives make sure people listen when someone has a mental health crisis.

Here is a list of tools to help you make a psychiatric advance directive:

- Mental Health America: Creating a Psychiatric Advance Directive: https://www.mhanational.org/creating-psychiatric-advance-directive

  This is a tool by Mental Health America. It uses a step-by-step process to help someone make a psychiatric advance directive.

- National Resource Center on Psychiatric Advance Directives: https://nrc-pad.org/

  This website has information about making psychiatric advance directives in each state. You can click on your state to find out more information.

- SMI Advisor: My Mental Health Crisis Plan app: https://smiadviser.org/getmyapp

  This is an app by SMI Advisor that helps people make a psychiatric advance directive on their smartphone. This makes it easier for someone to always have their psychiatric advance directive with them.

Tools to help plan for a mental health crisis

- * Fireweed Collective: Crisis Toolkit: https://fireweedcollective.org/crisis-toolkit/

  This toolkit has links to many helpful pages that can help during a mental health crisis. The toolkit has information about:

  - ◊ Planning for a mental health crisis.
  - ◊ What to do if you feel like hurting yourself.
  - ◊ Where to call for help if you have a mental health crisis.
  - ◊ Different kinds of mental health medication.

- * Fireweed Collective: Madness & Oppression: Paths to Personal Transformation and Collective Liberation: https://fireweedcollective.org/publication/madness-oppression-paths-to-personal-transformation-and-collective-liberation/

  Oppression is when a group of people gets treated unfairly by others because of who they are. Oppression makes it so some groups of people get treated better than other groups. Oppression happens because one group gets more power than others.

  For example, people of color in the U.S. go through oppression because of their race. White people don't go through oppression because of their race. White people have most of the power in the U.S. That power gets used to oppress people of color.

This toolkit talks about how people with mental health disabilities get oppressed. It talks about how oppression makes people feel, and how to cope with feelings about being oppressed. The toolkit talks about fighting back against oppression.

- Mental Health Minnesota: Crisis Plan for Your Support System: https://screening.mhanational.org/content/worksheet-crisis-plan-for-your-support-system/

  This short tool is easy to fill out, and can help you plan for a mental health crisis. You can give a copy to your family or friends so they know how to help you during a mental health crisis.

- * Oakland Power Projects of Critical Resistance: SAGE Response to a Psychosocial Crisis: https://docs.google.com/document/d/1DFE6KTf6EZkURlGyBo30jLvpu2hAiM4BLSdgkG7Tdso/edit

  This is a guide for people who want to support someone else having a mental health crisis. The guide has information to help someone through a mental health crisis. It has tips to help stay calm and figure out the best way to handle an emergency.

- * Project LETS: Anti-Carceral Crisis Plan: https://drive.google.com/file/d/1cXgw_a30JMkuhN3KUiu_H5B_PKVzTE0c/view

  This tool helps keep people from going to jail or an institution because of a mental health crisis. It helps people plan so that police don’t need to step in during a mental health crisis. This tool helps people stay in the community while getting mental health support. This tool can help people make better choices during a mental health crisis.

- Wellness Recovery Action Plan: https://www.wellnessrecoveryactionplan.com/what-is-wrap/

  This is a longer tool to plan for a mental health crisis. It helps people make plans to stay well and have less mental health problems. It can help people plan out their day and figure out what things hurt their mental health. This tool can also help people figure out when a mental health crisis is coming, and how to get through it faster.

Tools to help plan for a mental health crisis. These tools are specifically for people with IDD and our supporters.

- Missouri Department of Mental Health: Crisis Safety Plan Assessment and Template for Plan: https://dmh.mo.gov/media/pdf/crisis-safety-plan-assessment-and-template-plan

  A safety plan is another tool to plan for a mental health crisis. They get made to fit each person who needs one. Safety plans lists things like:

  - ◊ What can cause a mental health crisis.
  - ◊ How to tell if someone is having a mental health crisis.
  - ◊ What to do to help with the mental health crisis.

  This tool lists what kinds of things should go in a safety plan. It also has empty safety plans to fill out. You can make your own safety plan.

- North Carolina Department of Health and Human Services: Crisis Prevention and Intervention Plan Training: https://www.trilliumhealthresources.org/sites/default/files/docs/Provider-documents/Crisis-Prevention-intervention-plan-training.pdf

  This is a tool for people that work with people with disabilities. It may be hard for people with disabilities to understand. This tool trains people on how to:

  - ◊ Know what to do if a mental health crisis happens.
  - ◊ Write a good crisis plan.
  - ◊ Help people with disabilities be a part of their crisis plan.

- Surrey Place Center: A Guide to Understanding Behavioural Problems and Emotional Concerns in Adults with Developmental Disabilities (DD) for Primary Care Providers and Caregivers: https://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/04/Guide_to_Understand_Bx_Probs-2.pdf

  This is a tool for doctors who help people with disabilities. It is also for family and friends who care for people with disabilities. The tool has checklists and flowcharts to go through. They can help people plan for a mental health crisis. Checklists make sure nobody misses anything important. Using flowcharts can help people know what to do next.

- Elspeth Bradley and Yona Lunsky/Surrey Place Center: Risk Assessment Tool for Adults with DD in Behavioural Crisis: https://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/03/Risk_Assessment_Tool.pdf

  This is a tool for people who care for people with IDD. It can help them figure out if someone they care for might have a mental health crisis. It helps plan out ways to keep people from hurting themselves or others.

- * Ambitious about Autism: What's Your 'Normal'? Toolkit: https://www.ambitiousaboutautism.org.uk/sites/default/files/youth-participation/toolkit/Ambitious-about-Autism-know-your-normal-toolkit.pdf

  This toolkit is for autistic people. But it can also help other people with IDD. Every autistic person is different. What is "normal" for one person might be different for someone else. This toolkit lets you list out what is "normal" for your life. You can list things like:

  - ◊ Your day-to-day routine.
  - ◊ Who you are closest with.
  - ◊ Your interests.
  - ◊ How you take care of yourself.
  - ◊ What your mood is usually like.

  This helps others know more about you. You could give a copy to your doctor. You could also give one to family or friends.

- * Ren Koloni, The Link Center: What To Do When I Don't Feel Okay: Big Ideas Guide: https://www.nasddds.org/wp-content/uploads/2023/11/What-To-Do-When-I-Dont-Feel-Okay.pdf

  This is a guide made by and for people with IDD. It is written in plain language. This helps more people understand the guide. This toolkit answers questions like:

  - ◊ What is a crisis?
  - ◊ Why does a crisis happen?
  - ◊ What is a crisis plan?
  - ◊ What should I think about when I make my crisis plan?
  - ◊ Who can help me?
  - ◊ What do I do if I do not know anyone who can help me?

Health Care Passports

It can be hard to remember all the information about your health, especially during a mental health crisis. Health care passports can make this easier. A **health care passport** is a paper or electronic document that lists out all the information about someone's health care.

A health care passport lists things like:

- Your name, birthday, and address.
- What medications you take.
- Your allergies.
- Your doctors and their contact information.
- What surgeries you have gotten.
- What helps you during a mental health crisis.
- And more!

Listing out this information can help your family, friends, and doctors. They will know where to look if they need to help you stay healthy.

Here are some tools to make your own health care passport:

- Melhas et al./Surrey Place Center: About My Health: Learning about the healthcare and communication needs of adults with intellectual and developmental disabilities: https://ddprimarycare.surreyplace.ca/wp-content/uploads/2021/03/5.1-About-My-Health-new.pdf

  This is a tool for people with disabilities. Doctors and family members can also use this tool. It lists out medical information about a person. It lists things the person wants others to know about them. It also says what doctors can do to make medical visits easier.

- Elizabeth Perkins/Florida Center for Inclusive Communities: My Health Passport: http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf

  This health care passport is called My Health Passport. It is one kind of healthcare passport that lets you list lots of different information. You can list things like:

  - ◊ Your name and birthday.
  - ◊ Your doctor’s name and phone number, and an emergency contact.
  - ◊ How you communicate best.
  - ◊ Your medical history, what medications you take, and your allergies.
  - ◊ What it looks like when you’re in pain or upset.
  - ◊ What kind of help you need in your day-to-day life.
  - ◊ Your favorite things and things you dislike.

- Virginia Department of Behavioral Health and Developmental Services: My Care Passport: https://dbhds.virginia.gov/wp-content/uploads/2022/09/DBHDS-My-Care-Passport-9.25.22.pdf

  This healthcare passport is called My Care Passport. It lets you list many of the same things as My Health Passport, but it also adds some other things like:

  - ◊ The people who know the most about you
  - ◊ The kind of home you live in
  - ◊ How others can help keep you safe
  - ◊ Who helps you make medical decisions
  - ◊ How you usually act on a normal day

My Health Passport also lets other people help fill it out. Doctors or other health care workers can add to it. That helps you and other people keep track of your health.

Other tools

- * Mia Mingus/Bay Area Transformative Justice Collective: Pods and Pod Mapping Worksheet: https://batjc.wordpress.com/resources/pods-and-pod-mapping-worksheet/

  Pods are groups of people who share a community. Or, that share the same ideas about how the world should work. People in pods can help each other. They can build their communities. Pods are a way to work together to make a better world.

  This tool can help you figure out who your pod is. Or, who could be in your pod. You can use the pod "map". That way, you can see what your pod looks like. It can help you think more about what you want your pod to become.

- * Autism Society of Minnesota: What is Pod Mapping?: https://ausm.org/wp-content/uploads/2021/11/Pod-Mapping.pdf

  This is an adapted version of the pod mapping resource we just talked about. This resource has more information to help people with IDD do pod mapping. This resource uses simpler language than the first pod mapping resource.

- Oregon ISP: One Page Profiles: https://oregonisp.org/1ppa/

  One page profiles are a little like health care passports. But they are shorter than health care passports. And they talk less about health. One-page profiles have information like:

  ◊ What people like about you.

  ◊ The things that are important to you.

  ◊ Ways other people can help you.

  This website lists out the parts of a one-page profile. It also has examples of one-page profiles. And it has empty profiles you can fill out yourself.

- Parents Helping Parents: Introduction to One-Page Descriptions: https://www.php.com/elearning/introduction-to-one-page-profiles/

  One-Page descriptions are another kind of one- page profile. This website has lots of different profile templates. You can use them to make your own one-page description.

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Part 10:
Words to Know

Words to Know in this Toolkit

988 Lifeline

A group of mental health crisis service providers people can reach by calling or texting 988. The 988 Lifeline will send the call or text to a local mental health crisis service who can help the person.

Abuse

Hurting someone or treating them badly as a way to control them.

Accommodations

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

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.

Antipsychotics

A type of mental health medication that treat psychosis.

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.

Augmentative and alternative communication (AAC)

Ways of communicating other than speaking with your mouth or using a sign language. AAC includes things like writing, pointing to letters and words, or typing words on a computer.

Behavior

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

Behavior support services

Services that help people deal with behavior that makes it hard for them to live the lives they want.

Behaviorism

A way of thinking about human behavior that says we should only think about the behavior we can see. Behaviorism focuses on changing a person's behavior but not on the person's thoughts or feelings. ABA is part of behaviorism.

Block treatment

When a group of people with disabilities all get the same services, even if they have different needs and wants.

Burnout

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

Centers for Medicare and Medicaid Services (CMS)

The part of the U.S. government that runs Medicaid on the national level. CMS makes rules that all state Medicaid programs have to follow.

Challenging behavior

A term some people use to talk about behavior that makes it hard for a person to live the life they want.

Chronic illnesses

Illnesses that last a long time, like cancer or diabetes.

Coercion

Trying to change someone’s behavior, even if that person does not want to change their behavior.

Communication

The different ways people tell each other information and ideas.

Community

A place where you can make choices about your own life. Communities can be places like neighborhoods, towns, or cities.

Community living

When people with disabilities live in the same places as people without disabilities.

COVID-19

A bad disease that has spread around the world and made a lot of people very sick. COVID-19 has made it hard for people with disabilities to get good services.

Crisis respites

Houses or apartments where people can stay for a few days until a mental health crisis has passed. Crisis respites often have services like support workers or therapy groups.

Crisis support plan

A document that helps people know what to do when someone has a mental health crisis. A crisis support plan talks about:

- What the person does when they are calm and happy.
- What the person does when they start to get upset.
- What the person does when they are in a mental health crisis.
- What things a person might do that look like a mental health crisis but are really not.
- What service providers and support workers can do to make mental health crises less likely.
- What service providers and support workers can do to help the person when they get upset.
- What kinds of things cause the person to get upset.
- How service providers and support workers can help the person stay safe during a mental health crisis.
- What people or groups in the community can help the person during a crisis.

Dangerous behavior

Behavior that:

- Hurts the person doing the behavior badly.
- Hurts someone else around the person badly.
- Could really hurt the person doing the behavior or someone else if the behavior does not stop.
- Could get the person in trouble with the police if the behavior does not stop.

Data

Facts and information about something.

Deinstitutionalization

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

Diagnostic overshadowing

When doctors blame medical problems a person with IDD has on the person’s disability.

Dignity of risk

The idea that people have the right to make choices, even if those choices might have risks or end badly.

Dual diagnosis

When someone has both an IDD and a mental health disability.

Environment

The different places a person lives, works, and plays in.

Food insecurity

When someone does not have enough food to eat and does not have money to buy more food.

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.

Hazard

Something that could hurt people. Common household and community hazards are household chemicals, furniture and large appliances, and wet or icy surfaces.

HCBS Settings Rule

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

HCBS workforce crisis

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

Health care passport

A document that lists out information about someone's health care, such as the medications they take or how to contact their doctors.

Home and community based services (HCBS)

LTSS someone gets in their home or in the community.

Homeless

When someone does not have a long-term place to live.

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.

Medically underserved population

A group of people who do not have enough access to health care.

Mental health crisis

When a person is having thoughts or feelings that hurt them that they cannot control. During a mental health crisis, a person might try to hurt themselves or others.

Mental health crisis services

Services that are supposed to help people who are dealing with emotions or behavior that hurt them that they cannot control.

Mental health disabilities

Disabilities that change how people think and feel. Mental health disabilities can make it hard for people to feel in control of their emotions.

Mental health services

Services that help people with mental health disabilities deal with their emotions and live in the community.

Mental health therapy

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

Occupational therapy

A service that helps people learn and practice skills they need in their everyday lives.

Olmstead v L.C.

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

Operant conditioning

Changing someone’s behavior using rewards and punishments.

Peer support

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

Peer worker

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

Person-centered planning

A way of figuring out what services might help a person live the life they want to live. Person-centered planning asks about a person’s needs, wants, hopes, and goals. Then, the person-centered planning team figures out services might help the person get those things.

Physical therapy

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

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.

Prevent

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

Preventive health care

Health care that can prevent, or stop, medical problems from happening or getting worse.

Primary care doctor

A doctor you see for regular, general health care, like getting shots or when you have the flu.

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.

Psychiatric advance directives

A way to plan for a mental health crisis that lets someone write down what they would or would not like to happen if they were in a mental health crisis.

Psychology

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

Psychosis

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

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.

Researchers

People who do research as their jobs.

Restraint

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

Reward

Something a person gets for having “good behavior.”

Seclusion

Locking someone in an empty room.

Secondary trauma

When someone has trauma from seeing someone else go through a really stressful experience

Self-direction

An option that some people who get HCBS through a waiver use. Self-direction lets a person design and run the HCBS they get.

Speech therapy

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

Support workers

People whose job it is to help people with IDD in our homes and in the community. Support workers are sometimes called direct support professionals.

Survey

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

Symptoms

Signs that a person has an illness or disability.

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.

Trauma-informed care

A way to provide services to people with trauma. Trauma-informed care focuses on not making people's trauma worse. Trauma-informed care helps people work through their trauma.

Turnover

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

Vacancy

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

Voluntary

When the person getting services chooses to get the services. If the person is forced or coerced into getting services, the services are not voluntary.

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.

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