

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 themselves. 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 themselves. 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 themselves 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 themselves 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:

Jarrold has an intellectual disability. He also has a mental health disability called alcohol use disorder. Jarrold used to drink too much alcohol. He would keep drinking alcohol all the time. Drinking too much alcohol caused Jarrold a lot of physical and mental health issues.

Now, Jarrold no longer drinks alcohol. Jarrold’s support worker wants to help make sure that Jarrold will not drink alcohol. So Jarrold’s support worker says that Jarrold 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.

Jarrold's support worker is trying to help Jarrold. But they are not letting Jarrold have all his rights. Jarrold has the right to go places in the community that serve alcohol. Just because the situation is risky for Jarrold 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:

- **Safe:** Support workers should make sure the person having the mental health crisis is safe.
- **Calm:** Support workers should keep calm. They should let the person know that it is okay to have a crisis and that they are safe.
- **Affirmation:** 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.
- **Routine:** 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.
- **Empathy:** 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.
- **Develop 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 themselves 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 themselves 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 themselves very badly. This can be a person trying to kill themselves. 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 themselves to the point where they are in danger. This can include:

- Not keeping themselves 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 themselves 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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