



Plain Language Edition

For Whose Benefit?

Evidence, Ethics, and Effectiveness of Autism Interventions

To Start

This toolkit will talk about different autism services. It will talk about whether those services are good or bad and how you can tell if a service is good or bad.

This toolkit will answer questions like:

- What are different kinds of autism services?
- What makes an autism service good?
- What makes an autism service bad?
- What do autistic people think about different autism services?
- What should autism service practitioners do better?
- What should people who study autism services do better?

Why did ASAN do this project?

We know that more people know about autism and more people are getting diagnosed with autism than in the past.

There are a lot of services for autism. **Services** are programs that try to help autistic people. In this toolkit, we also call services “therapies.” Some services don’t help autistic people and some services even hurt autistic people.

Not many people study whether these services help autistic people. When people do study autism services, they usually don’t include autistic people. Autistic people usually don’t get to help with making new autism services or studying autism services.

ASAN is a group of autistic people. We work on disability rights. ASAN wanted to know what kinds of autism services there are and what autistic people think about different autism services.

One of the most popular autism services is **Applied Behavioral Analysis (ABA)**. ABA focuses on changing how autistic children act. ABA wants autistic children to look and act like they are not autistic. It teaches autistic children to hide the things that make them “look” autistic. ASAN thinks ABA is a bad service that hurts autistic people.

ABA teaches autistic children to hide the things that make them look autistic, which is sometimes called “masking.” People have done studies on masking that found that masking makes autistic adults more likely to feel bad. Masking makes autistic adults more likely to hurt ourselves or want to kill ourselves.

We also know that ABA wants to make autistic children look “normal.” It isn’t good at helping autistic children with skills that will help them in life.

ASAN thinks ABA is a bad service. A lot of autistic people think ABA is a bad service. We think that nobody should ever use ABA. But we also have other problems with autism services. We think other services can be bad, too, and we want people to be careful with other services, too.

What did ASAN do for this project?

ASAN wanted to know what autistic people think about different services, so we read what autistic people have written about services. We read things from autistic people of a lot of different backgrounds. We read things from autistic people who have gone through different services.

We also wanted to know what evidence there is for different services. **Evidence** is facts that show something is true. You get evidence from studying something. We looked at studies about services.

Most of these studies weren’t done by autistic people, but some of the studies were.

What did ASAN talk about in our report?

Good and bad evidence

We talk about how good or bad the evidence for different services is. The evidence for a lot of services is not good! The evidence says that those services don't work and that the services don't help autistic people. Or, sometimes, the evidence says that the services do work, but the evidence says that those services don't help very much.

Studies done badly

We talk about how a lot of studies of autism services were done in bad ways. The people who did those studies didn't treat autistic people right. They might have hurt the autistic people they were studying. Some studies did not hurt the people they were studying, but the science still was not good, so the evidence from those studies isn't good.

Things we don't like in autism services

We talk about things we don't like about autism services. We talk about how a lot of autism therapies try to make autistic people "normal," but that's not the only thing we don't like about a lot of services.

Practitioners don't respect us

We also don't like how a lot of practitioners don't respect autistic people. A **practitioner** is someone who gives a service to autistic people. Sometimes, practitioners don't respect our bodies. They touch us when it's not needed for the service. That's wrong.

Services say autistic behavior is bad behavior

We don't like how some services say that the way autistic people act is wrong. Sometimes, an autistic person will do the same thing as a non-autistic person. A bad service will say the non-autistic person's behavior is okay, but the service will say the autistic person's behavior isn't okay. That's wrong.

Services can hurt us

Some services affect autistic people badly. They do things to us like have practitioners yell at us, force us to do things we don't want to do for no good reason, or say we're not allowed to stim. Services shouldn't hurt us or treat us badly. We should get better services and services that help us.

Things we don't like in ABA specifically

We also talk about ABA specifically. ABA is one of the most popular autism services. A lot of autistic people go through ABA. ABA is a bad service that hurts autistic people. It can't help autistic people, even if it tries to.

We wrote 3 reasons why we don't like ABA.

ABA hurts autistic people really badly

ABA has been around for a long time. It used to do really bad things to autistic people.

It would hurt us by doing things like not giving us food, having people scream at us, and shocking us with electricity. Some people who practice ABA still do this. That's wrong. It hurts autistic people. That should never happen.

ABA is connected to conversion therapy

Conversion therapy is trying to change someone's gender or sexuality. Conversion therapy happens mostly to gay, lesbian, bisexual, and transgender people. It tries to make them not be gay, lesbian, bisexual, or transgender. Conversion therapy is wrong. Nobody should ever do it.

A lot of autistic people have called ABA "autistic conversion therapy." They say ABA tries to make autistic people not be autistic and that it is a kind of conversion therapy.

ABA was invented by a man named O. Ivar Lovaas. He also did a study about conversion therapy. The study was on a young boy who Lovaas said "acted like a girl." Lovaas used ABA to punish the boy. He thought this would keep the boy from being gay when he grew up. Lovaas did this because he thought being gay was a bad thing.

ABA and conversion therapy come from the same ideas; they both use rewards and punishments to try to change who a person is.

ABA sees autistic people as less than human

ABA treats autistic people like we're not human. It doesn't think about our emotions. ABA tries to change what we do. It doesn't care about why we do the things we do. ABA hurts autistic people this way.

Two arguments we hear a lot about autism services

ASAN hears a lot of arguments about autism services. We chose 2 that we wanted to talk about. These arguments didn't fit in the other sections, but they are still important to talk about.

“New ABA” is not okay

Sometimes, people will say that “new ABA” is okay. “New ABA” is a type of ABA. It is like old ABA. It still tries to make autistic people “less autistic.” It just does this in different ways from old ABA. But new ABA is still bad because it still hurts us. People might not be able to tell it hurts us. New ABA can hurt us in sneaky ways that other people can't see easily. New ABA is still wrong because it is still like the old ABA. ASAN doesn't like “new ABA.”

Be careful with all services

ASAN wants people to be careful of all autism services. Some services, like ABA, are always bad. A lot of services can sometimes be good, but they can also be bad sometimes. We don't think any service is always good. We want people to look closely at services. We want them to make sure the services are doing a good job.

Core principles for autism services

We wrote a list of things we want autism services to remember. We call these “core principles.” Core principles are things that autism services need to know in order to do a good job.

We know that there are a lot of services out there. We couldn't write core principles for every one. So we wrote our core principles as broadly as possible. We wanted them to apply to as many services as possible. We don't want to focus on just one kind of service.

5 questions to ask to see if a service is good or bad

We wanted to help people figure out if a service is good or bad, so we wrote 5 big questions. These aren't the only questions people should ask about a service. These questions can't tell you everything about a service, but they are a good starting point. They can tell you some things about whether a service is good or bad.

1. What are the goals of the service? Who comes up with those goals? Does the autistic person get to come up with their own goals?
2. What does the service believe about autism? Why does it target a specific skill or behavior?
3. Who gets the most out of the service? What do various people involved in the service get out of it? These can be people like, the autistic person, their parents/family, or their support people.
4. Would you say this service was okay if it happened to a non-autistic person?
5. What could happen in the future if the autistic person has this service? What could happen in the future if the autistic person doesn't have this service?

Things all practitioners need to know from the very start.

These are things we want all practitioners to know from the very start. A service can't be good or helpful without these things.

Autistic people are people.

We have feelings, thoughts, wants, needs, and dreams, just like non-autistic people do. Our lives are different from non-autistic people's lives, and that's okay. Our lives are still important. People should care about our lives. Our lives are worth living.

We have trouble with things non-autistic people don't. But we are still humans and we still have rights. Autism is not a reason to hurt us. It is not a reason to put us into bad services.

Autistic people's lives are important.

That's true of all autistic people.

It's true of:

- Autistic children
- Autistic adults
- Autistic people of color
- Autistic women
- Autistic non-binary people
- Autistic people with intellectual disabilities
- Physically disabled autistic people
- Autistic people with mental health disabilities
- Autistic people who went through restraint or seclusion
- Autistic people who have lived in an institution
- Autistic people who went through services they didn't want

It is true of all autistic people.

It is not okay to hurt any autistic person.

Sometimes people say it's okay to hurt autistic people. They say it's okay because we're autistic, or, they say that it's okay to hurt certain autistic people. That is not true. It is not okay to hurt any autistic people, just like it is not okay to hurt anyone.

Other people shouldn't say we have to change our autistic traits.

Autistic traits are things that are part of being autistic.

Some examples of autistic traits are stimming, not making eye contact, or needing extra time to make a choice. Just because something is an autistic trait does not make it bad. It does not mean that trait needs to be changed. It's not okay to try to change our autistic traits.

Autistic people are people too. We don't need to be "less autistic."

Autistic people don't exist all by ourselves. We live in the same world as everyone else. We see other people every day. What those other people do affects us.

Sometimes we have problems with other people. Other people shouldn't say it's always our fault. The other people should help us fix the problem.

Sometimes we don't agree with other people about something. This isn't always a problem. People can disagree! Being autistic does not mean we always need to agree with people.

Autistic people have the right to say "yes" or "no" to a service.

We have the same right non-autistic people do. This is called **giving informed consent**. We have the right to learn about the services we get.

Sometimes autistic people can't give informed consent. For example, children can't give informed consent, because only adults can give informed consent. But people who can't give informed consent can still say "yes" or "no." This is called **giving informed assent**. Everyone should have the chance to say "yes" or "no."

Services should focus on making autistic people's lives better.

They should focus on the goals the autistic person has. They should focus on giving the autistic person more chances for:

- **Self-determination**, or making your own choices
- **Communication**, or the different ways people talk to each other
- Self-advocacy

Practitioners should ask autistic people what goals we have. Then, they should help us meet those goals.

Sometimes, we might not be able to share our goals. Say an autistic person doesn't have a way to communicate yet. They might not be able to share their goals. In that case, the practitioner should look at the person's life. They should look at what the autistic person needs most. They should look at what the autistic person is good at. Then they should make their best guess about the autistic person's goals.

Sometimes, other people might have to set goals for us. We might need to work on skills to keep us safe. In these cases, people should tell us why they are setting the goal and what the goal will help with. They should make sure we have as much control over the goal as possible.

For example:

Marco has to cross the street to get to school. Every day, he runs into the street. He nearly gets hit by a car. Marco could get really hurt! So his teacher wants to help him learn to cross the street safely. Marco doesn't want to learn to cross the street. But he needs to so he doesn't get hurt. Marco's teacher tells him, "I don't want you to get hit by a car. Let's practice using the crosswalk. Then, cars will see you coming." Marco's teacher helps him use the crosswalk. They take breaks whenever Marco needs them.

Autistic children do well when they have the help they need to do well.

They are just like non-autistic children in this way.

- Autistic children do well when adults:
- Speak to them with words they can understand
- Give them lots of attention
- Support their communication
- Do things they enjoy together
- Give them lots of love and support

It is really important that adults do these things, but that isn't the same as "treating" autism. An autistic child who gets these things might look happier or do better in school, but that doesn't mean they're less autistic. They're just showing what they can do with the right help.

Autistic people are like non-autistic people in a lot of ways.

We know a lot about how humans work in general. We know autistic people are like non-autistic people in a lot of ways. Services should use what we know about humans in general. Services should know that autistic people can do a lot of things if we have the right support. They shouldn't treat us like we're totally different from non-autistic people.

Autistic people don't need to be in "autism-only" services.

A lot of the time, autistic people get put in services that are only for autistic people. These services don't serve any non-autistic people. But services don't need to be just for autistic people to help us. Autistic people can learn from lots of services that help other disabled people.

For example:

Joaquim is autistic. He has a lot of trouble with handwriting and his handwriting is really hard to read. Joaquim goes to an occupational therapist. The occupational therapist usually works with people with other disabilities, but they help Joaquim too. They show him how to hold a pencil so it's easier for him to write.

Autistic people can also learn from services that are designed for non-disabled people.

For example:

Malak is an autistic adult. She wants to learn how to drive a car. There is a driving school in Malak's town. They teach all kinds of people to drive. They aren't just for disabled people. Malak calls the driving school and sets up driving lessons. The school teaches Malak to drive.

Our hobbies shouldn't be turned into services.

Autistic people have a lot of different things we like to do, a lot of different special interests, and a lot of different hobbies.

A lot of times, practitioners will try to turn the things we like to do into “services.” They shouldn’t do that. We should be able to do the things we want to do. We should be able to have fun. Having fun doesn’t have to be a service.

For example:

Hanna likes to go swimming every weekend. Her therapist notices this. The therapist writes in Hanna’s service notes that she goes to “swimming therapy” on the weekends, but just because Hanna likes to go swimming, it doesn’t make it swimming therapy.

What a service calls itself is not as important as what it actually is.

Services go by a lot of different names. Sometimes a bad service, like ABA, will call itself something else so people will think it’s a good service.

Some health insurance will only pay for ABA for autistic people. They won’t pay for other kinds of services, so a good service might call itself ABA so it can get paid, but it’s still not ABA.

We want people to know that what name a service has doesn’t always tell you if it’s a good or bad service. We want people to look closely at the different parts of the service. We want them to decide whether a service is good or bad after looking at it closely.

Things we want more services and practitioners to do

Know that autistic people have a lot of trauma.

Sometimes people are in scary situations that hurt them. After this happens, it can change how the person thinks and feels. Those changes are called **trauma**. Trauma can last a long time.

Practitioners should know that many autistic people have a lot of trauma. They might have to do things differently because of our trauma. They shouldn't make our trauma worse. They should help us get better from our trauma.

Know about autistic people's backgrounds.

Autistic people come from lots of different backgrounds. There are autistic people of all races, genders, religions, and from all different countries.

Practitioners should know this. They should know that our backgrounds affect us. They should give us services in ways that work for us. They should care about our backgrounds.

Make sure we always have a way of communicating that other people can understand.

Autistic people should always have a way to communicate. This way should let us say whatever we want to say! It shouldn't only let us say what other people want us to say.

Some autistic people are **non-speaking**, meaning they can't talk with their mouths. That is okay. They should be given another way to communicate.

Some other ways of communicating are:

- Typing on a computer. The computer speaks what the person types.
- Pointing to pictures on an iPad.
- Writing messages on a whiteboard.

Good services also use the language the autistic person uses.

For example:

Gigi is autistic. Gigi's family speaks Spanish at home. Gigi is more comfortable speaking Spanish. She has a hard time speaking English. Gigi goes to occupational therapy. The therapist speaks to her in Spanish. Gigi's therapist is doing a good job!

Give us time and space to move our bodies

Give us time and space to move around, stim, take breaks, and feel comfortable in the space.

Tell us it's okay to say if something is wrong.

Practitioners should tell us that we can say something is wrong in many ways, like using words, crying, pointing, or walking away.

Ask us what our goals are for the service.

Practitioners should include us as part of the team that plans out the service.

For example:

Zippy is 14. He is autistic. Zippy gets services through his school. Zippy's parents and teachers meet once a year to talk about the services he gets. They always invite Zippy to the meetings. They ask Zippy what his goals are. They talk with him about how his services could help with his goals. Zippy's parents and teachers are doing a good job!

Presume competence

If we get the right help, autistic people can learn, think, communicate, and do new things. Practitioners should know this. Knowing this is called "**presuming competence.**" Practitioners should presume competence.

Good services look at what help autistic people need to do these things. Good services don't assume we can't do something just because we need help with it.

Limit how much time the practitioner is touching the autistic person.

Some services do need touch in order to work, but the person giving the service shouldn't touch us more than they need to, and they should always ask if it's okay before they touch us.

For example:

Halley is autistic. They have a lot of trouble holding things without dropping them. Halley goes to physical therapy. The physical therapist wants to show Halley another way to hold a cup. The physical therapist asks "Halley, is it okay for me to move your fingers so you can hold the cup?"

Halley says, "Okay!" The physical therapist is doing a good job.

Figure out when something around the autistic person needs to change.

Autistic people live in the same world as everyone else. The world we live in affects us. The people around us affect us. When we get upset, something around us might need to change.

For example:

Jacques is autistic. Every weekend, their neighbor mows the lawn on Saturday morning. The lawnmower is really loud. It makes Jacques have a meltdown.

Jacques has soccer practice on Sunday mornings. They won't be home when they have soccer practice. So Jacques asks their neighbor if the neighbor can mow the lawn on Sunday mornings instead. The neighbor says yes. They mow the lawn while Jacques is at soccer practice. Then, Jacques doesn't have meltdowns when the neighbor mows the lawn.

Figure out when a problem could be solved by giving the autistic person assistive technology.

There are lots of kinds of assistive technology that help people with disabilities live more independently. Some examples are wheelchairs, hearing aids, communication devices, and stim toys.

For example:

Isak is autistic. When they get nervous, they chew on their shirt. All of Isak's shirts have holes in them. Isak wants to find a way to stop chewing their shirts. Isak's therapist sees this. The therapist gives Isak a stim toy to chew on instead. Isak chews on the stim toy. They don't chew on their shirts anymore. The therapist is doing a good job!

Focus on specific skills instead of just "autism."

Services should say exactly what they're helping with. No service can help with all the parts of being autistic, so services should focus on specific things.

For example, an autistic adult could go to services to learn how to drive a car, get help finding a job, or figure out how to hurt themselves less when they get upset.

Ask "is this a problem that needs an autism-specific service?"

Many problems can be solved with services that aren't just for autistic people.

Make sure that when autistic people have problems, it's not because we need to see a doctor.

Sometimes, autistic people act differently when we have health problems. Before practitioners work with us on a problem, they should make sure it is not a health problem. They need to make sure we see a doctor if we are having health problems.

For example:

Joshua gets bad headaches. Every time he gets a headache, he curls up into a ball and cries. His headaches can last for hours or even all day. Joshua's therapist thinks he might be having headaches. She does not try to make Joshua stop crying. She sends Joshua to a doctor. The doctor says Joshua is having headaches. The doctor gives Joshua medicine to help with his headaches. Joshua stops having bad headaches. He stops curling up into a ball and crying when he has headaches. Joshua's therapist did the right thing!

Have services in places where autistic and non-autistic people are together.

Autistic people shouldn't have to go to a separate place where there are only other autistic people.

Let the autistic person choose where they want to have services.

For example:

Kelsey is autistic and has speech therapy every Tuesday. Kelsey's therapist lets Kelsey choose where they meet. Sometimes they meet in the therapist's office, or at Kelsey's house, or at the park. Kelsey's therapist is doing a good job!

Not use functioning labels.

Functioning labels are calling someone “high-functioning” or “low-functioning.” An example of a functioning label is saying someone is “low-functioning” because they can’t speak, or saying someone is “high-functioning” because they have a job. Functioning labels hurt autistic people. They don’t actually tell people what we need help with. Practitioners should say exactly what we need help with instead.

For example:

Darica is autistic and has an intellectual disability. She doesn’t speak. Darica’s therapist doesn’t say Darica is “low-functioning.” Instead, the therapist says that Darica is autistic and has an intellectual disability. The therapist also says Darica communicates by pointing to pictures. Darica’s therapist is doing a good job.

Say what autistic people are good at!

Practitioners should help us find out what we are good at. Then, practitioners should help us do those things more. Practitioners should connect their service to our interest. This can help us find the service more enjoyable.

For example:

Tomas goes to physical therapy. He thinks physical therapy is really boring. Tomas really likes superheroes. So his physical therapist names each therapy exercise after a superhero. Tomas thinks that is cool. He starts to like physical therapy more.

Know that everyone grows up differently.

A lot of times, practitioners talk about how autistic people grow up “more slowly” than non-autistic people, or they say that autistic people with intellectual disabilities don’t grow up at all. This is wrong! All people grow up differently. All people learn to do different things at different times in their life. Some people may need more time to learn to do something, but that doesn’t mean they don’t grow up.

Things we don't want any services or practitioners to do

Say something an autistic person does is bad, even if everyone does it.

For example:

Anushe is 15. She is autistic. Anushe loves to play video games. She wants to play them after school and all day on the weekends. Anushe's therapist says that this is bad. The therapist says wanting to play video games all day is because of autism. The therapist says Anushe shouldn't do that. But lots of 15-year-olds like playing video games! Lots of non-autistic people want to play video games all day! Anushe's therapist is doing a bad job. The therapist shouldn't say Anushe is wrong for doing something people her age do.

Say a behavior is good or bad based on whether most people do it.

For example:

Mikael is 18. He likes to watch cartoons on TV after school. Mikael's therapist doesn't like this. The therapist says Mikael should be watching more "grown up" shows, like sports. Mikael's therapist tells Mikael he has to work on watching more "grown up" shows. This isn't okay! Mikael should be allowed to watch cartoons if he wants to.

There are some skills people usually learn at a certain age. For example, most children learn to read when they are about 5 or 6 years old. Autistic children can learn to read at 5 or 6 years old, too. We're not saying autistic people shouldn't learn skills when other people their age do, but autistic people shouldn't have to do things only because other people their age do.

It is good for children to learn how to read. Reading is important. Autistic children need to know how to read. But autistic people don't need to watch sports just because other people watch sports.

Say that there is only one way for people to learn to do something.

People learn in lots of different ways. This is true of autistic people and of non-autistic people.

Most people learn some skills in a certain way, but that doesn't mean the way they learn skills is the best way. Other ways of learning skills are just as good.

For example:

Julienne, Liam, and Adela all want to learn how to bake a cake. Liam and Adela find a cookbook. They look up a recipe. Then they follow the recipe to bake a cake.

Julienne has trouble following written recipes, so she looks up a recipe video online. She watches the video. She has trouble with one of the steps, so she asks Adela for help. Adela helps Julienne. Then Julienne bakes her cake.

Julienne learned to bake a cake differently from Liam and Adela, but she still learned to bake a cake. Julienne's way is still just as good.

Say that because someone cannot speak, it means they cannot think.

Or, saying because someone can't show what they're feeling, it means they don't have feelings.

Everyone can think! Everyone has feelings! Autistic people might not be able to speak. We might have a hard time showing how we feel, but that does not mean we can't think or that we don't have feelings.

People shouldn't assume what we think or feel based on if we can speak. They shouldn't assume what we think or feel based on if we show our feelings.

Teach autistic children to think that their ideas are always wrong.

Autistic people sometimes have trouble knowing what to do in a social situation. For example, we might not know what to do at a party. A lot of bad services teach us to ignore our feelings in these situations, or they teach us that what we think in these situations is always wrong.

Bad services teach us that what non-autistic people think is always right. They teach us that we always need to do what non-autistic people do.

Punish autistic people differently from non-autistic people for the same thing.

Autistic people often get in trouble for things non-autistic people don't. This happens even if both people do the same thing!

For example:

Morgan and Kalla are both in the same class at school. Morgan is autistic. Kalla is not autistic. They both say the same swear word. The teacher hears both of them. The teacher tells Kalla “don’t say that word, please.” The teacher sends Morgan to the principal’s office. Morgan got in more trouble than Kalla, even though they did the same thing! This isn’t okay.

Focus on “social skills” instead of skills the autistic person wants to learn.

A lot of the time, autism services focus only on “social skills.” **Social skills** are skills that have to do with getting along with other people. Social skills are important, but they’re not the only kind of skills that people need.

A lot of the time, autism services only focus on social skills. They don’t focus on other skills. This can hurt autistic people.

For example:

Harli is autistic. They have a lot of trouble taking the bus to work. The bus is really loud. It hurts Harli’s ears. And they have trouble remembering the different steps to getting off the bus. A social skills service wouldn’t help Harli. They don’t need help with talking to other people. That’s not why they have problems on the bus.

Sometimes, autistic people need help with social skills, but we also need help with other skills, too. Services need to help us with other skills.

For example:

JP is autistic. He wants to apply for a job. A social skills service might help JP. Learning about getting along with people can help with jobs. But JP also needs help applying for the job. A social skills service wouldn't help him with that. He needs a service that can help him with applying for the job, like a job coach.

Teach autistic people to “act non-autistic” instead of helping us handle different social situations.

We might need help in social situations. We might not know what to say in social situations.

There are ways to help us with this, but those ways shouldn't say that being autistic is wrong in social situations. A lot of bad services say that if someone looks autistic, they're doing a bad job. That's not true.

Social skills services shouldn't train us to look non-autistic. They should give us tools to help us self-advocate. They should give us tools to help us make decisions in social situations.

Some social skills services focus on specific situations or types of skills.

These could be services like a sexual education class, a job interview skills workshop, or a class about healthy ways to disagree with friends. We think these kinds of services are okay. We think autistic people and non-autistic people should be in them together.

Have a goal of making autistic people look and act non-autistic.

Some bad services have a goal of making autistic people act “normal.” They want us to seem like we are not autistic. This hurts autistic people. It teaches us that being the way we are is bad.

Have a goal of making someone stim less.

Autistic people should be able to stim as much as we like. Other people shouldn't stop us from stimming. If a service tries to force us to stop stimming, it is a bad service.

There are some cases where someone might want to stop stimming as much. These cases don't happen that often.

For example:

Marion is autistic. She is non-speaking. She communicates by typing on an iPad. Marion stims by hitting her iPad over and over again. She isn't typing on it when she stims. Her stimming makes it hard for her to type. She wants to stop stimming like that. She wants to stim a different way so she can communicate better.

There are cases where someone might need to stim differently to keep themselves safe.

For example:

Jason is autistic. He stims by hitting his head hard with his hands. Jason doesn't like this. His stimming gives him headaches. He is worried he will hurt his brain. Jason wants to find a different way to stim.

Even when someone wants to stim differently, they shouldn't have to stop stimming entirely. Think about the examples we just talked about! Marion could stim by hitting a table instead of her iPad. Jason could stim by hitting a pillow instead of his head. Marion and Jason can still stim. But their stimming doesn't get in the way of what they want to do as much. Their stimming doesn't hurt as much.

Use restraints or seclusion of any kind.

Restraints are holding or tying a person down. **Seclusion** is putting someone in a room by themselves and not letting them out. Restraints and seclusion are dangerous. Autistic people have died in restraints or seclusion. Nobody should ever be in restraints. Nobody should ever be in seclusion.

Use aversives of any kind.

An **aversive** is using something a person doesn't like. People use aversives to get a person to stop doing something.

For example:

Ta'lilla is autistic. She stims by waving her hands. Ta'lilla's therapist doesn't like Ta'lilla stimming. Every time Ta'lilla waves her hands, her therapist pinches her arm. Ta'lilla doesn't like this. It hurts when the therapist pinches her arm. So she tries to stop stimming as much. Ta'lilla's therapist is using an aversive. That isn't okay.

Hurt someone as part of the service.

This can be things like hitting someone, saying bad or mean things, ignoring a person, telling someone what they feel is bad or wrong, or touching someone's body when they don't want to be touched.

Use basic needs as rewards when the autistic person does

something the practitioner likes.

Basic needs can be things like food, drinks, toys, things the autistic person likes, taking a break, changing the activity, giving the autistic person attention, or special interests.

Take away basic needs as a punishment when the autistic person does something the practitioner doesn't like.

Or, not letting the autistic person have their basic needs until they do something the practitioner likes.

Bother someone who has said "no" until they say "yes".

Part of giving informed consent or assent is making the choice you want to make. Nobody gets to tell you how to choose. If someone tells you to change your choice, it's not informed consent or assent.

Do something anyway to an autistic person even after they've said no.

Or, saying that an autistic person saying "no" is bad.

Sometimes, everyone has to do things they don't want to do. For example, you have to wear shoes in stores. If you went to the store without your shoes on, you would have to put them on. We're not talking about cases like this here. We're talking about cases where an autistic person doesn't have to do something. But people make them do it anyway. We're talking about cases where people call autistic people saying "no" a bad thing.

Use exposure therapy.

Exposure therapy is when a practitioner makes an autistic person be around something scary. Practitioners use exposure therapy to make autistic people “get used to” things that scare us.

There are scary things in the world! Sometimes we have to deal with being scared, but services shouldn't make us get used to being scared. Services should give us tools to help us control when we have to be near scary things. Services should give us tools to help us feel less scared when we have to be near scary things.

Use patronizing language.

Patronizing language is language that treats autistic people as younger than we are. When a person uses patronizing language towards autistic people, that person isn't showing respect.

For example:

Meghana is autistic. She is 16. At school, Meghana's classmates speak to each other normally. But they speak to Meghana like she's a baby. They speak to her like she can't understand their regular speech. Meghana's classmates are using patronizing language. That's not okay.

Here are two things that patronizing language DOES NOT mean.

1. Letting an autistic person do things that most people their age don't do. For example, letting an autistic adult watch children's cartoons on TV.
2. Giving an autistic person information in Easy-Read or plain language.

Sometimes, people say doing these things is patronizing. That's wrong. It's okay to let people do things that most people their age don't do. It's okay to give people information in Easy-Read or plain language.

Use "mental age."

This is when someone says a person has "the mental age" of someone younger than the person. **Mental age** gets used a lot against people with intellectual disabilities. People use it to say people with intellectual disabilities aren't smart. People use it to say adults with intellectual disabilities aren't really adults. People use it to say teenagers with intellectual disabilities aren't really teenagers. All of this is wrong.

Teenagers with intellectual disabilities are teenagers. Adults with intellectual disabilities are adults. People with intellectual disabilities are smart.

For example:

Laisha is an autistic adult with an intellectual disability. She has a lot of trouble reading books. Laisha's support worker sees that Laisha needs help reading. The support worker says that Laisha has "the mind of an 8-year-old." This is wrong. The support worker is wrong. Laisha needs help reading. But she still is an adult. She still has grown up. She still knows lots of things as an adult. It is wrong to say she has "the mind of an 8-year-old" when she is not 8 years old.

Talk mostly about what an autistic person needs help with.

Autistic people do need help with a lot of things, but we also are good at a lot of things. Services need to focus on what we need help with and what we are good at.

Touch autistic people when it isn't needed for the service.

We talked about how some services need touch to work. For example, some kinds of physical therapy. But not all services need touch to work. Touching the autistic person during these services isn't okay.

One common practice in a lot of bad services is hand-over-hand. This is where the practitioner puts their hand on top of the autistic person's hand, then the practitioner uses their hand to move the autistic person's hand. Hand-over-hand controls the way autistic people move. It doesn't let us move our hands the way we want to. It lets other people touch us when we don't want them to. Practitioners shouldn't use hand-over-hand. They shouldn't touch us at all if it's not needed for the service.

Say that a service is "the only way an autistic person can learn."

Autistic people learn differently from how most non-autistic people learn, but we still learn in many different ways. There is no one service that will help every autistic person.

Some autistic people need a lot of help. They might need one-on-one support to learn, but that doesn't mean they can't learn in lots of different ways. They just need the right supports.

Some practitioners say their services are "the only way autistic people can learn." That's not true. If a practitioner says that, they are lying.

Say that autistic people are completely different from non-autistic people.

Or, saying that the things we know about humans don't apply to autistic people. Autistic people are human beings, just like everyone else. Our brains work differently, but that doesn't make us less human.

Say that an autistic person won't be happy unless they have many hours of a specific service every day.

Sometimes, a practitioner will say autistic people need hours of their services every day.

They will say that without hours of their services every day, we won't be happy, "get better," or meet our goals. This often happens with ABA.

This is wrong. Autistic people can need a lot of help. But that doesn't mean we need hours of a service like ABA every single day.

Make an autistic person do many hours of a service every day.

This can get to the point where:

- The person can't sleep, eat, or relax
- The person is obviously upset
- There is no purpose for how many hours of the service the person has to do.

This doesn't have to be many hours of one service each day. It could be a few hours of many different services each day, or it could be hours of a service after the person gets back from school each day.

Say that autistic people can't get certain services without going through other services first.

For example:

Aliosha is very sensitive to light. Bright lights hurt his eyes. Aliosha wants his Medicaid waiver to pay for different lamps in his house. That way, the light won't hurt his eyes. Medicaid says no. Medicaid says Aliosha has to go through ABA therapy first. Medicaid wants Aliosha to get used to the bright lights. This isn't fair! Medicaid should pay for Aliosha to get different lamps. They shouldn't make him go to ABA service first.

Say that autistic people can't get services unless they can already do something.

For example:

Tony is autistic. He stims by flapping his hands. Tony wants to take a computer class. The computer class teacher says Tony can't come to class unless he stops stimming. This is wrong. Tony's stimming doesn't have anything to do with using the computer. Tony doesn't need to stop stimming in order to take the class.

Say that autistic people can't use assistive technology in services.

People have a right to use their assistive technology. Assistive technology helps autistic people access the world. It helps us in different services. We should be able to use assistive technology if we want to.

There might be times when someone really can't use their assistive technology. For example, if using the assistive technology would hurt or damage it. But the person still needs to be offered a different tool to help them instead.

For example:

Jeannette is autistic. She uses an AAC device to communicate. The AAC device is a computer. Jeannette wants to go swimming. She can't take her device in the pool. If she did, the device would stop working. So Jeannette uses a whiteboard and marker instead. She writes what she wants to say on the whiteboard. Jeannette can't use her assistive technology in the pool. But she uses another tool to help her instead.

Things we want people who study autism services to do

Work with autistic people

Autistic people should help with studying autism services. We need to be part of the team that studies autism services. We need to be part of designing how the studies of autism services will work.

There need to be many autistic people on the team studying autism services. There shouldn't just be one autistic person. When people study services, they should look at how autistic people feel about the service. They should look at what we like or don't like about the service. They shouldn't just look at how our behavior changes during the service.

Focus on the results that matter to autistic people.

These can be results like:

- Communication
- Self-determination
- How we deal with sensory input
- How we deal with our emotions
- Self-advocacy
- Daily living skills
- How we stay on track when we have things to do
- Mental health
- How we feel in general

People who design and study autism services should focus on these results. They shouldn't focus on results like reducing our autistic traits.

Focus on getting good evidence for services besides ABA.

A lot of the evidence for ABA is not very good. The evidence often comes from studies that were not done well. The same thing happens for other services. There is not good evidence for most autism services. We want practitioners of other services to focus on getting good evidence.

Include all kinds of autistic people.

People who study autism interventions need to include:

- Autistic people of color
- Non-speaking autistic people
- Autistic people with intellectual disabilities
- Autistic people with mental health disabilities
- Autistic people who also have other disabilities
- Autistic people who need a lot of support

These groups need to be part of the team doing the study. They shouldn't just be people the team is studying.

The autistic people on the team are experts on how autistic people feel. They know whether autistic people think the study is good or bad. The non-autistic people on the team need to know this. If the non-autistic people on the team have questions, they need to ask the autistic people.

Focus on helping groups of people who are most likely to be put into ABA.

This can be groups like:

- Non-speaking autistic people
- Autistic people with intellectual disabilities
- Autistic people with mental health disabilities
- Autistic people who hurt themselves or other people

Often, autistic people in these groups only get ABA. That is wrong. More people need to study services for these groups. People who study autism services need to think of ways to help these groups. They need to make sure these groups have access to things like mental health and communication supports.

Know that different kinds of studying and writing about autism services are important.

A lot of the time, when people talk about studying services, they mean quantitative studies. **Quantitative studies** use numbers as their evidence.

For example:

Simon studies autism services. He wants to know if autistic people stop hurting themselves after a service. He looks at the people he is studying. He counts how many times per day they hurt themselves before the service. Then he looks at how many times per day they hurt themselves after the service. Simon is doing a quantitative study.

But there are other ways of studying and writing about autism services! A different kind of studying autism services are **qualitative studies**. Qualitative studies use words as their evidence.

For example:

Christina also studies autism services. She works on the same study as Simon, but Christina wants to know why autistic people hurt themselves. First, she asks autistic people before the service why they hurt themselves. She writes down their answers. Then, she asks autistic people after the service why they hurt themselves. She writes down their answers. Christina is doing a qualitative study.

We think qualitative studies can be just as good as quantitative studies. We want people who study autism services to do more qualitative studies. We also know that a lot of autistic people write about autism services. Most of these people aren't people who study autism services, and because they don't study autism services, people don't take their writing seriously.

All autistic people get left out of studying autism services. We don't get the same chances non-autistic people get, but some autistic people especially don't get the same chances, including:

- Autistic people of color
- Autistic women
- Autistic non-binary people
- Autistic young people
- Autistic people from the southern half of the world.
- Non-speaking autistic people
- Autistic people with intellectual disabilities

We want people who study autism services to take what all autistic people say seriously.

Treat autistic people in their studies right

There are rules that all studies have to follow to make sure people in the studies don't get hurt. The rules make sure the people in the studies can give informed consent or informed assent. We want people who study autism to follow these rules. We want people to watch and make sure the studies follow these rules.

We know that autistic people can be part of autism studies. We might need help to be part of autism studies, but we can still take part. We shouldn't be left out because we need help. Studies shouldn't treat us badly because we need help. They still have to follow the rules even if we need help.

Give autistic people accommodations if we need them.

The people doing the study need to give autistic people accommodations if we need them. Accommodations are changes that make things easier for people with disabilities. They help us get the same things as non-disabled people.

Here are some kinds of accommodations:

- Easy-Read materials
- Taking more breaks
- Using a different way to communicate, like typing on a computer
- Having a support person during the study
- Meeting the team doing the study before the study

These aren't the only kinds of accommodations. There are more kinds of accommodations. Autistic people need to have the accommodations we ask for.

Autistic people need to always be able to stop if we want to.

The people doing the study need to ask for our informed consent/assent often. They need to tell us it's always okay if we need to stop, and they need to tell us that nothing bad will happen if we need to stop. If we say we need to stop, they need to listen, then they need to stop right away.

Follow the same rules as studies that aren't about autism.

A lot of the time, autism services studies aren't good. They don't collect good evidence. They don't treat the autistic people they study well. They might even hurt the autistic people they study, and the people doing the studies don't get in trouble for this.

This is wrong. Autism services studies should follow the same rules that other studies have to. They should treat autistic people well. They should collect good evidence. They shouldn't hurt people.

Talk about their conflicts of interest.

A **conflict of interest** is when someone's life affects their ability to study a service fairly.

For example:

Michelle studies autism services. Michelle is also an ABA practitioner. Michelle does a study of different autism services. She wants to know which one works best. The study's evidence says that all the services work equally well. Michelle doesn't like this. She wants the study to say ABA works the best.

Michelle has a conflict of interest. Because she uses ABA, she might not be fair when she talks about the study.

Take criticism of their services from autistic people seriously.

Criticism is when someone says they have a problem with the service. Sometimes, people who have had a specific service criticize it. Practitioners should take this very seriously. People who have been through a service know how it affected them.

Tell autistic people it's okay to say if something is wrong in the service.

They should tell autistic people it's okay to speak up if the service hurts them. Practitioners should also tell people around the autistic person to speak up if something is wrong. This can be people like parents, caregivers, and support staff.

Words to Know

- **Applied Behavioral Analysis (ABA)** - A bad autism service that focuses on changing how autistic children behave. ABA wants autistic children to look and behave like they are not autistic. It teaches autistic children to hide the things that make them “look” autistic.
- **Aversive** - Using something a person doesn't like to get the person to stop doing something.
- **Basic Needs** - Things like food, drinks, toys, things an autistic person likes, taking a break, changing what activity the person is doing, giving the autistic person attention, and special interests.
- **Communication** - The different ways people talk to each other.
- **Conflict of Interest** - When someone's life affects their ability to study a service fairly.
- **Conversion therapy** - Trying to change someone's gender or sexuality.
- **Criticism** - When someone says they have a problem with a service.
- **Evidence** - Facts that show something is true. You get evidence from studying something.
- **Exposure therapy** - When a practitioner makes an autistic person be around something scary or painful so the person can “get used to” the scary thing.
- **Functioning labels** - Calling someone “high-functioning” or “low-functioning”.
- **Giving informed assent** - Saying “yes” or “no” to a service when you can't give informed consent.
- **Giving informed consent** - Saying “yes” or “no” to a service.

- **Mental age** - Saying a person has “the mental age” of someone younger than how old the person actually is. Mental age gets used a lot against people with intellectual disabilities.
- **Non-speaking** - When someone can’t talk with their mouth.
- **Patronizing language** - Language that treats autistic people as younger than we are.
- **Practitioner** - Someone who gives a service to autistic people.
- **Presuming competence** - Knowing that if we get the right help, autistic people can learn, think, communicate, and do new things.
- **Qualitative studies** - Studies that use words as their evidence.
- **Quantitative studies** - Studies that use numbers as their evidence.
- **Restraints** - Holding or tying a person down.
- **Seclusion** - Putting someone in a room by themselves and not letting them out.
- **Self-determination** - Making your own choices.
- **Service** - A program that tries to help autistic people. In this toolkit, we also call services “therapies”.
- **Social skills** - Skills that have to do with getting along with other people
- **Trauma** - Changes in the way someone thinks and feels, after something scary hurt them. Trauma can last a long time.

To Learn More

