



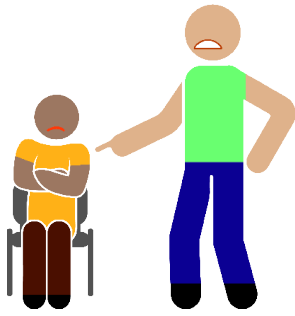
Easy Read Edition

For Whose Benefit?

Evidence, Ethics, and Effectiveness of Autism Interventions

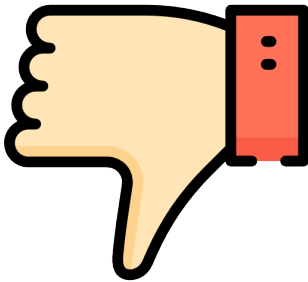
**Part 5: Things we don't want any
services or practitioners to do**

Words to Know in Part 5



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.



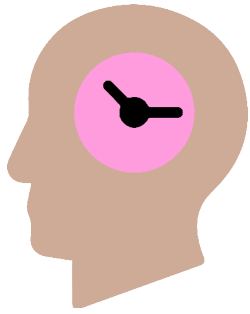
Basic Needs

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.



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.



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.



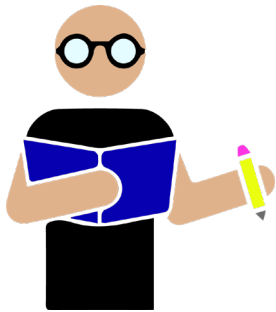
Non-speaking

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.



Restraints

Holding or tying a person down.



Seclusion

Putting someone in a room by themselves and not letting them out.



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.

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.



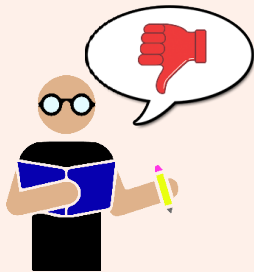
She is autistic.



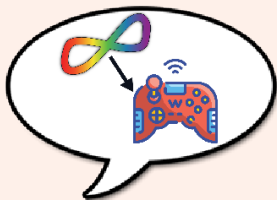
Anushe loves to play video games.



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.



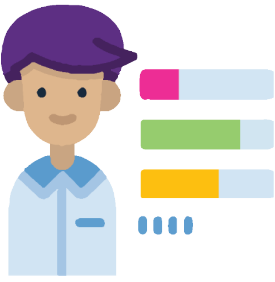
Mikael's therapist tells Mikael he has to work on watching more "grown up" shows.



This isn't okay!



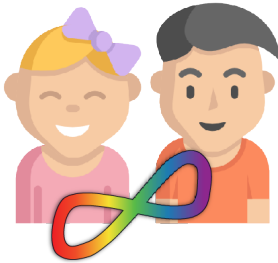
Mikael should be allowed to watch cartoons if he wants to.



There are some skills people usually learn at a certain age.



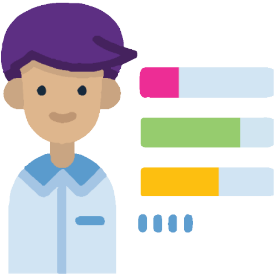
For example, most children learn to read when they are about 5 or 6 years old.



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.



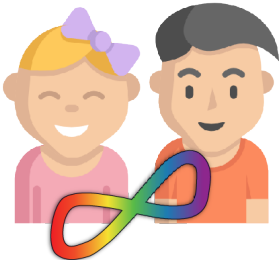
But autistic people shouldn't have to do things only because other people their age do.



It is good for children to learn how to read.



Reading is important.

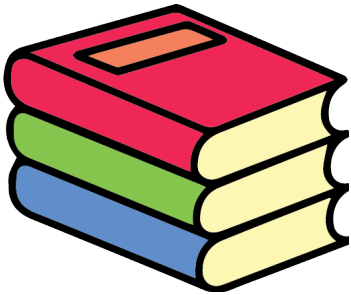


Autistic children need to know how to read.

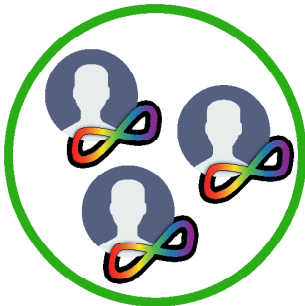


But autistic people don't need to watch sports just because other people watch sports.

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.



It is true 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:



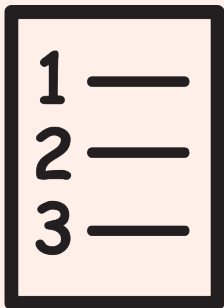
Julienne, Liam, and Adela all want to learn how to bake a cake.



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.



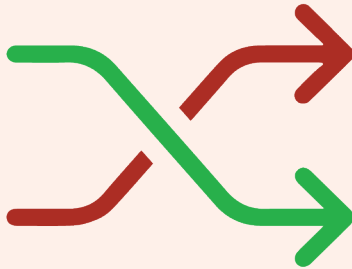
She has trouble with one of the steps, so she asks Adela for help.



Adela helps Julienne.



Then Julianne bakes her cake.



Julienne learned to bake a cake differently from Liam and Adela.

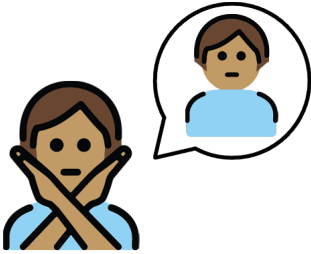


But she still learned to bake a cake.



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.



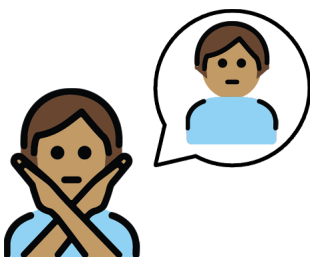
But that does not mean we can't think.



It doesn't mean 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.



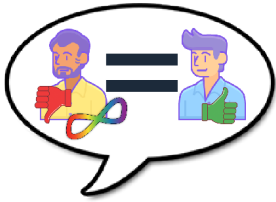
For example, we might not know what to do at a party.



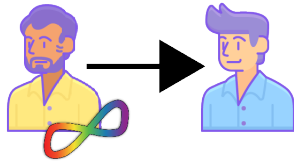
A lot of bad services teach us to ignore our feelings in these situations.



Or, they teach us that what we think in these situations is always wrong.

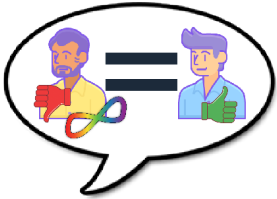


Bad services teach us that what non-autistic people think is always right.



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.



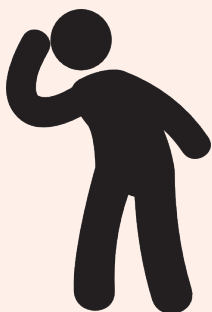
Morgan is autistic.



Kalla is not autistic.



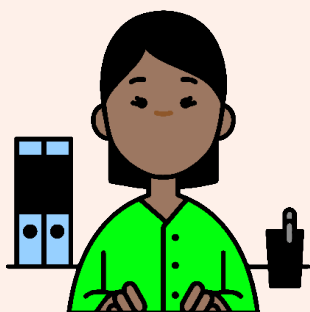
They both say the same swear word.



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.



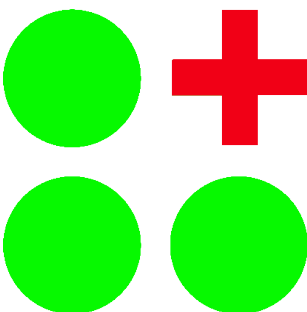
A lot of the time, autism services focus only on “social skills.”



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.



And 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.

1... 2...
3... 4...

And they have trouble remembering the different steps to getting off the bus.



A social skills service wouldn't help Harli.



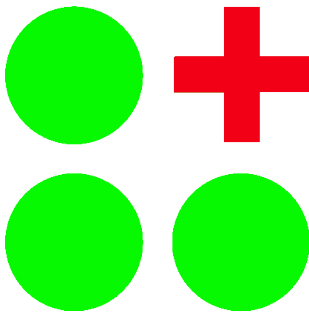
They don't need help getting along with other people.



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!



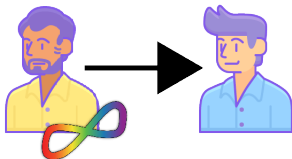
But those ways shouldn't say that being autistic is wrong in social situations.



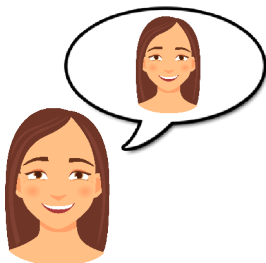
A lot of bad services say that if someone looks autistic, they're doing a bad job.



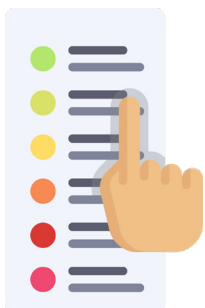
That's not true.



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



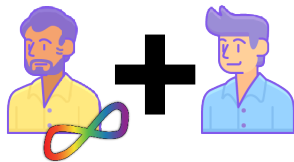
- A job interview skills workshop



- A class about healthy ways to disagree with friends



We think these kinds of services are okay.

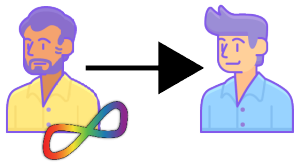


We think autistic people and non-autistic people should be in them together.

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.

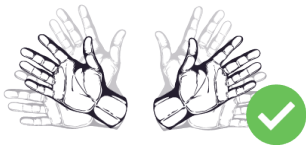


This hurts autistic people.



It teaches us that being the way we are is bad.

Have a goal of making someone stim less.



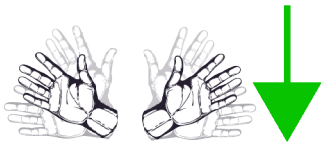
Autistic people should be able to stim as much as we like.



Other people shouldn't stop us from stimming.



If a service tries to force us to stop stimming, it is a bad service.

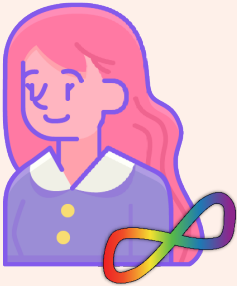


There are some cases where someone might want to stop stimming as much.



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.



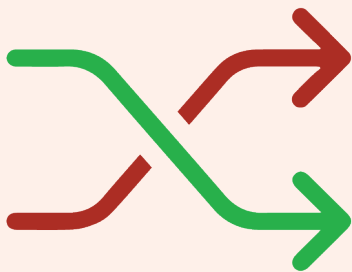
She isn't typing on it when she stims.



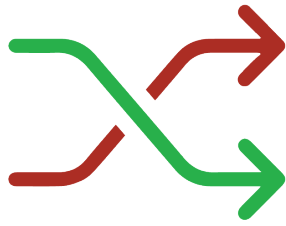
Her stimming makes it hard for her to type.



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.



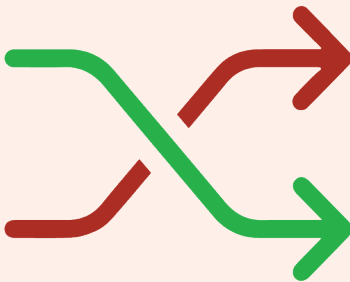
Jason doesn't like this.



His stimming gives him headaches.



He is worried he will hurt his brain.



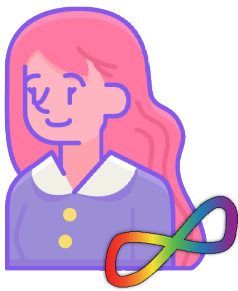
Jason wants to find a different way to stim.



Even when someone wants to stim differently, they shouldn't have to stop stimming entirely.



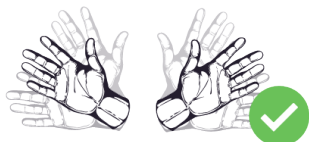
Think about the examples we just talked about!



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.

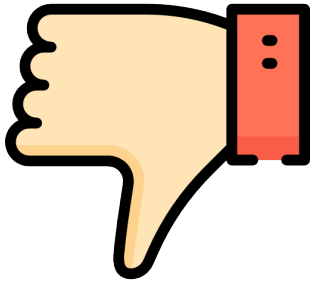


Nobody should ever be in restraints.



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.

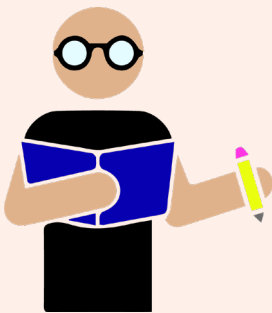
For example:



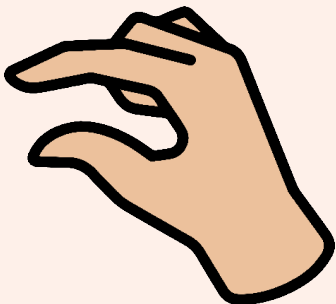
Ta'lilla is autistic.



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.



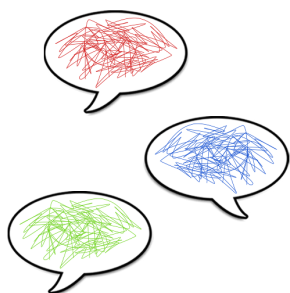
That isn't okay.

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



- 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:



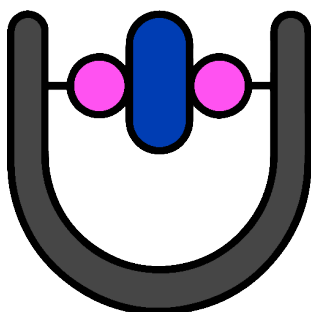
- Food



- Drinks



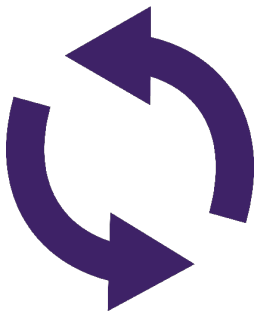
- Toys



- Things the autistic person likes, like a stim toy



- Taking a break



- Changing what activity the person is doing



- Giving the autistic person attention



- 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 is making the choice you want to make.



Part of giving informed 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.



If someone tells you to change your choice, it's not informed 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.

16

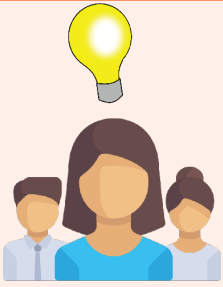
She is 16.



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.

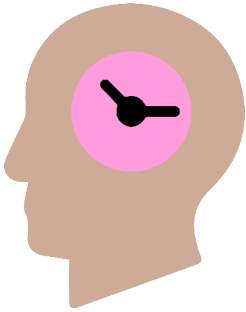


That's wrong. It's okay to let people do things that most people their age don't do.



It's okay to give people information in Easy-Read or plain language.

Use “mental age.”



Mental age 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.



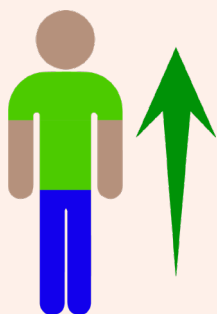
The support worker is wrong.



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.

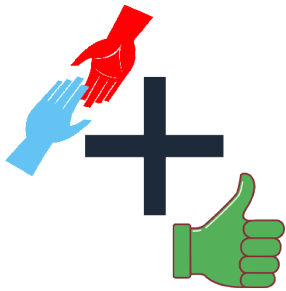
Talk mostly about what an autistic person needs help with.



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.



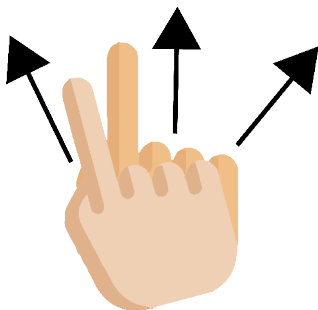
Touching the autistic person during these services isn't okay.



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.

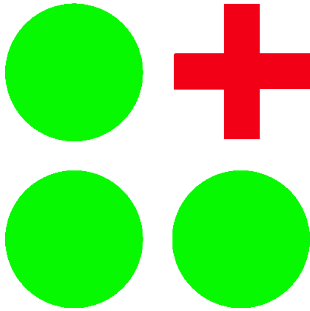


Practitioners shouldn't use hand-over-hand.



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.



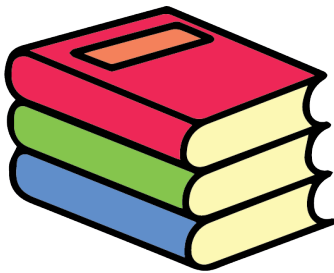
There is no one service that will help every autistic person.



Some autistic people need a lot of help.



They might need one-on-one support to learn.



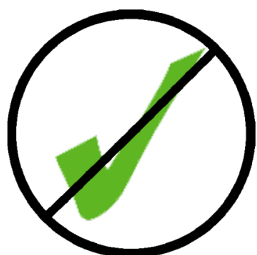
But that doesn't mean they can't learn in lots of different ways.



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.



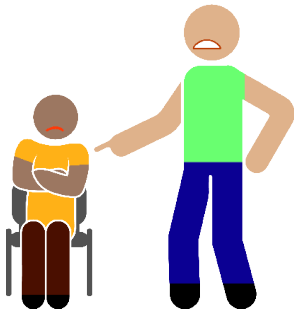
They will say that without hours of their services every day, we won't be happy.



They will say that without hours of their services every day, we will never “get better”.



They will say that without hours of their services every day, we will never 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



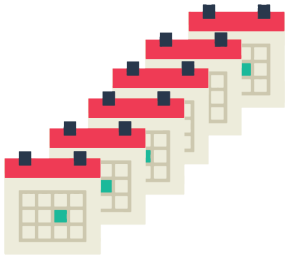
- The person is obviously upset



- 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.



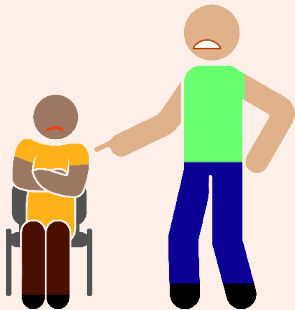
Aliosha wants his Medicaid waiver to pay
for different lamps in his house.



That way, the light won't hurt his eyes.



Medicaid says no.



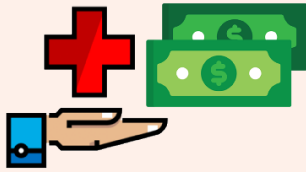
Medicaid says Aliosha has to go through ABA therapy first.



Medicaid wants Aliosha to get used to the bright lights.



This isn't fair!



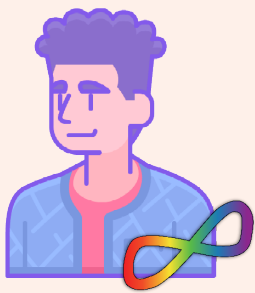
Medicaid should pay for Aliosha to get different lamps.



They shouldn't make him go to ABA therapy 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.



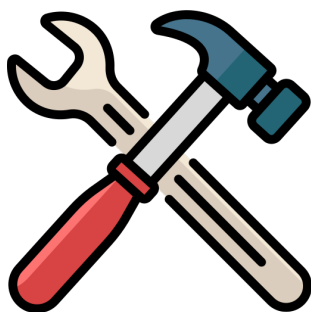
People have a right to use their assistive technology.



Assistive technology helps autistic people access the world.



It helps us in different services.



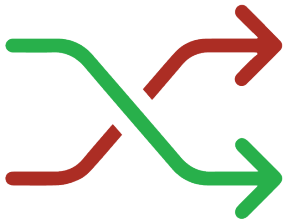
We should be able to use assistive technology if we want to.



There might be times when someone really can't use their assistive technology.

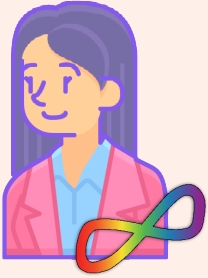


For example, if using the assistive technology would hurt or damage it.



But the person still needs to be offered a different tool to help them instead.

For example:



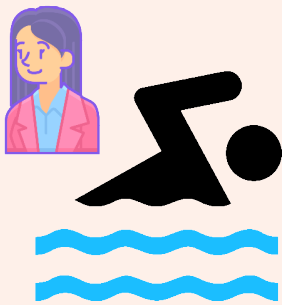
Jeannette is autistic.



She uses an AAC device to communicate.



The AAC device is a computer.



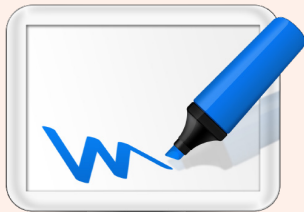
Jeannette wants to go swimming.



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.