



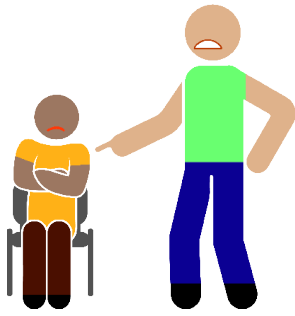
*Easy Read Edition*

# **For Whose Benefit?**

## **Evidence, Ethics, and Effectiveness of Autism Interventions**

**Part 6: Things we want people  
who study autism services to do**

# Words to Know in Part 6



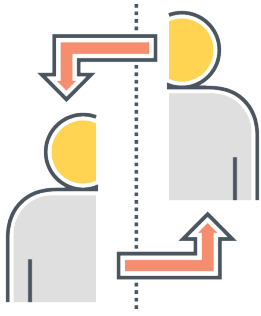
## Applied Behavioral Analysis (ABA)

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.



## Communication

The different ways people talk to each other.



## Conflict of Interest

When someone's life affects their ability to study a service fairly.



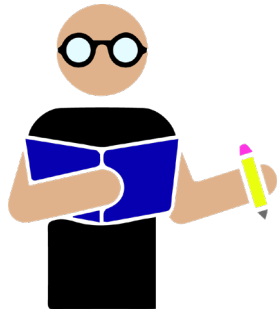
## Evidence

Facts that show something is true. You get evidence from studying something.



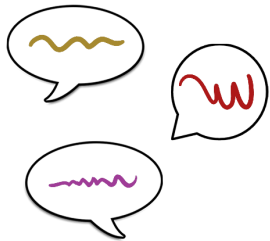
## Non-speaking

When someone can't talk with their mouth.



## Practitioner

Someone who gives a service to autistic people.



## Qualitative Studies

Studies that use words as their evidence.



## Quantitative Studies

Studies that use numbers as their evidence.



## Self-Determination

Making your own choices.



## Service

A program that tries to help autistic people. In this toolkit, we also call services “therapies”.

# 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.



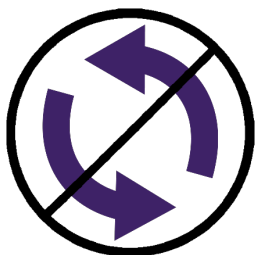
There shouldn't just be one autistic person.



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.

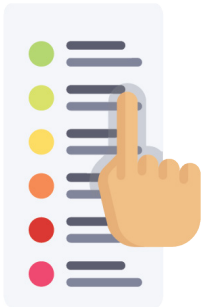


# Focus on the results that matter to autistic people.

These can be results like:



- Communication



- Self-determination

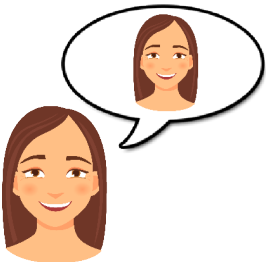


- How we deal with sensory input

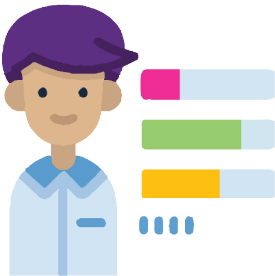


- How we deal with our emotions

- Self-advocacy



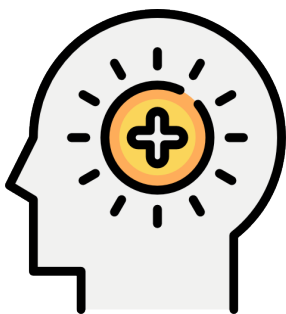
- Daily living skills



- How we stay on track when we have things to do



- Mental health

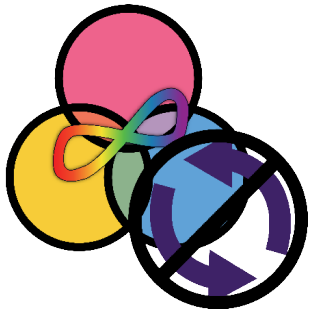


- How we feel in general





People who design and study autism services should focus on these results.



They shouldn't focus on results like changing our autistic traits.

## Focus on getting good evidence for services besides ABA.



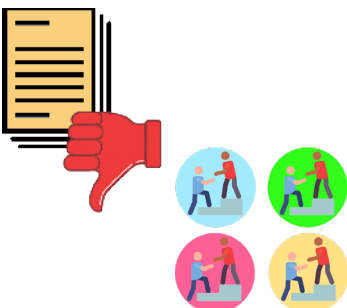
A lot of the evidence for ABA is not very good.



The evidence often comes from studies that were not done well.



The same thing happens for other services.



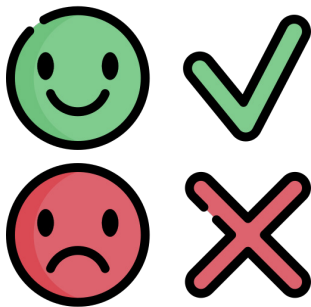
There is not good evidence for most autism services.



We want practitioners of other services to focus on getting good evidence.



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.

# Include all kinds of autistic people.

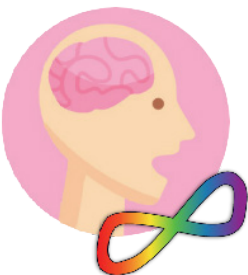
People who study autism interventions need to include:



- 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.

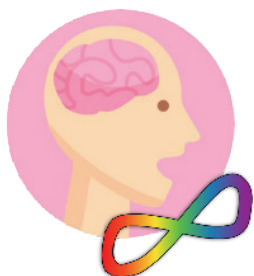


## Focus on helping groups of people who are most likely to be put into ABA.

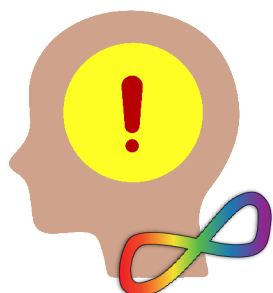
This can be groups like:



- Non-speaking autistic people



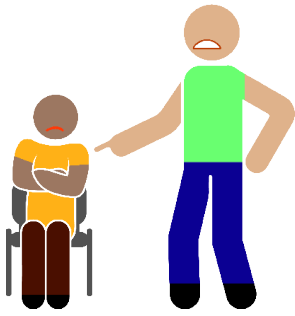
- Autistic people with intellectual disabilities



- Autistic people with mental health disabilities



- Autistic people who hurt themselves or other people



Often, autistic people in these groups only get ABA.



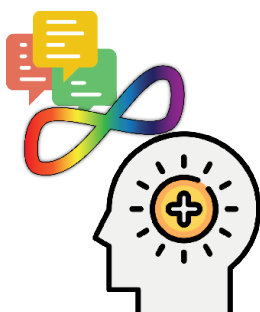
That is wrong.



More people need to study services for these groups.

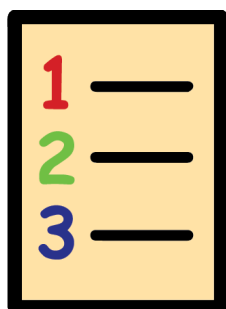


People who study autism services need to think of ways to help these groups.



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.

2 4  
6 8

**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.



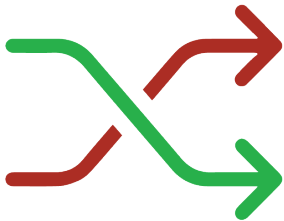
Then he counts how many times per day they hurt themselves after the service.

2 4  
6 8

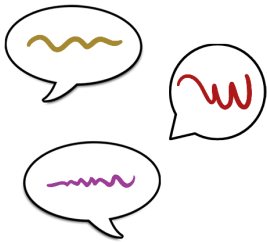
Simon is doing a quantitative study.



But there are other ways of studying and writing about autism services!



A different kind of studying autism services are qualitative studies.

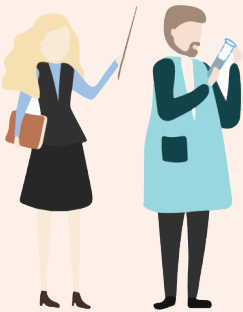


**Qualitative studies** use words as their evidence.

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.



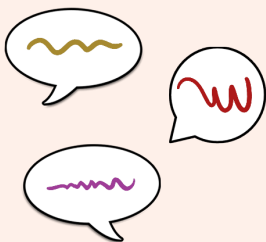
She writes down their answers.



Then, she asks autistic people after the service why they hurt themselves.

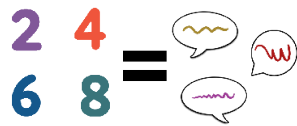


She writes down their answers.



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.



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:



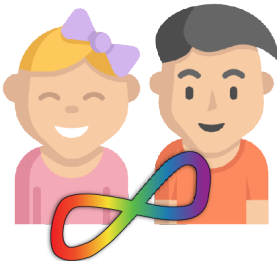
- Autistic people of color



- Autistic women



- Autistic non-binary people



- Autistic young people



- Autistic people from the southern half of the world.



- Nonspeaking 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

1.=

There are rules that all studies have to follow.

2.=



The rules make sure the people in the studies don't get hurt.




The rules make sure the people in the studies can give informed consent.



Or, the rules make sure the people in the studies can give informed assent.

1.=  
2.=

We want people who study autism to follow these rules.

1.=  
2.= 

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.

1.=

2.=



Studies about us 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.



Accommodations 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.



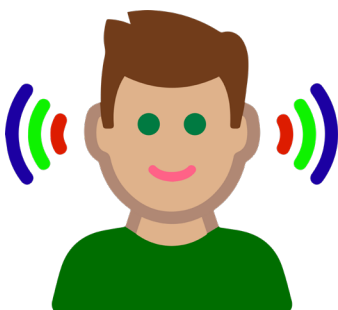
The people doing the study need to ask for our informed consent/assent often.



They need to tell us it's always okay if we need to stop.



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.



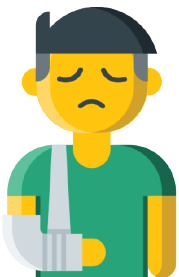
A lot of the time, autism services studies aren't good.



They don't collect good evidence.



They don't treat the autistic people they study well.



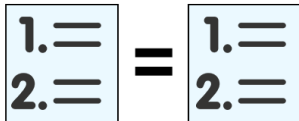
They might even hurt the autistic people they study.



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.

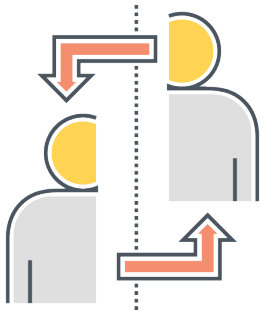


They should collect good evidence.



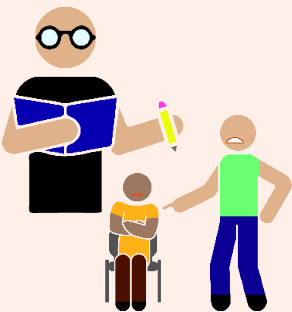
They shouldn't hurt people.

## 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.





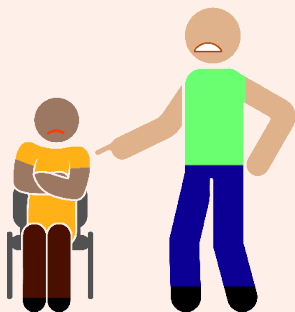
She wants to know which one works best.



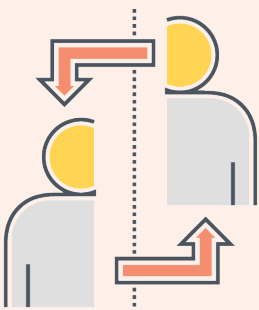
The study's evidence says that all the services work equally well.



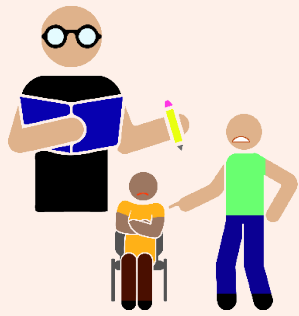
Michelle doesn't like this.



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.

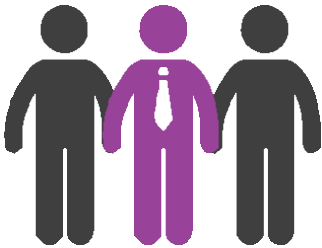


People who have been through a service know how it affected them.

## 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



- Support staff

