Easy Read Edition

For Whose Benefit?
Evidence, Ethics, and Effectiveness of Autism Interventions

Part 3: Things all practitioners need to know from the very start
Words to Know in Part 3
Communication

The different ways people talk to each other

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.
Practitioner

Someone who gives a service to autistic people.

Self-Determination

Making your own choices

Service

A program that tries to help autistic people. In this toolkit, we also call services “therapies”.
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 without these things.

A service can’t be helpful without these things.
Autistic people are people.

We have feelings like non-autistic people do.

We have thoughts like non-autistic people do.

We have wants like non-autistic people do.

We have needs like non-autistic people do.
We have dreams like non-autistic people do.

Our lives are different from non-autistic people’s lives.

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.

We 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
• Non-speaking autistic people

• 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.

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

• 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.

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.

They should tell us what the goal will help us 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.

They might 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 handwriting.

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.

She 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.

We have many different special interests.

We have many 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.