Easy Read Edition

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

Part 4: Things we want more services and practitioners to do
Words to Know in Part 4
Communication

The different ways people talk to each other.

Functioning Labels

Calling someone “high-functioning” or “low-functioning”.

Non-speaking

When someone can’t talk with their mouth.
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.

Self-Determination

Making your own choices.
Service

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

Trauma

Changes in the way someone thinks and feels, after something scary hurt them. Trauma can last a long time.
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.

There are autistic people of all genders.

There are autistic people of all religions.

There are autistic people 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.

That means 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.

¡Hola!

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

Giving us time and space to:

• Move around

• Stim

• Take breaks

• 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 to say something is wrong

• Crying

• Pointing

• 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
• Do new things
Practitioners should know this.

Knowing this is called “presuming 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 tools.

There are lots of tools that help people with disabilities live more independently.
Some examples are:

- Wheelchairs
- Hearing aids
- AAC devices
- 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
- 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. Sometimes they last 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.

She has speech therapy every Tuesday.

Kelsey’s therapist lets Kelsey choose where they meet.
Sometimes they meet in the therapist’s office.

Sometimes they meet at Kelsey’s house.

Sometimes they meet 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.