

Disability Is Not A Dirty Word

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Hi!

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ASAN

National self-advocacy organization run by and for autistic adults, speaking for ourselves

Focus on systems change and policy advocacy, focus on adults across the spectrum

Nothing About Us, Without Us!

How we think about autism



Neurodiversity

Autism is one of many different forms of neurological variation.

Autism is neither bad nor good. It just is.

Different, not less.

Embracing and celebrating difference makes us stronger.

Rethinking autism

Instead of:

- Restricted interests
- Stereotypies
- Pedantic
- Nonfunctional play
- Independent/not independent
- Developmental delays

What about:

- Deep passion and enthusiasm
- “Her body does her happy”
- Precise, thoughtful
- Functional for him
- Interdependent
- Different developmental trajectories

Difference vs disability

This is a false dichotomy. Autism is a neurological difference, and it's also a disability.

At the same time. In the same person.

But disability is different than you think.

Models of disability

Medical model of disability

- Problem located within a body/person
- Focus on deficit
- Focus on remediation

Social model of disability

- Problem located within society
- Focus on access barriers
- Focus on inclusion

Models of disability



Disability is a natural part of the human experience

We have always been here.

We will always be here, although the “face” of disability may change.

We are complete people, just as we are.

We have a right to be included.

Disability rights movement

The disability rights movement was created by people who experienced significant disabilities and used the social model.

The self-advocacy movement came from people with intellectual disabilities who were institutionalized.

Disability rights and self-advocacy are for everyone.

All means all

Functioning labels are antithetical to neurodiversity.

Neurodiversity includes people with intellectual disabilities, people who are nonspeaking, people who have challenging behaviors, etc.

It is okay to need support. It is okay to need a lot of support. The world is still for you.

The Importance Of Self- Advocacy

Autistic kids grow up into autistic adults

Despite what you may have heard, we are not kids forever.

In fact, we are autistic adults for most of our lives!

We need to be prepared for this.

What does the future look like?

The goal is not a child--or an adult--who can pass as NT.

The goal is a

- happy,
- healthy,
- empowered

autistic adult, living a life that is meaningful to them.

We need to know & understand our disability

We need to know and understand:

- What my disability is
- What that means for me
- What can I do?
- What can't I do?
- What do I need help with?
- What kind of help do I need?
- How do I feel about all of this? What do I want to do with those feelings?

Why is this important?

You need to understand your disability in order to advocate for yourself effectively.

Understanding your disability doesn't limit you--it empowers you. It gives you the tools you need to do what you want.

Own it.

What is self-advocacy?

Self-advocacy is about speaking up for yourself and making your preferences and opinions known. It is about being in charge of your life and your future.

It looks different for everyone.

It is the key to having a good life.

Self-advocacy is a life skill

- Your kids are going to be disabled their entire life.
- Your kids are systematically taught by the outside world that they are wrong, that they do not matter, that they do not have power.
- You can give them an alternative.

Self-advocacy is the future



What does self-advocacy look like?

There are a lot of different ways self-advocacy can look like! Here are 4:

1. Formal advocacy
2. Self-determination
3. Making day-to-day choices
4. No!

Formal advocacy

This is what ASAN does

Advocacy on behalf of your community, not just yourself

Nothing about us, without us!

Self-determination

Setting your own goals

What do I want to do? What do I want to be when I grow up? How do I want to spend my time?

Being in charge of your life

Making day to day choices

“Eggs for breakfast”

Expressing preferences

Being listened to

No!

Behavior is communication.

Yes, even “challenging behaviors.”

The most important skill someone with a developmental disability can have is the ability to say no.

What ISN'T self-advocacy?

Self-advocacy isn't about “making good choices.”

Self-advocacy isn't linear.

Self-advocacy isn't all-or-nothing.

Self-advocacy doesn't come with pre-requisites.

Pre-requisites for self-advocacy

To be a self-advocate you need exactly 2 things:

1: An ability to independently move 1 or more muscles somewhere on your body.

2: Preferences

That's it.

Self-advocacy is
for everyone, all
the time.

Supporting self-advocacy in your kids



Relax

Self-advocacy is a practice, and it looks different for everyone. You don't have to do everything at once! You can take some time.

Every day gives you hundreds of opportunities, big and small, to practice supporting self-advocacy in your child.

Just keep practicing.

Communication & choices

Communication: does your child have access to an effective method of communication?

How can you support their communication skills?

We make hundreds of choices every day. What choices does your child make now? What about typical kids? How can you expand that?

Rethink “behavior”

What is this behavior telling me?

How can I support my child in their self-advocacy?

How can I help them self-advocate more effectively?

Therapies: who is this for?

Think carefully about therapies and therapy goals. Who is this for? What is the goal here?

Self-determined adulthood vs indistinguishability

Remember the golden rule.

Presuming competence

With the right supports, everyone can learn, grow, and do more

Everyone is a person, with thoughts and feelings

The least dangerous assumption

Metacognition and self-determination

Modeling

Goal-setting

Reflecting

The IEP

Nothing about us, without us!

Start small, start early

Explore technology

If you wouldn't say it with us in the room, don't say it

Transition

Increasing responsibility

Dignity of risk

Letting go

Tell your child they are autistic

They are already labelled.

It's their passport to understanding.

It can be a process. That's normal.

Autistic community

Peer support!

Seek out autistic adults: mentors and possibility models.

Find and tell new stories.

One more time: all means
all

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All means all

There is nothing about the importance of acceptance, support, inclusion, self-advocacy, or civil rights that is unique to autistic students who don't have intellectual disabilities and who can speak with their mouths.

All means all

Disability is not a dirty word.

Don't run from it--embrace it.

Help us find our power.

Thank you

