

Supporting Self-Advocacy and Self-Determination

at Home, at School, and in the Community

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April 27, 2026

Before We Begin

This talk is designed for everyone in this room.

Young people and adults with lived experience. Parents. Providers. Community members. All of you.

People with X and Y variations belong in this conversation.

Not as the subject being discussed — but as full participants. This is critical. This is the foundation of self-determination.

When providers/educators speak in the presence of the people they serve, it changes how they talk.

It pushes them toward language that is clearer, more respectful, and more humane. That is good for everyone.

It models something for families too.

When we speak about young people and adults respectfully, in their presence, we show families what that language sounds like.

"Nothing About Us Without Us" — and that means we do this together, and we do it with respect.

“Pencil broke.”

The student sat frozen. The teacher kept asking him to get started with his work. Nothing worked — until the teacher walked over with a small whiteboard and wrote: Anything you need?

The student picked up a marker and wrote, “pencil broke”

What this story teaches us about self-advocacy

- 1 Self-advocacy is important for everyone.
- 2 Sometimes it's just two words.
- 3 The environment has to meet the person halfway.
- 4 Our job is to find the best ways each person can self advocate. (e.g. what is your “whiteboard”?)

The Most Important Shift

Advocacy FOR them

Parents and providers speak on behalf of the person.

They lead the story.

They explain the needs.

They advocate to schools, doctors, and multiple systems.

WHY?

- Parents are often effective
- Hierarchy where parents have influence
- Some parents want to control the narrative/outcome



Advocacy WITH them

Parents model self-advocacy and support the person to communicate for themselves.

Communication takes many forms — words, check boxes, texts, gestures, devices.

The goal: building the skill and habit of the person advocating for themselves, with support when needed

WHY: Fairness, choice, freedom, and better outcomes

Three Concepts, One Goal

Understanding self-efficacy, self-advocacy, and self-determination — and how they connect.

THE BELIEF

Self-Efficacy

Believing your voice matters and that speaking up can change things.

Without this belief, most people don't try.

Built through experience: every time speaking up leads to something, self-efficacy grows.

Example: 'I think my teacher will listen if I tell her what I need.'



THE ACTION

Self-Advocacy

Using your voice to communicate your needs, wants, and rights — in any form that works for you.

Words, check boxes, textures, gestures, pictures, communication devices.

Example: 'I need more time.' 'That hurts.' 'I don't understand.'



THE LIFE

Self-Determination

Being the author of your own life. Making real choices. Setting your own goals. Having genuine say in decisions that affect you.

Not doing everything alone — but being in the driver's seat, with whatever support you need.

Example: Deciding where to live, how you spend your time, what support works best for you.

Self-efficacy is the belief. Self-advocacy is the action. Self-determination is building the life you want.

Why These Matter: What the Research Shows

Self-advocacy is how self-determination is built — and both predict better outcomes across education, work, and life.

Education	Community Participation	Employment	Quality of Life
Higher self-determination predicts college enrollment, completion, and use of supports. (Wehmeyer & Palmer, 2003)	Greater self-determination predicts higher community access, more social relationships, and more independent living. (Shogren et al., 2015)	Higher self-determination when leaving high school predicts employment in adulthood (Shogren, Wehmeyer et al., 2015)	Self-determination is linked to higher quality of life and life satisfaction across disability groups. (Wehmeyer & Schwartz, 1998; Nota et al., 2007)

Critical finding:

For those with neurodevelopmental differences: young people are consistently less self-determined than peers — not because of fixed traits, but fewer opportunities to practice. For those with chronic medical needs: self-efficacy and self-advocacy predict better health outcomes, treatment adherence, and quality of life. All of this can be taught and built.

Self-determination is not a personality trait. It is a set of skills. It can be taught, practiced, and grown at any age.

Self-Efficacy Across the X and Y Variation Community

X and Y variations are genetic and chromosomal. Their expression varies widely — and so do the relevant needs.

Diverse Medical Needs

- Hormone-related needs
- Cardiovascular health
- Metabolic & reproductive considerations; fertility
- Ongoing specialist care

Self-efficacy here means: believing you can manage your healthcare, ask questions, and advocate with your medical team.

Neurodivergence (for some)

- Autistic or autism characteristics
- ADHD
- Language-based learning differences
- Dyscalculia
- Anxiety

Self-efficacy here means: believing you can communicate your needs even when language or processing is challenging.

Research: Self-efficacy in youth with chronic conditions predicts treatment adherence, health management, and quality of life. (Schoenmakers et al., 2015)

Why This Matters for Our Community

What we know about X and Y variations

- Language & communication differences (for some)
- Executive function challenges (for some)
- Anxiety — very common across variations
- ADHD — frequent co-occurrence
- Learning differences (for some)
- Autism characteristics (for some)
- Diverse medical needs — sometimes complex

All of these can increase both the need for self-advocacy and the challenges in doing it.

The advocacy challenge

- X and Y variations are often hidden — not obvious to teachers, doctors, or peers
- Parents become the explainers — carrying the story for their child
- As kids grow up, they need to be able to tell their own story
- But the skills to do that need to be built intentionally
- The skills to do this confidently may not come naturally
- A specific challenge: what do you even call your variation when self-advocating? How much do you share — and with whom?

Finding Your Words: A Language Menu

You get to choose what you share, with whom, and in what words.

About Your Variation	About Your Neurodivergence	About How You Learn	About What You Need
<ul style="list-style-type: none">· I have a genetic variation · I have a chromosomal variation · I have a medical condition	<ul style="list-style-type: none">· I'm neurodivergent · My brain is wired differently than average · I have a condition that affects how I learn and process things	<ul style="list-style-type: none">· I have learning differences · I learn differently · I process information differently · I need extra support in some areas	<ul style="list-style-type: none">· I do better with written instructions · I need more time to process · Loud spaces are hard for me · I work best when I can take breaks

Executive Function: The Building Blocks of Self-Advocacy

Self-advocacy requires more than courage — it requires specific cognitive skills.

Executive function (EF) is the set of mental skills that help us plan, organize, initiate, and regulate our actions toward a goal.

Initiation

Getting started on the act of speaking up — even when anxious or overwhelmed

Working Memory

Holding your need in mind long enough to communicate it

Cognitive Flexibility

Plan B thinking — adapting when your first request doesn't work

Planning & Organization

Setting self-advocacy goals and sequencing the steps to get there

Social Cognition

Reading the room — knowing when, how, and to whom to advocate

Research finding:

Greater EF difficulties are directly associated with lower self-determination and lower self-efficacy. This is especially relevant for people with X and Y variations, where EF challenges are very common.

Supporting EF to Improve Self-Advocacy

Concrete supports matched to each executive function domain.

Initiation	Working Memory	Cognitive Flexibility	Planning & Organization	Social Cognition
<ul style="list-style-type: none">· Use a structured prompt to get started· Reduce open-ended demands (checklists, not open ended questions!)· Build in warm-up time before high-stakes moments	<ul style="list-style-type: none">· Write it down before the meeting· Use visual supports and reminder cards· Prepare a one-page "about me" summary	<ul style="list-style-type: none">· Teach Plan A / B / C explicitly· Practice "what if" scenarios at home	<ul style="list-style-type: none">· Break self-advocacy goals into small steps· Use goal-setting tools and templates· Help the individual think about what is even possible	<ul style="list-style-type: none">· Explicitly teach reading the room· Role-play different audiences and situations· Discuss disclosure decisions in advance

FROM OUR
CURRICULUM

Unstuck and On Target!

Ages 14–22

*An Executive Function Curriculum
to Support Self-Determination,
Flexibility, Planning, and Organization*

Unstuck and On Target! Ages 14-22: An Executive Function Curriculum to Support Self-Determination, Flexibility, Planning, and Organization by Pugliese, Kenworthy, Adler Werner, Alexander, Cannon, Strang, and Anthony. Copyright 2026 Paul H. Brookes Publishing Co., Inc. All rights reserved.

A dedicated self-advocacy chapter

Built for teens and young adults

Ages 14–22, with neurodevelopmental differences

Self-knowledge first

Know your goals, know your challenges, know what helps

The formula

A simple, repeatable structure for any self-advocacy situation

Needs AND strengths

Self-advocacy isn't only about what's hard — it's also about what you're good at

Flexible thinking

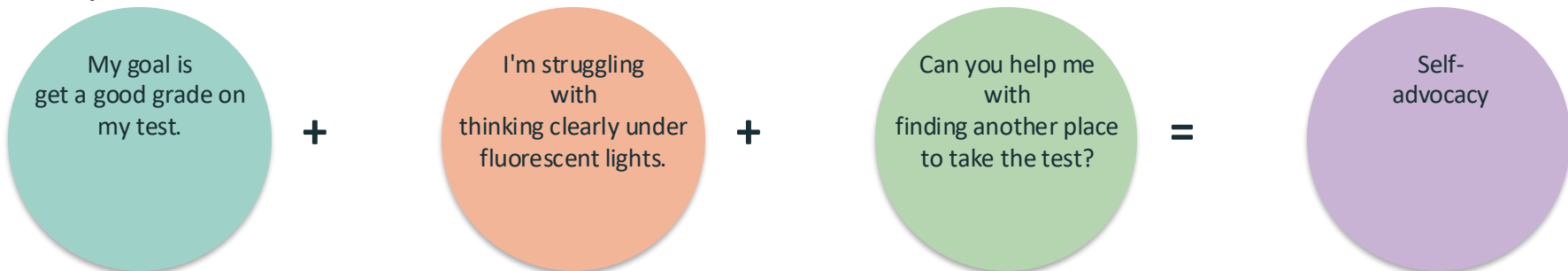
Plan A, Plan B — and the mindset to try again

How Do You Get What You Need? Self-Advocate!

Self-advocacy means asking for what you need so that others can help you meet your goals.



Example:



Self-Advocacy: Needs AND Strengths

When something is hard:



Ask for what you need.
Name the challenge.
Request a specific support.

*"I need more time to do math.
Can I have more time on this test?"*

Mismatch: when the match is poor between
your skillset and what you need to do.

When you have something to offer:



Lead with what you do well.
Ask to use your strengths.
Contribute to others.

*"I'm really good at visual stuff.
Can I do the diagram part of this project?"*

**"Sharing my strengths gives me
power to help others!"**

Teaching Flexible Thinking Supports Self-Advocacy

Stuck thoughts get you off track
and can make you feel bad.

*"This will never work,
so why bother
even trying?"*

Flexible thoughts keep you
on target to reach your goal.

*"Even though this is hard,
I can get help if I need it."*

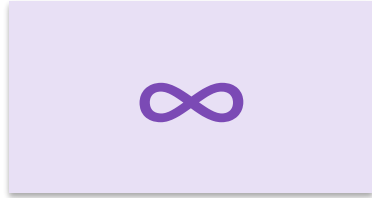
*"I don't need to panic.
I can make a plan to ask for help."*

Flexible thinking is self-efficacy in action.

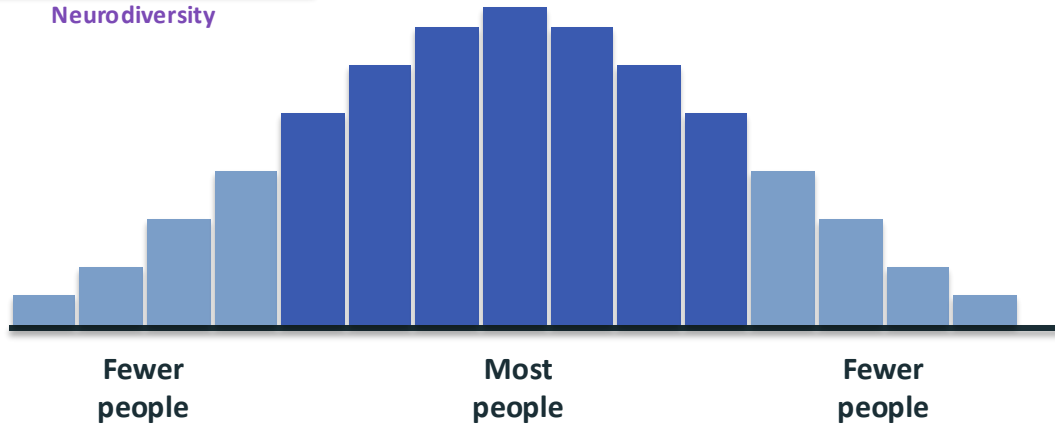
You have to believe your voice can make a difference before you use it. Plan A + Plan B thinking builds that belief.

The World is Built for the Majority...

But is This Fair?



Neurodiversity



EQUALITY

Same support
for everyone

vs

EQUITY

Support that fits
what each
person
actually needs

Self-advocacy is how you claim your equity.

The world is built for most people — self-advocacy is how people outside the majority get what they need.

Disclosure and Self-Advocacy

**“I'm autistic.
I can't sit over there —
it's too noisy.”**

And the vibe of the entire space changed.

At a pharmacy. A woman struggling to communicate, to organize her thoughts.

The pharmacist was losing patience. People in line were muttering. Pharmacist asked her to sit in the waiting area.

Then she said those words. And everything shifted.

Disclosure: Power, Perceived Risk, and Choice

The Power

Naming your variation or disability can recast the entire situation.

It gives others a frame.

It can unlock empathy that was not there before.

It can open doors to accommodation and support.

The Perceived Risk

Not everyone responds with empathy.

Disclosure can bring judgment or discrimination.

For some communities and contexts, disclosure carries real risk.

For many people, disclosure also carries shame — and we want to work against that.

Figuring out your own disclosure approach is itself an act of self-determination.

What to share, with whom, when, and in what words — that is self-determination in action.

Pride and Identity

What research tells us about minority identities

What the research shows

In cross-cultural research with neurodivergent people, we see:

- Greater disability pride in some cultural contexts than others
- A sense of gratitude — that the variation is an important part of who they are
- Pride and identity are shaped by community and how young people are raised

Why pride is protective

We know from research on other minoritized communities:

- Identity pride buffers against shame and internalized stigma
- It protects mental health
- It builds resilience
- It is woven into you — your genes, your brain, your identity
It is not a mistake

A Growing Movement: Pride in X and Y Variations

"This is a source of great strength for me."

— increasingly, what we hear from young adults with X and Y variations in their twenties

Mirrors the autism community

Just as autistic adults have found identity, community, and pride in their neurodivergence — people with X and Y variations have the same journey. The language, the frameworks, the sense of belonging are emerging.

Both strength AND disability

This is not about pretending there are no challenges. It's about holding both: yes, this can be hard. And yes, this is part of who I am and I am proud of that. Both things are true.

In-group power

Finding others with your variation — knowing you are not alone — has a protective power of its own. Community belonging is itself a form of self-determination.

This is an exciting moment — and our young people are big part of it.

Starting Early: Self-Advocacy Across the Lifespan

Early Childhood

Learn to say 'I need help.'
Learn to say 'That's too loud.'
Learn to say 'I don't understand.'

Elementary School

Know your diagnosis in age-appropriate language.
Participate in IEP meetings.
Ask for accommodations.

Middle & High School

Explain your learning profile.
Use self-advocacy in class.
Take the lead at IEP meetings.

Adulthood

Manage your own healthcare.
Request accommodations at work.
Know your rights.
Build your support network.

Structure Is Support

Making self-advocacy equitable means changing the question, not just asking louder.

The barrier: open-ended demands

"What do you need?"

Sounds supportive. But it requires:

- Language retrieval
- Big picture thinking
- Self-knowledge
- Confidence under pressure

For many individuals,
open-ended situations and questions are hard.

Silence ≠ having no needs.

The support: structured options

"Here are things many people need.
Are any of these important to you?"

This approach:

- Lowers the demand
- Shows what's even possible
- Gives real choice
- Opens a door, without putting words
in anyone's mouth

People often don't know what they
need until they see it named.

Structured options in plain language describing what's possible — that is equitable self-advocacy support.

At Home – for parents

Building the foundation

Give youth choices — real ones.

Not 'do you want to do your homework?' but 'do you want to start with math or reading?' Even small choices build the muscle.

Include them in family decisions.

Let them weigh in on things that affect them — vacation plans, weekend schedules, where to eat. Their voice matters.

Narrate your advocacy with them.

When you call the school or doctor, tell them what you're doing and why. 'I'm calling because you said the noise in gym was too much. I'm asking them to help.'

Practice the words together.

Role-play situations. 'What would you say to your teacher if you didn't understand the instructions?' Rehearsal builds confidence.

A key principle:

Parents can be the scaffolding.

Scaffolding holds things up while the building goes up — and then comes down when it's no longer needed.

The goal is always to need less scaffolding over time.

At School

From IEP participation to daily advocacy

(IEP = Individualized Education Program; similar to EHC Plan in UK, IEP in Canada)

The IEP as a self-advocacy tool

Students can attend their own IEP meetings — even elementary age. Start with 5 minutes to share one strength and one goal.

Knowing your accommodations

Students should know what their accommodations are and be able to ask for them. 'I have extended time — can I use that today?'

The teacher relationship

Teach students to introduce themselves: 'I learn best when... / I have a hard time with...'. One conversation can change everything.

Asking for help

This is sometimes harder than it sounds. Many students go silent rather than ask. Practice the exact words and situations.

In the Community

Healthcare, employment, adulthood

At the doctor

Can describe their diagnosis in plain language. Can say what symptoms they're experiencing. Can ask 'what does that mean?'

In college

Can register with disability services. Can advocate with professors. Doesn't disappear when things get hard.

At work

Can request accommodations. Can communicate when something isn't working. Knows their rights under the ADA.

In daily life

Can navigate unexpected situations. Can safely identify the authorities and speak up when something is wrong.

NASCARR

Priorities of youth and young adults with X and Y variations.



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Research Study: Building a Self-Advocacy and Empowerment Tool

Centering youth voice

Youth are not just participants — they are at the center. Advocacy organizations, parents, and providers are all at the table, but the tool is built around what young people themselves say they need.

Plain language throughout

Items are written so young people can understand and respond to supports they may never have been able to name or conceptualize before.

Equity across access

Includes young people with access to state-of-the-art interdisciplinary care AND those without — because those without may not have vocabulary for what's even possible. The tool has to work for everyone.

Rigorous iterative process

Developed with a National Council of people with lived experience. Three rounds of cognitive interviews with diverse young people across the US — testing comprehension, respect, and relevance. Final round beginning now.

Many families here tonight may be invited to be part of this project.

Your Stories & Questions

[Recording stops here]

What does self-advocacy look like in your family right now?

What has worked? What has been hard?

What questions do you have?