SAIL
SOUTHERN ADIRONDACK
INDEPENDENT LIVING
Disability-Led Collaboration in Rural Communities

What happens when we design a system for people without asking the people who actually have to live inside that system?

Usually, the answer is: we create a system that looks good on paper and doesn't work in real life.

Meet SAIL

Helping people live more independently.

Serving 7,000 people annually across 17 counties throughout New York's North Country and Capital Region through 16 grant programs. Delivering programs including health insurance enrollment, equipment loans, community-based care, housing, nutrition, and more.

At the core: by people with disabilities, for people with disabilities, with people with disabilities.

Meet Tyler Whitney

President and CEO

Southern Adirondack Independent Living

- Non-profit leader
- Disability advocate
- Human-centered approach
- Passionate about community change

Meet Cam Cardinale

Director of External Affairs

Southern Adirondack Independent Living

- Community organizer
- Disability rights advocate
- Policy strategist
- Systems change leader

The Problem Isn't People. It's Systems.

People with disabilities are often described as:

- Hard to reach
- Hard to serve
- High-need
- Transportation-dependent
- Medically complex
- Difficult to engage

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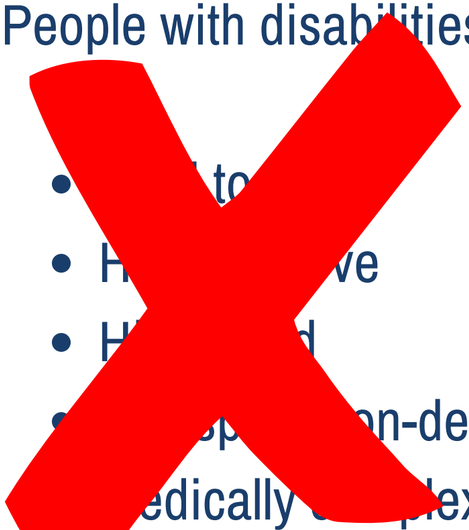
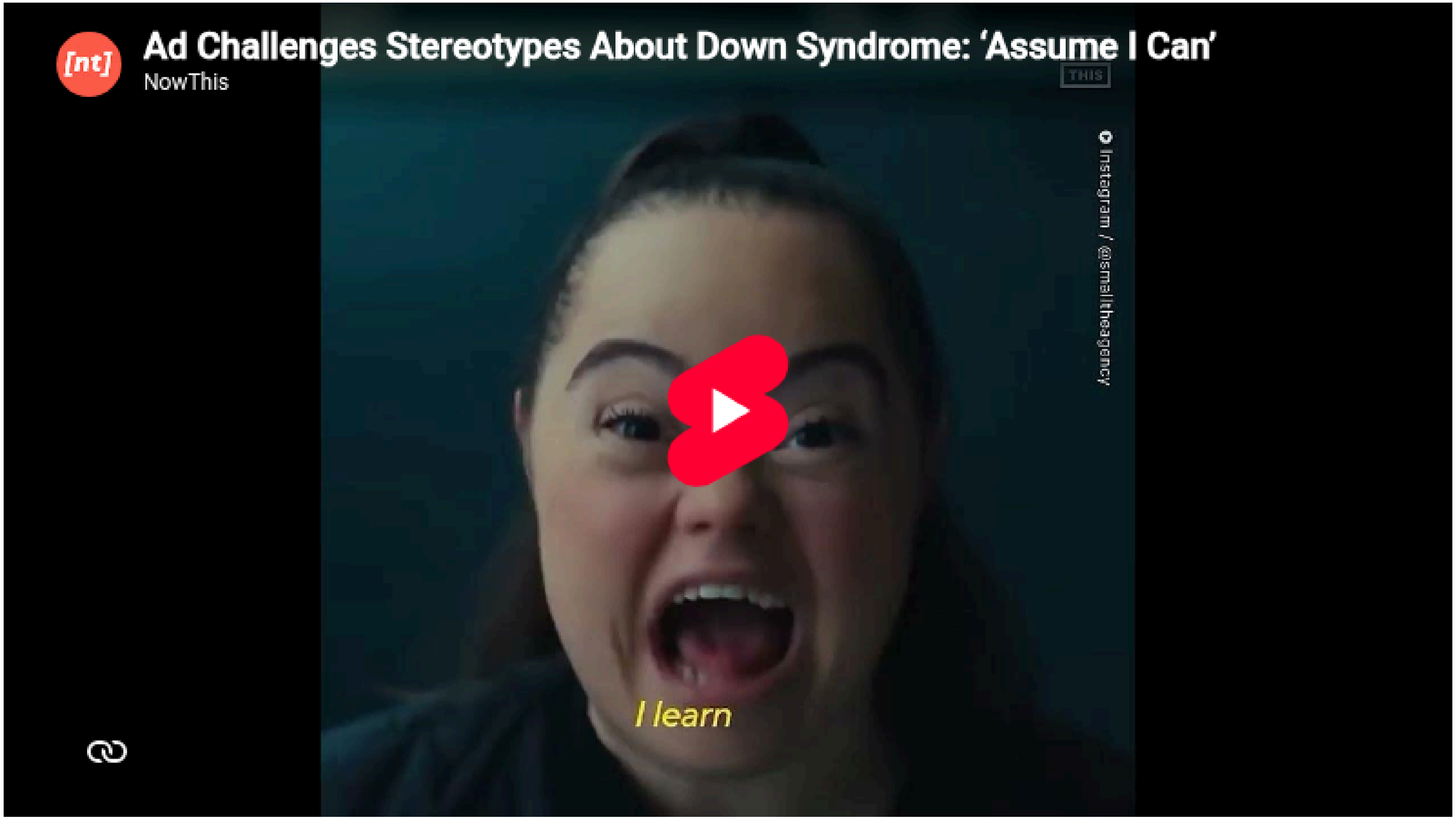


- [illegible] to
- H[illegible]ve
- H[illegible]d
- [illegible]p[illegible]on-dependent
- [illegible]edically [illegible]plex
- Difficult to engage

What if the system is hard to navigate?


[nt]
Ad Challenges Stereotypes About Down Syndrome: 'Assume I Can'
NowThis
THIS
Instagram / @smalltheagency
I learn

What does “rural” actually mean?

Don't define rural solely by population.

Rural disability access can mean:

- The nearest specialist is 60 miles away
- There is no public transportation
- The accessible apartment waitlist is years long
- One missed bus means missing an appointment
- A wheelchair repair requires leaving the county
- Broadband isn't reliable enough for telehealth
- There are only two providers—and everyone knows each other

The “Rural Stack”

- Healthcare
- Transportation
- Housing
- Employment
- Food Access
- Social Connection

Nothing About Us Without Us

Consulted → Included → Paid → Trusted → Leading

Consulted after the decision has already been made.

Tokenism vs. Partnership

- One disability representative
- Invited after decisions are made
- Asked to “review” materials
- Expected to volunteer
- Their feedback is optional
- “We have a disability advisory committee”

- Shared decision-making
- Accessible meetings
- Compensation
- Leadership opportunities
- Disability organizations at the table early
- Lived experience treated as expertise
- Accountability when recommendations aren't followed

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Lived Experience is Expertise

Clinical expertise knows medicine.

Administrative expertise knows systems.

Policy expertise knows rules.

Lived expertise knows what actually happens when those systems meet a human being.

What’s the strongest solution?

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Let’s talk barriers.

The Rural Advantage

Rural communities have something cities often don't: proximity.

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In rural communities:

- People know one another
- Organizations overlap
- Leaders sit on multiple boards
- Partnerships can happen quickly
- Local knowledge is powerful
- A small number of people can move a system

The same network that creates silos can become the network that breaks them.

Doing the Work

1. **LISTEN –** Start with people with disabilities.

2. **CONNECT –** Bring organizations together.

3. **DESIGN –** Build solutions collaboratively.

4. **TEST –** Try them in the real world.

5. **CHANGE –** Use what you learn to change systems.

Let's Try This

Can a person with a disability...

GET THERE?
GET IN?
UNDERSTAND IT?
AFFORD IT?
USE IT?
GET HELP WHEN SOMETHING GOES WRONG?
COME BACK?

Wait...

Who did you ask?

Putting it into Practice

1. One barrier people with disabilities face.

2. One organization currently working on it.

3. One organization that SHOULD be involved but isn't.

4. One person with lived experience who needs to be at the table.

5. One action you can take in the next 30 days.

Monday’s Goal:

Fix rural healthcare. Done.

Taking the Next Steps

- Invite a disability-led organization into your next planning meeting.
- Pay someone with lived experience to participate.
- Audit one program for accessibility.
- Build a referral relationship.
- Share data across organizations.
- Include disability in your community needs assessment.
- Add accessibility to your grant budgets.
- Ask who isn't represented.
- Change one policy.
- Stop doing something that doesn't work.

“How do we serve people with disabilities?”

“How do w[illegible]rve people with di[illegible]lities?”

“How do we build a system where people with disabilities have power?”

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