

# Improving Digital Literacy in the Age of Disinformation

# Hello!



Kevin Ryle  
Manager of Federal  
Government Relations

# NDSS Mission Statement

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*NDSS works to create a world where individuals  
with Down syndrome thrive*

# Responsible Communication for Complex and Contested Issues

# Organizational Trust

NDSS is a trusted community resource. When things are busy the community trusts us to provide up-to-date, unbiased information



**70,000 general  
newsletter  
subscribers**



**65,000 website  
views per month**



**7,000 policy  
newsletter  
subscribers**

# Case Study: Medicaid cuts

- Last year, Republicans proposed cuts to Medicaid as part of the "One Big Beautiful Bill Act"
- Republican leaders on Capitol Hill said these cuts wouldn't impact people with disabilities
- Democrat leaders said the opposite

# Case Study: Medicaid cuts

- While the bill had carveouts to protect people with disabilities from things like work requirements, NDSS was concerned that individuals with Down syndrome could be harmed when states had to make cuts to their budgets

# Case Study: Medicaid cuts

## What We Did

- ✓ Worked with Communications to simplify social media messaging
- ✓ Cited specific bill language
- ✓ Addressed fears and concerns about the future
- ✓ Had conversations 1:1 about Medicaid and community concerns
- ✓ Responded to positive and negative DMs

## WHAT IS NDSS CONCERNED ABOUT IN THE BILL?

### STATE DIRECTED PAYMENTS (SDP) TAX DECREASE

#### HOUSE-PASSED BILL

States would be more limited in their ability to pay their share of Medicaid. When funding is tight, optional yet critical services (Home and Community-Based Services) are typically the first cuts.

#### SENATE PROPOSALS

Makes deeper cuts to SDPs which will put a larger strain on state's budgets.

## WHAT IS NDSS DOING?

We are actively engaging with Members of Congress through meetings, phone calls, and letters; developing toolkits and resources for our community; and working collaboratively alongside other Down syndrome and disability advocacy groups.

**Medicaid is not perfect**, but drastic cuts or changes to Medicaid could have a negative impact on individuals with Down syndrome and their families.

**NDSS is committed to working with Members of Congress in a bipartisan way to improve Medicaid.**

# Case Study: Medicaid cuts

Hard Work + Patience + Staff time

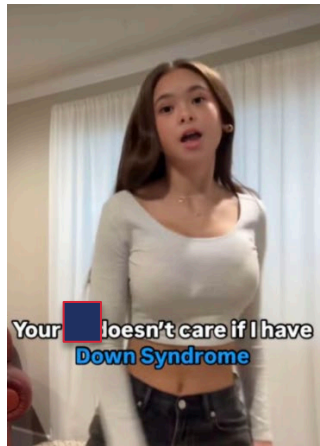


Confident advocates with increased  
organizational trust

# How We Can Help Spot and Combat AI-Generated Content

# Example 1

- Last year, our staff became aware of accounts on social media using AI technology to make it appear as if they had Down syndrome to promote OnlyFans accounts, or gaming websites



## Example 2

- More recently, an account went viral on Instagram that highlighted a young man with Down syndrome reacting to a hate comment and promoting his small business that made coasters
- This video went viral, receiving comments from celebrities, and attention from well respected people in the community.

# Example 2



# Methods to spot AI-generated content

- NDSS discussed these issues publicly and privately, offered support, and reached out to tech companies to remedy the issue
- By showing our community that we could respond rapidly and efficiently, we built trust
- Again, we offered our time to discuss potential AI generated content



ndssorg and 2 others

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**Social media accounts are using AI to impersonate people with Down syndrome**

CBS News Confirmed found more than 30 accounts across TikTok, Instagram and YouTube that are exploiting real advocates, and **making money in the process.**

Many of the profiles also pushed users to adults-only websites outside of their platforms.

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**How the Down syndrome community is responding →**



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**Down syndrome advocates respond**

Approximately 5,700 people are born with Down syndrome in the U.S. every year, according to the Centers for Disease Control and Prevention.

Many of them use social media as a platform to connect, advocate and share.

*"Those are our stories. I work so hard to advocate and share my journey online and I can't believe people would try to take that away from me,"*

Alex Bolden, who works for the National Down Syndrome Society (NDSS).

*"While there are many reasons why these fake accounts are wrong, the principle here is that individuals with Down syndrome are the only people who should be speaking about what it's like to have Down syndrome,"*

NDSS President & CEO Kandi Pickard

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**What social media platforms say →**

# Methods to spot AI-generated content

- The expectation is to ask, ask, ask
- Our community is busy handling IEP meetings, Medicaid waiver forms, and ensuring their children and loved ones with Down syndrome can thrive
- We can't make the expectation that the average person is equipped to spot AI content

# Methods to spot AI-generated content

1. Offer to review content that may appear digitally altered or AI-generated
2. Ask trusted community members if they have heard of or worked with a business seen on social media
3. Allow people to make mistakes and learn
4. Encourage patience and thoughtful responses before reacting online
5. Recognize that AI can create misleading content, and help our community respond with care, caution, and understanding

# Takeaways



Understand the AI-content is designed to and can trick anyone



Offer patience and your time to build trust



Act and respond quickly, but rationally