

# From Data to Action: Using Employment Data to Advocate for Change

October 23, 2024

# NDSS Mission

*NDSS empowers individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions.*

# NDSS Core Programs

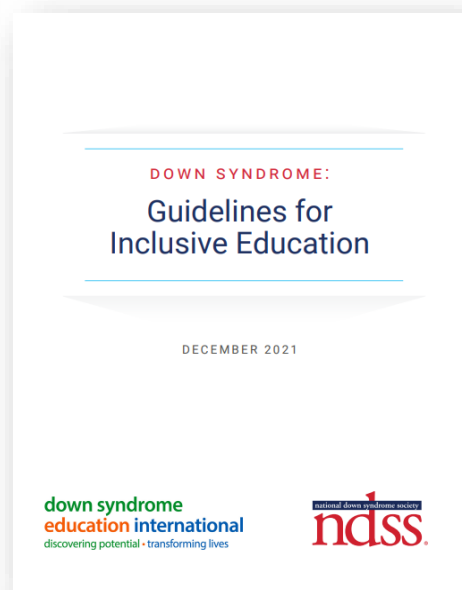
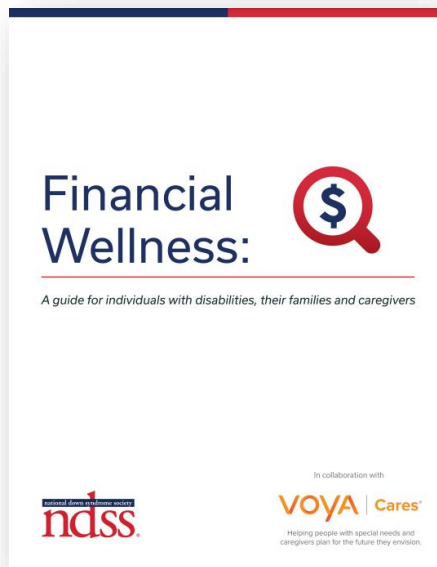
**NDSS supports and advocates for the Down syndrome community by focusing on three key areas of programming:**

- Resources & Support
- Advocacy & Policy
- Community Engagement

# NDSS Core Programs

## Resources & Support

- 1-800 helpline and info email
- Resources and information from birth to end of life
- Education, employment, health and wellness, aging, caregiving and more



# NDSS Core Programs

## Advocacy & Policy

- Federal, state and local advocacy
- Develop and improve laws to positively impact people with Down syndrome across the country and affirm their human rights
- Legislative agenda spans the life experience of individuals with Down syndrome



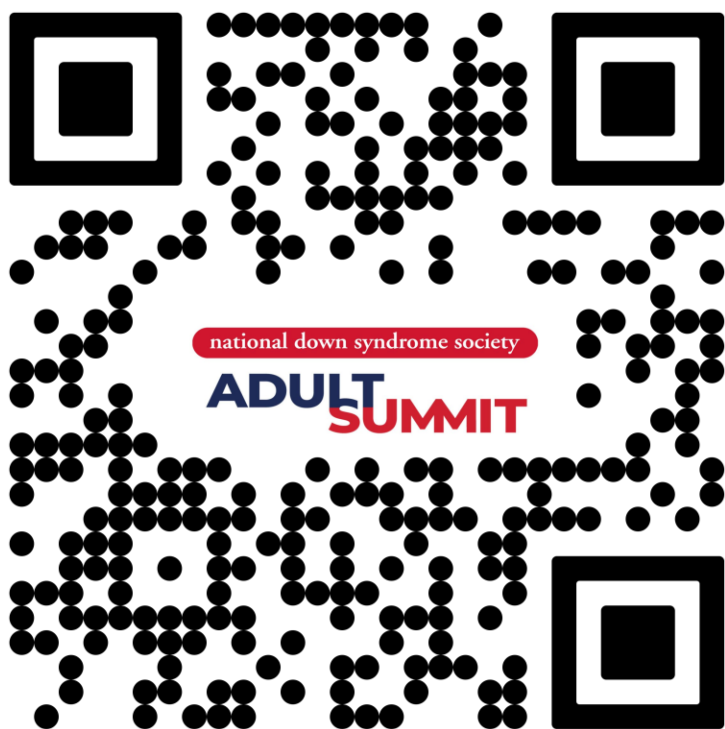
# NDSS Core Programs

## Community Engagement

- Scholarships, grants, and awards
- National Buddy Walk® Program
- Times Square Video presentation
- Athlete Ambassador Program
- Virtual Racing for 3.21 for World Down Syndrome Day
- Gala, golf, and more!



# NDSS 2024 Adult Summit



**Where:** The Westin South Coast Plaza in Costa Mesa, CA

**When:** November 14-16, 2024

**Session Topics:** Health, finance, research, advocacy, employment, education, and self-advocacy

**[Get your tickets today!](#)**

# Down Syndrome Advocacy Conference



national down syndrome society®

## Down Syndrome Advocacy Conference

**Where:** Renaissance  
Arlington Capital View Hotel,  
Washington, DC

**When:** April 28 – 30, 2025

**Register today!**



# Meet our Speakers!



**Lindsay DuBois**

*Research Associate*  
Human Services Research Institute



**Laura Vegas**

*Director of Quality Initiatives and  
Supporting Families*  
National Association of State Directors of  
Developmental Disabilities Services



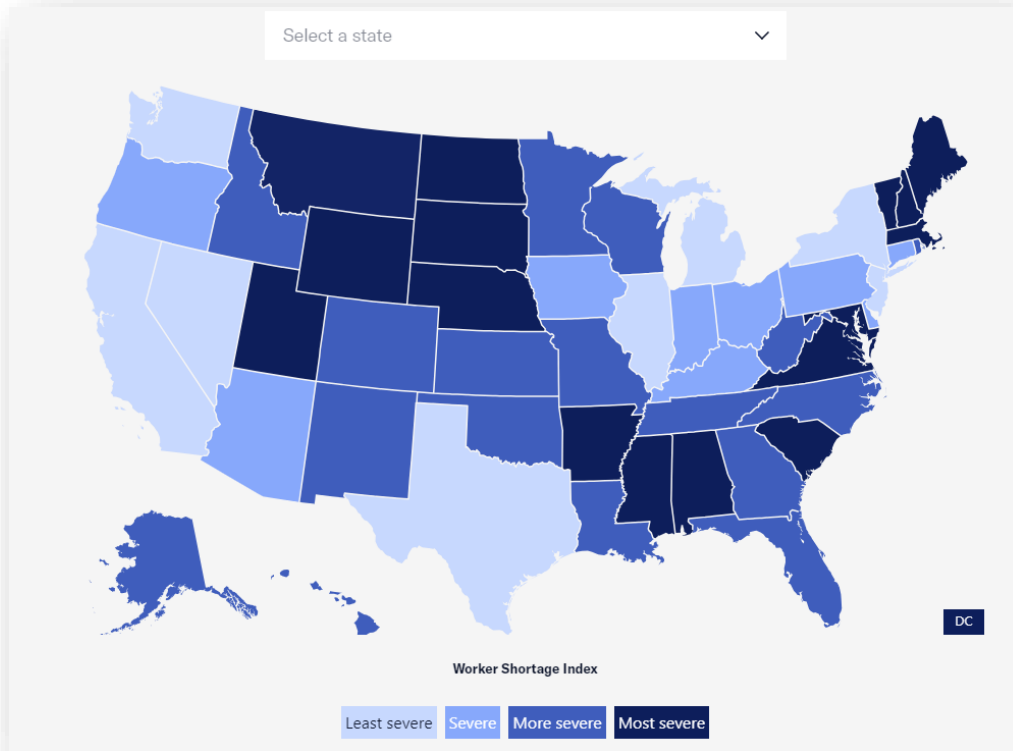
# From Data to Action: Using NCI-IDD Employment Data to Advocate for Change

# Why does employment matter?

- Nationally, high rates of employment are signs that the economy is good. So, we often see news that focuses on employment data.
- At a more individual level, having a good job is how many adults **measure their self-worth and define success**
- Employment can **lead to other good outcomes**, like being active in the community, friendships, good health, and economic stability



# Opportunities for employment



Current rate of unemployment in US (9/2024): 4.1%

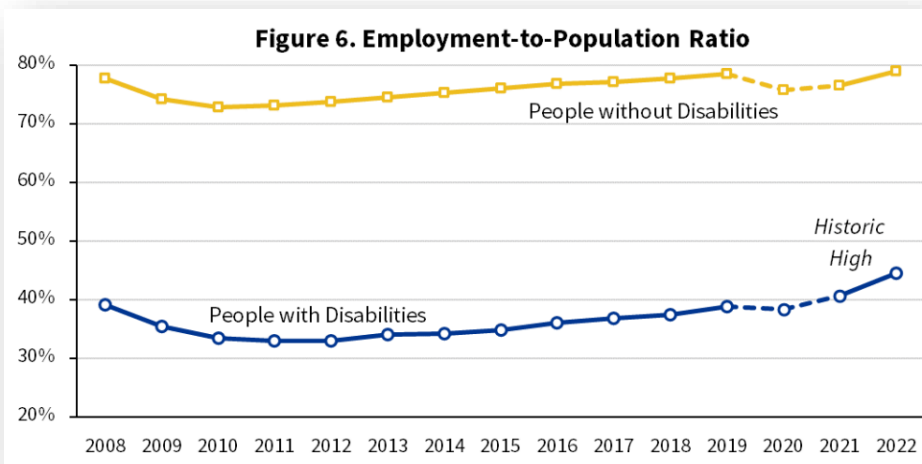
US Chamber of Commerce:

- 7.7M open jobs in the US
- 7.1M unemployed workers in the US

This map shows the worker shortage index for different states. Darker colors are the states where there are many more jobs than workers.

<https://www.uschamber.com/workforce/the-states-suffering-most-from-the-labor-shortage>

# Employment among people with disabilities (all types)



- Despite steady improvement in the rate of employment among people with disabilities, there is still a big gap between those with and those without disabilities.
- This gap is also true for wages and earnings from employment

Houtenville, A., & Bach, S. (2024). Annual Report on People with Disabilities in America: 2024. Durham, NH: University of New Hampshire, Institute on Disability

# Transition supports for people with intellectual and developmental disabilities

- Significant investments by states to enhance their transition and postsecondary programs for students with IDD
  - As of March 2023, these efforts have supported almost **5,000 college students with ID**
- Work-based learning experiences are also becoming more common in school-based transition programs



Think College National Coordinating Center. (2023). The TPSID Initiative: Opening Doors to Learning and Better Outcomes for Students with Intellectual Disability. Institute for Community Inclusion, University of Massachusetts Boston.

# Employment supports for people with intellectual and developmental disabilities



- In 2022, across the US, state IDD agencies spent slightly more than **\$1 Billion in funding on integrated employment services.**
  - This represents about 10% of all funds for employment and day services
- Employment and day services provided to **598,303 people with IDD**, of which **140,521 received an integrated employment service** from the IDD agency

Winsor, J., Butterworth, J., Migliore, A., et al. (2023). StateData: The national report on employment services and outcomes through 2021. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

# Vocational Rehabilitation Services

- Services to support people with various disabilities in achieving employment, and administered through the state's VR agency
- Data from July 2022-June 2023 shows that VR agencies helped **25% of people with ID who had a case opened with VR obtain a stable job** in their community within 1 year of starting services



Winsor, J., Butterworth, J., Migliore, A., et al. (2023). StateData: The national report on employment services and outcomes through 2021. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.





**There is a need to talk with people with IDD to find out more about their experiences with employment...**

# 14(c) certificates



- **1938:** Congress passes the Fair Labor Standards Act, including standards for basic minimum wage. Includes exceptions to pay workers with disabilities less than minimum wage
- **As of 10/1/2024,** the Dept of Labor has issued 714 14(c) certificates. These certificates cover **37,875 workers who are paid sub-minimum wages.**
- **15 states** have passed legislation to eliminate 14(c) certificates in their state

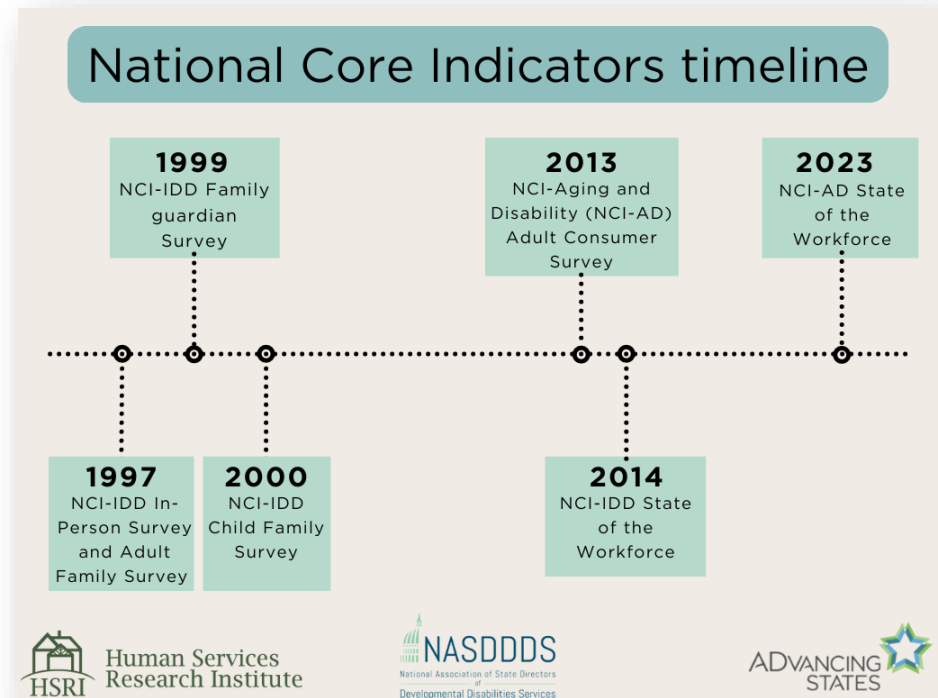
# National Core Indicators (NCI)

NCI tools collect data on performance and quality of life indicators directly from:

1. people who use disability and/or aging services systems;
2. families; and
3. those who deliver services

Participating states:

- NCI-IDD IPS and Family Surveys: 48
- NCI-AD: 26
- State of the Workforce: 30 states for the NCI-IDD SoTW, and 6 states for NCI-AD SoTW



# Goals of NCI



Establish a **nationally recognized set of performance and outcome indicators** for aging & disability (including IDD) service systems



Use **valid and reliable** data collection methods & statistical techniques to capture information directly for people who use services



Report individual state results and **national benchmarks** of indicators of system-level performance

# NCI-IDD In-Person Survey (IPS)



**Sampling:** States design their samples with guidance from HSRI. Final samples should be representative of the population that uses services.

**Inclusion criteria:**

- IDD: Person receiving at least one service in addition to case management

**Consent:** Surveyors follow state-specific consent requirements

- Those who are surveyed are informed that their services will not be impacted directly by their responses

**Surveyor training:** All surveyors complete standardized training. IPS uses peer-surveyors as well.

**Survey features:**

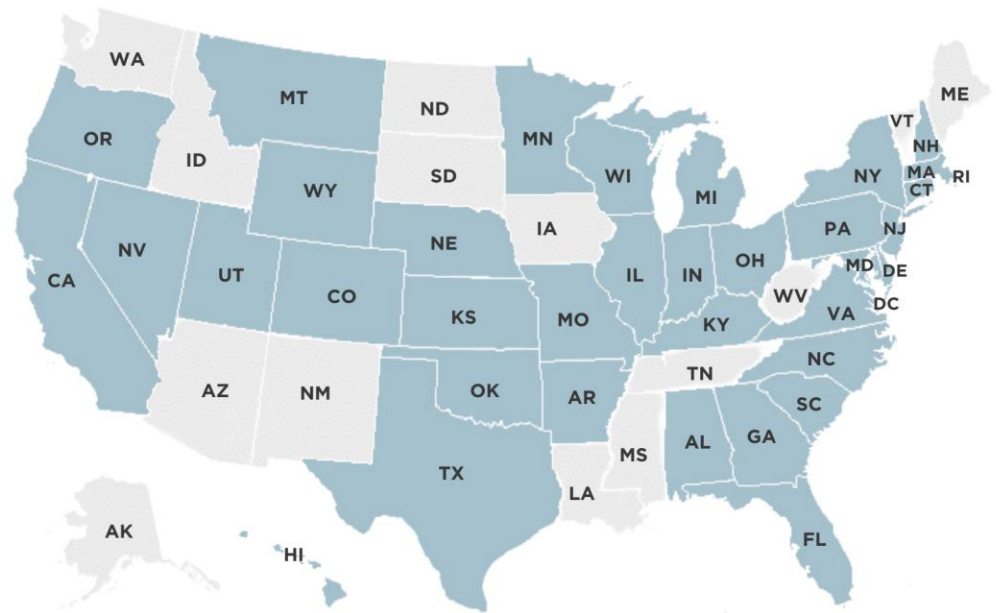
- May be conducted in-person or remotely
- Includes detailed Background Information section that primarily comes from existing records
- Surveys are available in multiple languages
- Questions may be rephrased or reworded
- Allows for use of proxy for select questions

# 2021-2023 Sample

**38,945** total respondents

**36** states

- **60% male**
- **44% aged 18-34**
- **Race/ethnicity**
  - *67% White; 17% Black; 11% Latino*
- **Diagnosis**
  - *86% ID; 29% ASD, 7% Down Syndrome*



# Other demographic data

## Residence type

- Parents/relatives' home: 44%
- Group residential setting: 33%
- Own home or apartment: 14%
- Foster care/host home: 6%
- Institutional setting: 4%

## Urbanicity

- Metropolitan: 91%
- Urban: 9%

**Co-occurring mood, anxiety, or psychotic disorder: 53%**

**Has a guardian: 50%**



# Employment among NCI-IDD respondents 2021-2023

**18%**

have a paid  
job in the  
community



**45%**

of those who  
**do not** have a  
community  
job want one





# Hours and Wages

Average hourly wages for those working an individual job in community-based settings



**\$11.80/hr**

Average hours worked over two-week period at individual job in community-based settings



**28.5 hours  
over 2 weeks**

# What is competitive integrated employment (CIE)?

Work that is performed on a full-time or part-time basis and:

- **Pays at or above minimum wage** (and comparable to peers without disabilities)
- Provides the same level of benefits to employees with and without disabilities
- **At a location where the employee interacts with others without disabilities**
- Presents opportunities for advancement similar to other employees without disabilities

# NCI-IDD data on “underemployment”



**Among those 18% of people with IDD who have a paid job:**

- About 2 out of 3 are “underemployed”
  - They earn less than minimum wage and/or
  - They work in settings that are not integrated with people without disabilities

# NCI-IDD data on competitive integrated employment

Among those 18% of people with IDD who have a paid job:

- About 1 in 3 are in “competitive integrated employment”
- This represents just 5% of the nearly 40,000 people with IDD that NCI interviewed

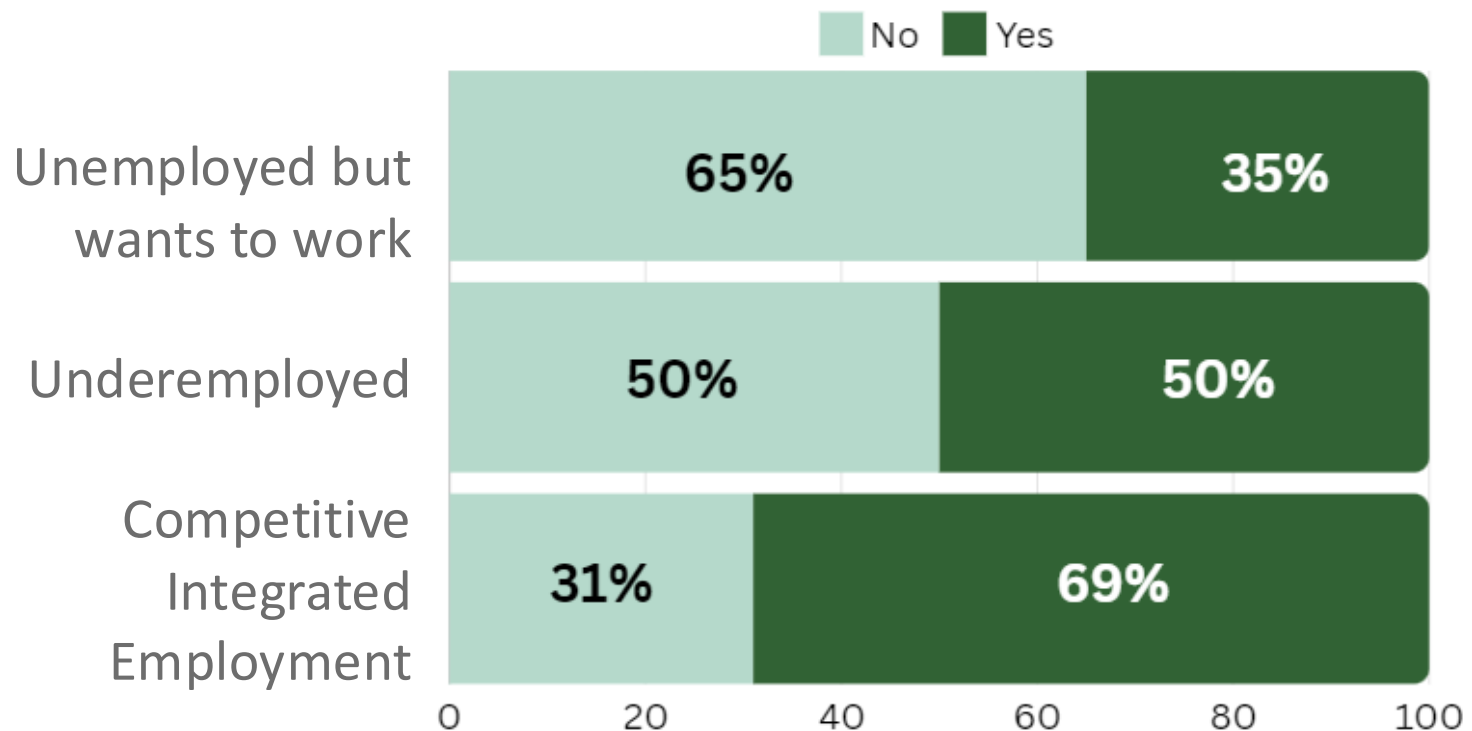


# Hours and wages for competitive integrated employment vs. underemployment settings



- **Average hours during a two-week period:**
  - Underemployed: 27.3
  - Competitive integrated employment: 28.8
- **Average hourly wages:**
  - Underemployed: \$10.70
  - Competitive integrated employment: \$11.94

# People in CIE have an employment goal at rates 2x higher than those who are unemployed



# People with Down syndrome have lower rates of unemployment but higher rates of underemployment

## Those with Down syndrome

- 37% are unemployed but want to work
- 44% are underemployed
- 20% are in CIE

## Peers with IDD without Down syndrome

- 49% are unemployed but want to work
- 32% are underemployed
- 20% are in CIE



## Improving employment outcomes



# At the individual level

- If you are still in school, make sure you are receiving transition services beginning when you are 14 years old
- Connect with friends and peers who are employed to learn more about how they got and keep their jobs
- Talk to your case manager/service coordinator about employment
- When choosing an employment service provider, look for one who has a good rate of success in getting people jobs
- Check out some resources about preparing for employment such as:
  - [Secure Your Financial Future toolkit](#) from the Dept of Labor
  - [NDSS Employment Resources](#)

# At the state level

- Work with your state to make sure they are developing strong transition programs that match students by their interests
  - Ask your state to share data about Indicator 14
- Most states are Employment First states, but they can also participate in the State Employment Leadership Network (SELN)
- Help your state eliminate 14C (subminimum wage) certificates
  - Reach out to NDSS staff if you are planning to meet with your local legislator for support
- Work with your state to explore options for people with disabilities to keep their Medicaid benefits even if they earn more money (also called Medicaid buy-in)

# Several States Offer A Continuum of Employment Services - Pay for Better Employment Outcomes

## Services

- Exploration
- Discovery
- Situational/Observational Assessment
- Job Development or Self-Employment Plan
- Job Development or Self-Employment Start-Up
- Job Coaching
- Coworker Supports
- Career Advancement
- Benefits Counseling

## State

- Alabama
- Arizona
- Maine (in development)
- Tennessee

# At the federal/National level

- Talk with your lawmakers about increasing the earnings limits allowed and keeping disability benefits.
- Talk with your lawmakers about continuing to fund the Disability Innovation Fund (DIF) program
- Talk with your lawmakers about laws and policies that create incentives to employers such as those in the Disability Employment Incentive Act
- Resources
  - [Americans with Disabilities Act](#)
  - [Work Innovation and Opportunity Act](#)

# Stay connected for updates!

NCI updates  
newsletter



NCI website:

[www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)

NCI facebook page:

[www.facebook.com/nationalcoreindicators](http://www.facebook.com/nationalcoreindicators)

# Thank you!

Contact us:

[ldubois@hsri.org](mailto:ldubois@hsri.org)

[lvegas@nasdds.org](mailto:lvegas@nasdds.org)



# Questions?



# DS-Ambassador Program



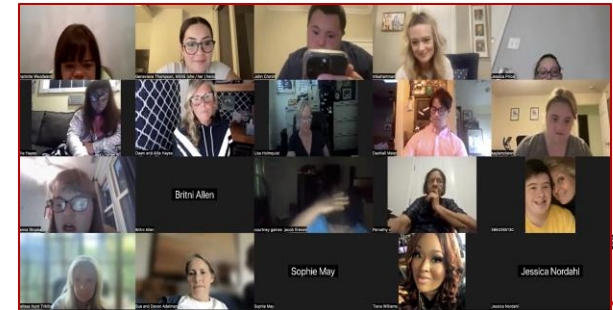
## Get Involved Today!

The overarching goal of the NDSS DS-Ambassador program is to build long-lasting relationships with decision-makers in their communities and at the federal, state, and local levels of government.

Participants in the DS-Ambassador program are volunteer advocates committed to improving the lives of the Down syndrome community.

- They advocate for policy issues impacting the Down syndrome community on the local, state and federal level.
- Ambassadors attend monthly and quarterly trainings to improve their advocacy skills.

For more information visit: <https://ndss.org/be-an-advocate>





# Post-Webinar Survey



Thank you!

Questions? Contact us at [employment@ndss.org](mailto:employment@ndss.org)