



## Human Development and Disability

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# DHDD Newsletter – April 2024



## A Note from the DHDD Director

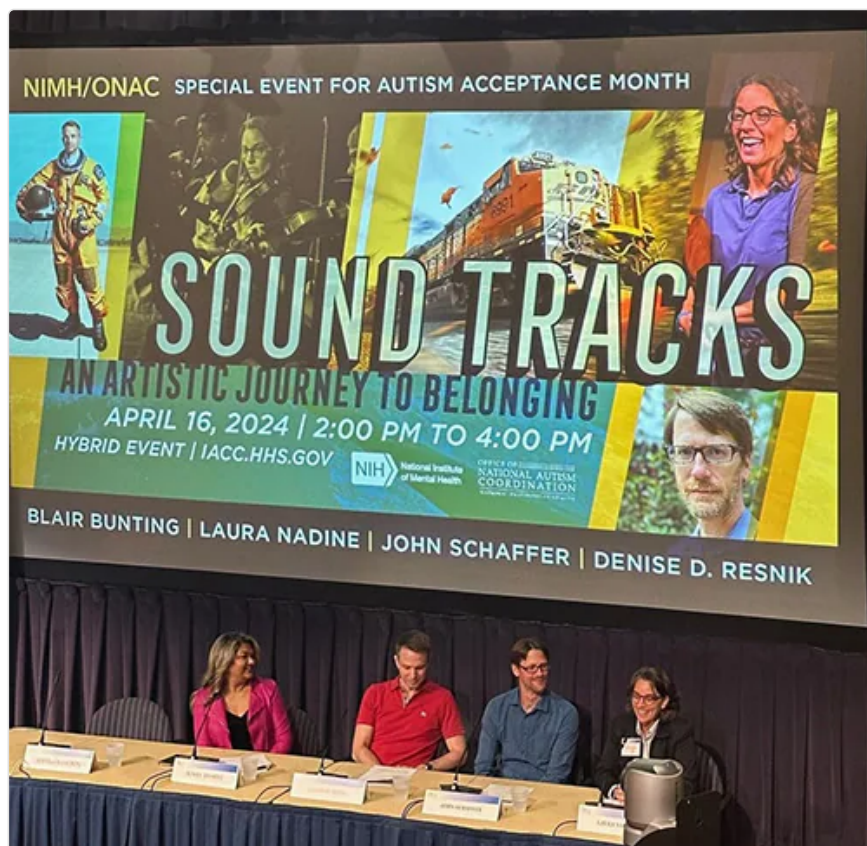
Dear DHDD Partners,

During spring, the blooming flowers and budding trees remind me of the potential that resides within everyone. At DHDD, our vision is for people with disabilities and developmental concerns to achieve their optimal health and well-being. Among our core values that are foundational to achieving that vision are diversity, equity, inclusion, accessibility and belonging. These values are demonstrated as we celebrate Autism Acceptance Month throughout April. This special observance promotes acceptance, celebrates neurodiversity, and advances inclusion and belonging for people with autism. In the months leading up to this recognition, DHDD met with partners and decision makers to share our work in understanding the number and characteristics of children with autism as well as early detection and intervention. We also discussed the importance of inclusive systems, services, and supports for belonging among children with autism.



Dr. Karyl Rattay,  
DHDD director

This month, I have also been invigorated to hear from our federal partners about their activities in autism research and education. I was particularly inspired by an event hosted by the National Institute of Mental Health's Office of National Autism Coordination titled, *Sound Tracks: An Artistic Journey to Belonging*. The event included a showing of the film *Sound Tracks*, directed by neurodivergent filmmaker John Schaffer and featuring autistic photographer Blair Bunting and autistic violinist Laura Nadine. The film was followed by an enlightening panel discussion among the three artists during which they spoke about the role of art in their lives as an important tool for communicating as well as showing emotion. The event reinforced the importance of providing opportunities in the arts to autistic people. If you did not get a chance to participate, I encourage you to view a recording of the event on the [Interagency Autism Coordinating Committee website](#) [🔗](#).



(l-r): Susan Daniels, Blair Bunting, John Schaffer, and Laura Nadine.

As demonstrated by this event, inclusion and belonging can help people with autism achieve their optimal health and well-being. DHDD has developed [online resources](#) to help you promote autism acceptance in your community. For additional information and materials, take a look at the Tools and Resources section of this newsletter. As a community of practitioners, we can advance health equity and inclusion for people with autism this month – and throughout the year.

With gratitude,  
Karyl

Karyl Rattay, MD, MS, FAAP  
DHDD Director

## In the Spotlight

### Engaging Partners on Disability Research, Training, and Outreach

Education and outreach on a variety of topics to diverse audiences is central to DHDD strategies and activities. Last month, DHDD engaged with policymakers and practitioners at federal, state, and local levels. Here's a snapshot of a few of our key activities:



(l-r): Kim Newsome, TAA Rising Leader Alexander Beck, Dr. Karyl Rattay, TAA Youth Ambassador Elinor Tu, and Helena Hutchins

### *Tourette syndrome Outreach*

In early March, DHDD participated with the Tourette Association of America (TAA) in a congressional briefing on Tourette syndrome. The briefing featured the Rising Leaders and Youth Ambassadors programs, which are supported by DHDD's partnership with TAA. These programs provide youth with TS an opportunity to increase TS awareness while developing their leadership skills.

Dr. Karyl Rattay, DHDD director, also spoke about the division's research to improve early identification of tics and tic disorders as well as capacity-building and training development for providers and educators to improve the health of individuals with TS. To learn more about our research or access free materials, visit the [DHDD TS website](#).

## Ambassador Training

DHDD's *Learn the Signs. Act Early.* (LTSAE) program hosted their annual Ambassador Training last month, with more than 50 Act Early Ambassadors participating from many states, territories, and tribal communities. Special guest speakers attended, including CDC director Dr. Mandy Cohen, NCBDDD director Dr. Karen Remley, and DHDD director Dr. Karyl Rattay. During the training, Act Early Ambassadors shared their achievements and brainstormed new ways to integrate LTSAE.



Learn the Signs. Act Early. Ambassadors participate in the annual Ambassador Training.

The Act Early Ambassadors support the work of LTSAE teams in their state to improve early identification of developmental delays and disabilities. For more information, visit the [LTSAE website](#).

## 2024 Early Hearing Detection and Intervention Conference

Several experts from DHDD's Early Hearing Detection and Intervention (EHDI) team presented the latest EHDI findings on deaf and hard-of-hearing infants at the annual conference. Topics included ways to [improve EHDI data reporting](#) as well as the importance of [comprehensive audiological exams](#) among infants who do not pass hearing screening.

DHDD also met with the Health Resources and Services Administration (HRSA) to discuss this year's collaborative efforts. Through the EHDI program, the division works with HRSA to improve early identification of children who are deaf or hard of hearing and get them the support they need. For more information on hearing health for children, visit the [DHDD EHDI website](#).



EHDI staff from DHDD and HRSA participate in the 2024 EHDI conference.

## Tools and Resources

### April is Autism Acceptance Month

Join us as we raise awareness to promote autism acceptance, celebrate neurodiversity and individual differences, and continue to advance inclusivity and connectedness throughout the community. It's also a time to renew our commitment to honor the unique lived experiences of people with autism. Working together, we can support young families as well as children and youth with autism as they transition into adulthood, helping each individual reach their full potential.



- Help show support by accessing materials and resources in CDC's [Autism Acceptance Month Partner Toolkit](#)
- Learn everyone's role in supporting [Healthcare Needs and Transition Planning for Youth with Autism](#)
- Find ways to support early identification among families with young children: [Why Act Early if You're Concerned about Development?](#)

## Publications

## Community Testing Practices for Autism within CDC's ADDM Network

A new CDC study looked at population-level testing practices among 8-year-old children identified with autism spectrum disorder (ASD) within CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network in 2018. Information about ASD test use in community practice is lacking. While there is no specific test or biomarker to diagnose ASD, an ASD test can support a diagnosis.

Findings from CDC's ADDM Network showed that ASD testing practices varied widely by ADDM site and differed by race and the presence of co-occurring intellectual disability. Across 11 ADDM Network sites, more than 60% of 8-year-old children identified with ASD had an ASD test in their records. Less than half of the children with ASD received an Autism Diagnostic Observation Schedule (ADOS) or Autism Diagnostic Interview-Revised (ADI-R).

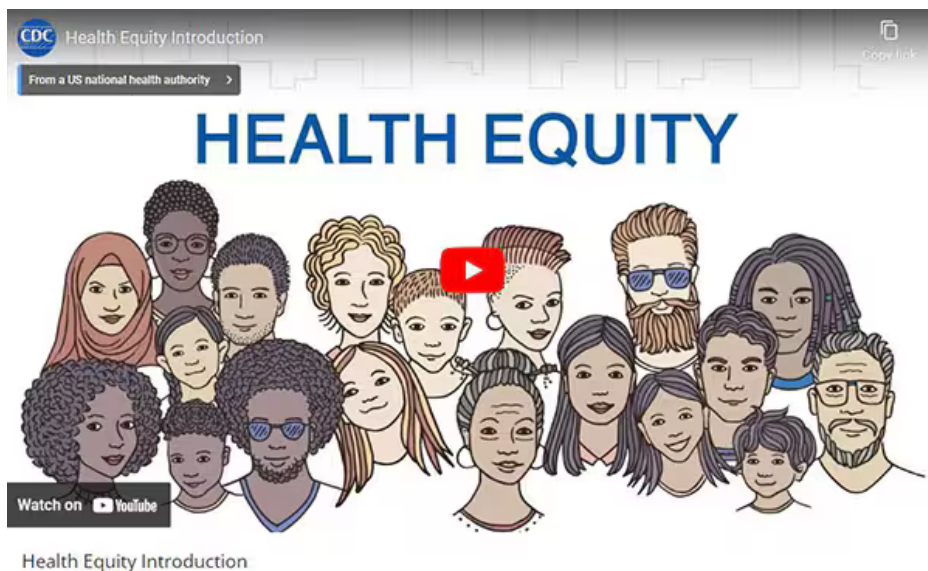
Information on ASD testing practices may help standardize and improve ASD identification to ensure all children with ASD are identified and receive the services and support they need.

[Read more from the study here.](#) 

## Around CDC

### New Resource: Communicating About Health Equity Concepts

Are you interested in communicating about health equity, but not sure where to start? CDC's Office of Health Equity (OHE) has developed the [Three Principles to Communicate About Health Equity Concepts](#) to help you communicate about health equity. The online resource includes tips for how to incorporate the principles into your communication products. OHE applied these communication principles to develop a [Health Equity Video Series](#) on health equity, social determinants of health, racism and health, and intersectionality.



[Learn more about CDC health equity resources.](#)

## Partner News and Announcements

### Surveying the Landscape of Disability Data and Statistics: A Toolkit for Interagency Collaboration

The Interagency Committee on Disability Research (ICDR) announces the release of a new toolkit titled, "[Surveying the Landscape of Disability Data and Statistics: A Toolkit for Interagency Collaboration](#)." Collecting complete and accurate data on disability is essential to addressing the many disparities that people with disabilities face across multiple facets of daily life (e.g., health, housing, employment) compared to people without disabilities. Improving data on disability will provide a strong evidence base for how to tailor policies and programs to address the equity challenges people with disabilities face. This toolkit provides an overview of the current federal landscape of disability data collection to help people with disabilities and those supporting them, disability researchers, and federal agency staff better understand current research and resources on disability data and statistics and where improvements and additional collaboration are needed. The toolkit also discusses current resources and research conducted by or funded by federal agencies and provides recommendations and resources from the field for next steps to improve disability data collection efforts.

[View the toolkit on the ICDR website.](#)

## Climate Change and the Health of People with Disabilities

In recognition of Earth Day, CDC and the [National Oceanic and Atmospheric Administration](#) (NOAA), along with other federal government partners, have released online resources about the effect of climate change on health, including among people with disabilities. Information includes the influence of climate change on health, tools to help assess risk, and ways to decrease heat risk. The resources include tools for the public and healthcare professionals.

- [CDC's Climate and Health website](#) – describes how climate change influences human health and ways to [protect yourself and others](#)
- [CDC's HeatRisk tool](#) – enter your zip code to see today's level of heat risk in your area.
- [HeatRisk Forecast Tool](#) – developed by CDC and [NOAA](#), provides a seven-day national-scale heat forecast that tells you when temperatures reach levels that could harm health.
- [CDC clinical guidance](#) – enables clinicians and their patients to create personalized plans to help ensure warmer months are enjoyed safely, with a focus on groups that may be sensitive to heat, such as people with disabilities.

Several resources provide additional information about people with disabilities, who may be at increased risk.

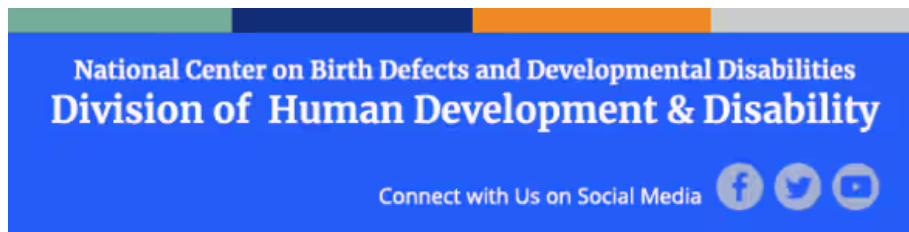
- [Environmental Protection Agency](#) – The EPA website includes a special section about the effect of climate change on the health of [people with disabilities](#).
- [National Integrated Heat Information System at Heat.gov](#) – Learn about people with disabilities and how to decrease their heat risk.
- [National Institutes of Health Climate Change and Health Initiative](#) – Discover the cross-cutting NIH effort to reduce health threats from climate change, especially among those at highest risk.

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**DHDD'S mission is to lead inclusive programs to optimize the health and development of children and adults with, or at risk for, disabilities.**



Last Reviewed: April 29, 2024

Source: National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention