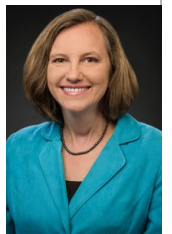




## DHDD Newsletter – July 2019



### A Note from the DHDD Director:



Dear colleagues –

The Americans with Disabilities Act, or ADA, turned '29' this month and DHDD was delighted to help celebrate this momentous occasion through the launch of a CDC Feature, an internal CDC article to agency staff, as well as continued publications and important meetings with your organizations. Additionally, we continue to promote disability inclusion through social media outlets and partner engagement. Thank you to you all for your continued collaboration and inspiring work!

– Dr. Georgina Peacock, Director, DHDD  
[dhdddirector@cdc.gov](mailto:dhdddirector@cdc.gov)

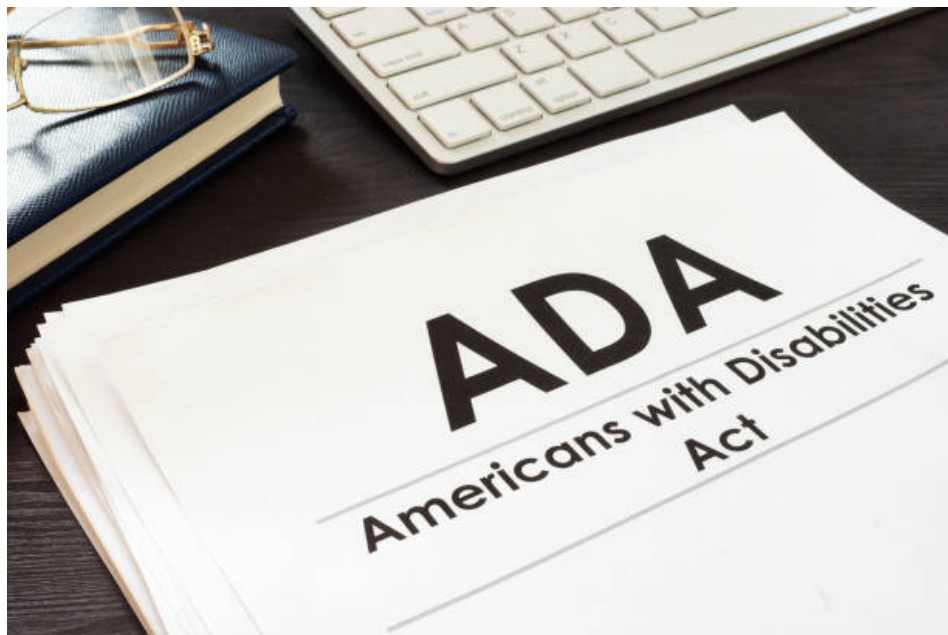
## DHDD Champions the Americans with Disabilities Act (ADA)

### NCBDDD Recognizes the 29-Year Anniversary of ADA

July 26 marks the [29th anniversary of ADA](#) [🔗](#), a landmark civil rights law that promotes equal opportunity, full participation, independent living, and economic self-sufficiency for people with disabilities, as well as protects individuals with disabilities from discrimination.

We invite you to celebrate with us and take advantage of the several resources we are highlighting this month:

- Read our [CDC feature](#) to learn how CDC is working to support the inclusion of people with disabilities in public health research and health promotion activities. Find helpful information about [disability inclusion](#) and learn more about:
  - [Barriers that people with disabilities usually experience in their communities](#)
  - [Strategies to create inclusive communities](#)
  - [Resources to include people with disabilities in public health programs and activities](#)



### Building Awareness for Disability Inclusion through Social Media

DHDD continued its disability inclusion awareness campaign this month by [celebrating the 29th anniversary of the ADA on Twitter!](#) Additionally, in late June, DHDD honored 20 years of the Olmstead decision on social media – a significant Supreme Court ruling that helps people with disabilities realize the legislative promise of full community integration. [#Olmstead](#) [#PWD](#) [#InclusionMatters](#) [#ADA29](#) [#Inclusion4Health](#)



## DHDD in Action – New Stories and Science

### [Living with Muscular Dystrophy](#)

CDC supports the Muscular Dystrophy Surveillance, Tracking, and Research Network, known as [MD STARnet](#). MD STARnet collects critical information about muscular dystrophy that will improve care for those living with the disease.

Myotonic dystrophy is one of the most common types of muscular dystrophy, characterized by progressive muscle weakness that can affect many parts of the body, including the heart and lungs.

[Read more about Paul and Carly's stories about living with Myotonic Dystrophy »](#)



### Fragile X Syndrome Awareness Day (July 22)

In a study entitled “Preventive Care Services and Health Behaviors in Children with Fragile X Syndrome [🔗](#)” researchers from CDC and other organizations present data on recommended preventive services received by children and young adults with [fragile X syndrome \(FXS\)](#).

This research points out the need for improvements in delivery of preventive services to children with FXS.

This study is based on a survey of parents of children and young adults with FXS. The survey of parents was fielded as part of the Fragile X Online Registry with Accessible Research Database, known as [FORWARD \[🔗\]\(#\)](#). FORWARD is supported by CDC.



### Composite of Post Event Wellbeing (COPEWELL) Project

A DHDD co-authored paper entitled “Top-down and bottom-up measurement to enhance community resilience to disasters” was recently accepted by the *American Journal of Public Health*.

This new paper stems from [CDC's Center for Preparedness and Response \(CPR\) COPEWELL project \[🔗\]\(#\)](#). Stay tuned for its upcoming publication!



## Tourette Syndrome Data

There are ticks, and there are *tics*. A new study authored by DHDD in the *Journal of Developmental and Behavioral* provides parent-reported data on what parents are saying about Tourette Syndrome and their child's development [↗](#).

[Learn about new data on tics here!](#)



## DHDD Partnering to Make an Impact



Photo (left to right) – Amanda Talty (TAA, President and CEO), Diana Shineman (TAA, VP Research and Medical Programs), Randi Zemsky (TAA, Board Chair), Chelsea Tollner (TAA, CDC Program Director), Jennifer Kaminski (DHDD/CDS), Elizabeth Walker (NCBDDD/OD), and Diana Felner (TAA, VP Public Policy]

This month, visitors from the [Tourette Association of America](#) [↗](#) met with leadership and staff from CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) to share their ongoing priorities, strategic vision, recent partnership efforts, and discuss new data on emerging issues for children and families living with TS.

[Learn more about the CDC's work to help children living with TS.](#)

[Check out what else DHDD and its partners have been up to here!](#)

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



Page last reviewed: May 5, 2020

Content source: [National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention](#)