

# The Delaware Network for Excellence in Autism



Quarterly Newsletter

Spring 2020/ Issue 3

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## Autism Acceptance Month: Acceptance in Action

Autism Acceptance Month is celebrated in April and focuses on the acceptance and celebration of people with autism - ourselves, our family and community members, friends, neighbors, coworkers, and classmates. During this time, we focus on messages of acceptance, respect, and inclusion of all autistic people, in all aspects of our society.

Delaware is committed to spreading the message of inclusion across our state; Governor Carney proclaimed April as Autism Acceptance and Inclusion Month!

The DNEA is proud to support autistic people, their families, and the professionals who serve them. We hope you will join us as we continue to advocate for high-quality services, education, and lifelong care for the autism community in Delaware.

[Learn more about Autism Acceptance](#)

[Learn more about the use of identity-first language \("autistic people"\)](#)



*DNEA team members from the Center for Disabilities Studies participating in Autism Delaware's Virtual Walk for Autism!*

## Highlights

### DNEA Response to COVID-19



As the world continues to adapt to the coronavirus outbreak, the DNEA remains committed to supporting the autism community in Delaware. Autism Delaware is continuing to find innovative ways to support families through programs such as Family Navigation, while Nemours Swank Autism Center is discovering opportunities to help children and their families through the use of telehealth services. The DNEA team at the Center for

Disabilities Studies is excited to offer the majority of its trainings virtually and provide virtual technical assistance to professionals and organizations in Delaware.

In this issue you will learn about some of the ways our Network members are adapting their work and finding creative solutions to ensure that individuals with autism, their families, and the professionals who serve them are supported during this challenging time. Check out the Letters from LEND on Supporting Early Autism Diagnosis in Delaware and the DNEA Evidence-Based Practice Tip of the Quarter on Social Narratives.

### CDC Announces Autism Prevalence Rate Increase

The Centers for Disease Control (CDC) published their biennial report on the number of children diagnosed with autism spectrum disorder (ASD) in March. These findings draw on data collected by the Autism and Developmental Disabilities Monitoring Network (ADDM) and represent a sampling from 11 different communities in the United States. The findings from this report offer important insights into the current state of autism identification and diagnosis across the country and will help shape future policy and practice.



[Click here to read the full report](#)

## CDC Announces Autism Prevalence Rate Increase, cont'd

### Key Findings from the Report:

**1 in 54**

8-year-olds identified with autism in 2016

The estimated percentage of 8-year-old children identified with ASD is higher than previous estimates. The current estimate of **1 in 54 children** (1.85%) represents an increase from previous reports, which indicated 1 in 59 children were identified with autism. Consistent with the 2018 report, **boys are 4 times more likely to be identified with ASD than girls.**

**1.2x**

MORE LIKELY among white and black children vs. Hispanic children

For the first time, ADDM Network data found no overall difference in the number of black children identified with ASD compared to white children. However, the **number of Hispanic children identified with ASD was lower compared to white or black children.**

Barriers to identification include stigma, lack of healthcare services, and having a primary language other than English.

**84%**

of 4-year-old children with ASD received an evaluation prior to 36 months

**Findings from the Early ADDM Report show important progress has been made toward the goal of increasing the early identification of children with ASD.** The 2016 data indicate a higher percentage (84%) of 4-year-old children identified with ASD received a developmental evaluation before 36 months of age compared to 2014 data, which indicated only 74% of 4-year-old children received an evaluation before 36 months of age.

### What is the Takeaway?

Promising progress is being made to ensure early screening and identification of children with ASD across communities. However, these findings suggest that the need for services and supports is likely to continue to increase over time.

## Evidence-Based Practice Tip of the Quarter

### Social Narratives

**What Is It?** Social narratives are short stories that use concrete text, photos, or drawings to explain situations or skills that may be confusing to an individual with autism. They use easily understood language and images to provide learners with an explanation of the event. This is often followed by examples of how to positively respond to the situation.

#### How do I use it?

1. Select a social narrative that explains the situation, event, or skill you want to teach your learner.
2. Choose a social narrative format that matches the way your learner best understands information:
  - **Photos** should be used if your learner understands photographs of real objects.
  - **Symbolic pictures** should be used if your learner understands colored drawings of objects.
  - **Line drawings** should be used if your learner understands black-and-white drawings of objects.
  - **Text** should be used if your learner understands written words and numbers.
3. Develop a routine of when you will read the social narrative with your learner. Try to do it at the same time every day. If possible, it is helpful to review it before the target situation or event occurs. It is important to use social narratives proactively.
4. Praise your learner for reading the social narrative with you every time that you review it.
5. When the event, situation, or skill occurs, it is helpful to prompt and praise your learner by using the language that is used in the social narrative.
6. If your learner needs help doing the skills explained in the social narrative, you can model how to do each skill or practice by doing the skill with them.

#### COVID-19 Social Narratives

Explaining COVID-19	Giving Personal Space	Handwashing	Social Distancing	Isolation
<a href="#">Text &amp; Pictures</a>				
<a href="#">Text Only</a>	<a href="#">Text Only</a>	<a href="#">Text &amp; Photos</a>		
		<a href="#">Text Only</a>		

## Letters from LEND

### Supporting Early Autism Diagnosis in Delaware

By: Emily Curtin, MA

Research shows early intervention leads to better cognitive performance, language development, and adaptive behaviors for many children with autism spectrum disorder (ASD) (Anderson et al., 2009; Estes et al., 2015; Warren et al., 2011). However, in order to access ASD-specific interventions, children with ASD must first be identified. Data suggest that ASD diagnoses made before age 2 are stable over time, yet most diagnoses occur after age 4 (Zwaigenbaum et al., 2015). Additionally, research shows that children who are part of racial or ethnic minority groups, from low socioeconomic status families, or living in under-resourced areas are at an increased risk of delayed diagnosis (Daniels & Mandell, 2013).



*Emily Curtin, second from right, and her fellow trainees participating in a LEND didactic session*

As part of my training in Delaware's Leadership Education in Neurodevelopmental Disabilities (LEND) program, I help conduct ASD diagnostic evaluations at Child Development Watch (CDW), Delaware's early intervention program. CDW and Nemours/Alfred I. duPont Hospital for Children have teamed up to provide ASD-focused evaluations in order to maximize the supports provided to children under three. I accompany Dr. Allyson Davis, a psychologist at Nemours Swank Autism Center and former LEND trainee, to the Dover and Milford CDW sites to conduct toddler ASD assessments with downstate families who might otherwise not have easy access to autism specialists.



First, families come in for an evaluation that consists of a parent interview and Autism Diagnostic Observation Schedule, Second Edition (ADOS-2). Parent interviews offer additional insight about the child's development, social communication skills, and behaviors. The ADOS-2 is a play-based observational measure that is considered the "gold standard" instrument for diagnosing autism. While it is not required, the results of the ADOS-2 are especially helpful in determining whether a diagnosis is appropriate.

## Supporting Early Autism Diagnosis in Delaware, cont'd

I have been administering the ADOS-2 under Dr. Davis' supervision since attending a clinical workshop in January. Working one-on-one with toddlers, some as young as 16-months old, has shown me how early the signs of autism can be present.

During the evaluation parents share their concerns, and although all are unique, we often hear similar statements:

“Even as an infant, he didn't look at me very much.”

“I thought she'd be speaking by now, but she's nearly 3 and only babbles.”

“He seems advanced in some areas but struggles in many others.”

“He plays on his terms and doesn't like others intruding.”

“She will tantrum for an hour and we can't calm her down.”

A few weeks after the evaluation appointment, parents attend a feedback session to receive the results of the assessment, a diagnosis if warranted, recommendations for next steps, and instructions about accessing further services. Dr. Davis explains the characteristics of ASD and how to work evidence-based behavioral interventions

into everyday home activities. Some parents nod as their child is described and say, “We always knew it was autism.” Others are skeptical and ask, “What if this is just a speech delay? Does he really need more services?” Research indicates that the manner in which the message about early intervention is shared with families is important to parents (Edwards et al., 2016). Accordingly, Dr. Davis and CDW service coordinators offer an empowering message: “You know your child best. By coming here to investigate your concerns, you've already made the right decision.”



*A Nemours clinician providing telehealth services.*

Unfortunately, waitlists for ASD assessments can be long, and COVID-19 has further complicated this problem. Although ASD diagnosis via telemedicine has made great strides, at present, the

## Supporting Early Autism Diagnosis in Delaware, contd.

ADOS-2 must be administered in-person. For now, Dr. Davis and I will meet with families via telemedicine to conduct the parent interview portion of the evaluation.

When it is safe to meet in person, we will administer the ADOS-2. Although this is not a perfect solution, I am excited to gain experience using telemedicine to assess ASD, as it is a growing mode of assessment (Juárez, et al., 2018; Stainbrook et al., 2018).

I will take what I've learned at CDW into my career as a school psychologist, and ideally, as a part of a district ASD assessment team. My LEND experience, and the CDW/Nemours partnership in particular, has given me invaluable experience with ASD evaluation and has demonstrated why early diagnosis and intervention are vital. Additionally, Dr. Davis and CDW service coordinators have modeled exceptional family-centered care. Most importantly, families have shown me how they courageously put their trust in providers and the early intervention model, even if they are doubtful or scared. As a future provider, I want to be worthy of their trust.

- ***Emily Curtin, MA** is a 2nd year graduate student studying School Psychology at the University of Delaware and a School Psychology Trainee in the Delaware LEND program.*

## About Letters from LEND



LEND (Leadership Education in Neurodevelopmental and related Disabilities) is an interdisciplinary leadership training program with 52 programs across the country. The Delaware LEND is led by the Center for Disabilities Studies at the University of Delaware and offers a short-term, medium-term, and long-term training

experiences. LEND trainees include graduate students from various fields, post-doctoral fellows, self-advocates, and family members of children with disabilities. Through participating in LEND, trainees develop knowledge and skills needed to become leaders working with and on behalf of people with disabilities. Visit the [Delaware LEND website](#) to learn more.

## By the Numbers

### Our Network Impact: 2016 - Present

#### Professionals Trained

- The DNEA has expanded its statewide trainings and developed intensive organization-specific initiatives in order to streamline and enhance the services provided to children and adults with autism and their families in Delaware.
- **3,798** education, mental health, healthcare, employment and other professionals trained statewide, with a **94% increase** in the total number trained over the past two years
- **208 first responders, mental health clinicians, and school professionals** currently engaged in intensive training, coaching, and/or case consultation in order to build internal capacity to support people with autism

#### Information & Resources

- The DNEA works hard to ensure the Delaware community is informed and knowledgeable about information and resources related to autism and issues that impact people with autism, their families, and professionals in our state.
- **10,000 + early childhood autism resource guides** distributed by Summer 2020 to community organizations, school districts, and medical providers, in collaboration with the DNEA
- **5,525 DNEA- supported autism resource and materials** distributed to Delaware families and professionals

#### Family Navigation

- With 15% of Family Navigation services funded by the DNEA, Network partner Autism Delaware has continued to strengthen its capacity to support individuals with autism and their families across Delaware.
- **1.5 Family Navigators** hired in FY17
- 10,697 Family Navigation contacts, a **75% increase** from FY17 to present
- 2x the number of **families supported in Kent and Sussex Counties from FY17 to present**

## Upcoming Trainings

**We are pleased to offer the following DNEA trainings virtually:**

**Introduction to the Principles of Applied Behavior Analysis (ABA) for Supporting Students with Autism**

April 22, 2020

9am - 12pm

May 13, 2020

9am - 12pm

**Evidence-Based Instructional Strategies for Autism: Least-to-Most Prompting, Most-to-Least Prompting, and Graduated Guidance**

April 22, 2020

1pm - 4pm

May 13, 2020

1pm - 4pm

**Introduction to Visual Supports for Students with Autism**

May 19, 2020

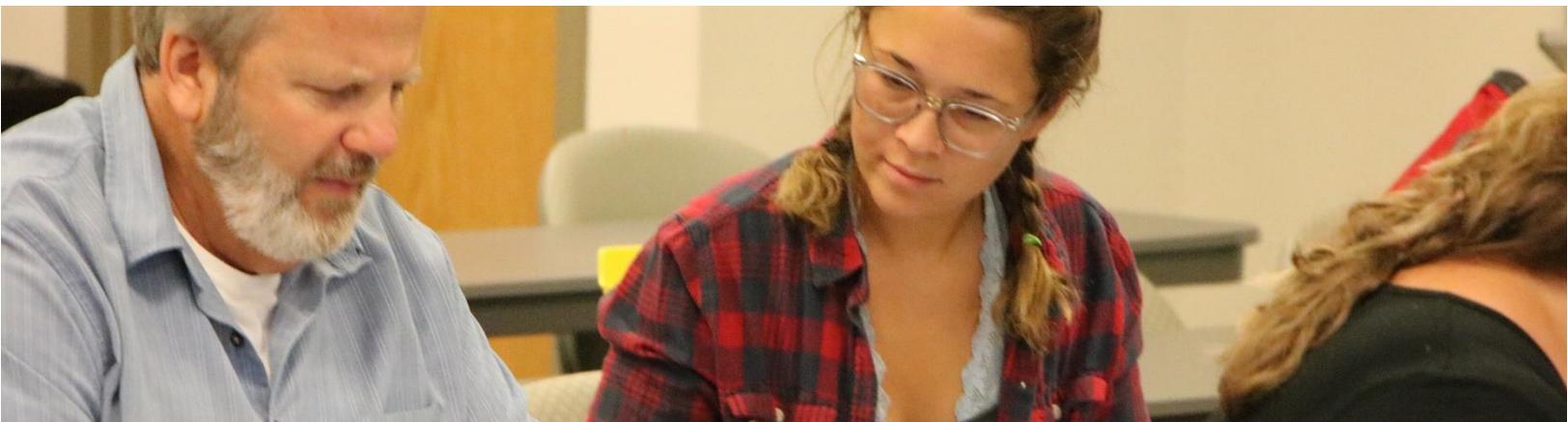
9am - 12pm

**Success with Social Skills**

May 19, 2020

9am - 12pm

[Click here to register](#)



# About the DNEA

The Delaware Network for Excellence in Autism (DNEA) is the state's training and technical assistance center for autism spectrum disorder (ASD).

Housed at the University of Delaware Center for Disabilities Studies and conducted in partnership with Autism Delaware and in collaboration with Nemours/Al duPont Children's Hospital, the DNEA provides training and support to professionals and organizations as well as children and adults with autism and their families.

We leverage interdisciplinary expertise and resources among our members and other organizations to ensure that individuals with autism and their families have access to high quality education, services, and evidence-based care.



## Connect With Us



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