

**Delaware Network for Excellence in Autism
Legislative Report
FY2020**

Delaware Network for Excellence in Autism Providers

University of Delaware Center for Disabilities Studies (CDS), DNEA Partner

Autism Delaware (AD), DNEA Partner

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A note on wording. In this report, we use the term *autism spectrum disorder (ASD)* and *autism* interchangeably. You will also see the use of “*person-first language*” (a person with ASD) and “*identify-first language*” (an autistic person).

Who We Are

The Blueprint for Collective Action

In 2013, Delaware published its Strategic Plan to Improve Services and Supports for Individuals with Autism Spectrum Disorder, referred to as the *Blueprint for Collective Action* (“the Blueprint”). The Blueprint is the result of a two-year comprehensive community needs assessment and planning process, with information gathered from and discussed among family members, people with autism spectrum disorder (ASD), providers and professionals, and other community members.

The Blueprint outlines important recommendations for the state categorized into seven Improvement Areas. These recommendations are designed to address the ongoing needs of infants, children, youth, and adults with autism and their families living in Delaware.

As a means to accomplish these recommendations, stakeholders collectively endorsed two systemic activities: (1) an autism resource center; and (2) an executive group of state-decision makers and parents.

In 2016, under the leadership of Senator Margaret Rose Henry and Representative Earl Jaques Jr., Delaware Senate Bill 93 (SB93) was passed. It resulted in the creation of the Delaware Network for Excellence in Autism (DNEA) and Interagency Committee on Autism (ICA).

The Delaware Network for Excellence in Autism

The DNEA is the state’s autism training and technical assistance center and is led by the University of Delaware Center for Disabilities Studies (CDS) in partnership with Autism Delaware. The DNEA provides training and support to professionals and organizations, as well as children and adults with autism and their families.

The DNEA leverages interdisciplinary expertise to ensure all Delawareans with autism and their families have access to high-quality education, services, and evidence-based care across the lifespan. The DNEA offers training and support to professionals and families in a variety of ways. For example, the DNEA offers large-scale statewide trainings; tailored workshops and technical assistance to meet specific organizational needs; and targeted support provided through webinars or onsite coaching. CDS mainly oversees the provision of professional training while Autism Delaware addresses family needs through family navigation and parent training. The DNEA subcontracts with other experts and organizations, as needed.

By establishing a network, the DNEA utilizes additional expertise and resources from ICA members and local, regional, and national experts in order to offer far-reaching, more impactful support for all community members.

The Interagency Committee on Autism

The ICA is composed of key stakeholders within the Delaware autism community. It includes 14 different state agencies and community organizations, a parent/caregiver from each county, and a person with autism. The DNEA director serves as the Administrative Chair of the ICA and facilitates the coordination of ICA meetings, reporting, and activities.

The ICA leverages resources across member organizations and agencies to develop coordinated approaches to implementing improvements outlined in the Blueprint. The ICA identifies gaps or overlaps in services, advises the Delaware General Assembly on recommendations for legislation, and oversees the development of goals and priorities for the DNEA.

Why We Matter

The Centers for Disease Control report 1 in 54 children is diagnosed with autism spectrum disorder (ASD; Maenner et al., 2020). ASD rates in Delaware mirror those reported nationally, with students with ASD representing between 9.41% (6 - 21-year-olds) and 16.15% (3 - 5-year-olds) of all students receiving special education services (Delaware Department of Education, 2020); this represents a more than *three-fold* increase since 2004.

Individuals with autism may face difficulties learning, communicating, and managing stress. However, the greater challenge is often living in a world that lacks the awareness and tools to effectively support autistic people and their families. People with autism are more likely to experience additional health and mental health concerns than the general population and often face barriers to accessing employment, transportation, community activities, health care services, and other services that support their day-to-day living needs (Roux, et al., 2017).

The Interagency Committee on Autism (ICA) and the Delaware Network for Excellence in Autism (DNEA) are the only entities of their kind in the state that are working to address roadblocks in providing high-quality care to all Delawareans with autism in an efficient, coordinated, and person-directed manner.

With an increasing prevalence of autism and a clear demonstration of the need for continued support, the DNEA has become a critical provider of large-scale and wide-spread training, technical assistance, coaching, and support for families and professionals in the state of Delaware. The DNEA's work ensures the state is equipped to provide high quality education, services, and evidence-based care to autistic people and their families by empowering professionals to work with and support children and adults on the spectrum.

Delaware Network for Excellence in Autism (DNEA) Activities

The following section reports on the activities of the Delaware Network for Excellence in Autism (DNEA) between July 2019 and June 2020. These activities are organized into five sections: (1) Statewide Trainings; (2) Capacity Building Initiatives; (3) Community Training and Technical Assistance Requests; (4) Information Dissemination and Community Outreach; and (5) Family Supports. Each section includes a summary of FY2020 DNEA activities by describing the scope and impact of the initiatives. Associated *Blueprint for Collective Action* improvement area(s), and DNEA network partner(s) and subcontractor(s) associated with the work will also be shared.

Statewide Trainings

Statewide trainings are large-scale trainings for professionals and family members who support individuals with autism. They are designed to be inclusive of individuals who work in a wide-range of settings and focus on evidence-based practices that can be implemented across the lifespan. DNEA statewide trainings address Blueprint for Collective Action Improvement Area 2 (Training and Technical Assistance) and are developed and led by University of Delaware Center for Disabilities Studies (CDS) DNEA staff in collaboration with Nemours Swank Autism Center staff.

The DNEA offered in-person trainings across all three counties until March 2020, at which time trainings were moved to a virtual platform in response to COVID-19. In FY2020, the DNEA made significant updates to its statewide trainings by releasing new content; updating existing content; and offering face-to-face and virtual training sessions.

New Training Content

A total of eight new trainings were developed and released in FY2020. These trainings broadened the depth and breadth of workshops available to families and professionals seeking to learn more about ASD and the evidence-based practices that can be used to support this growing population of Delawareans. The training content ranged from introductory to advanced, thus providing interested professionals the opportunity to select a training entry point that matched their current ability and systematically build their knowledge and skills over time. An abstract of each of the new training topics can be found below.

Introduction to Autism Spectrum Disorder. This introductory training provides a basic overview of autism. It includes content about disability-friendly language, the history of autism, core characteristics of autism, and general tips and considerations when supporting people with autism across a variety of settings. Delaware resources are also reviewed.

Introduction to Evidence-Based Practices for Autism Spectrum Disorder. Designed as a follow-up training to *Introduction to Autism Spectrum Disorder*, this training provides an overview of the evidence-based practices that are most effective when supporting individuals with autism of all ages. The training reviews the core characteristics of autism and introduces three evidence-based practices: visual supports, prompting, and reinforcement.

Introduction to Applied Behavior Analysis (ABA) for Supporting the Instruction of Students with Autism. This introductory training is designed to focus on educational settings by providing attendees with foundational knowledge about the principles of applied behavior analysis (ABA) and how they are incorporated into evidence-based practices for individuals with autism. Participants review the core characteristics and the learning needs of students identified as having autism. Time is spent understanding ABA, task analysis, reinforcement, and the learning cycle in preparation for more advanced instructional trainings.

Introduction to Evidence-Based Instructional Practices for Autism Spectrum Disorder: Least-to-Most Prompting, Most-to-Least Prompting, Graduated Guidance, and Simultaneous Prompting. Participants are introduced to the basics of instructional prompting and trained in four specific evidence-based practices for supporting the learning of individuals with autism:

least-to-most prompting, most-to-least prompting, graduated guidance, and simultaneous prompting. Data collection procedures for these strategies are introduced.

Advanced Instructional Practices for Autism Spectrum Disorder: Progressive and Constant Time Delay. Participants review the basics of instructional prompting and are trained in three specific evidence-based practices for supporting the learning of individuals with autism: simultaneous prompting, constant time delay, and progressive time delay. Data collection procedures for these strategies are introduced.

Introduction to Visual Supports for Students with Autism. This introductory training provides participants with an overview of the importance of the evidence-based practice of visual supports for students with autism. Participants learn the process for implementing visual schedules, cues, boundaries, and timers within an educational setting.

Classroom Data Collection. This training reviews classroom-based data collection systems, procedures, and methods designed to measure student learning and instructional efficacy. Participants learn how to design data collection systems that ensure fidelity across team members and tracking mechanisms for streamlining team planning.

Understanding Autism and Strategies for Childcare Providers. CDS DNEA staff collaborated with Autism Delaware to develop a childcare training aligned with the Delaware Institute for Excellence in Early Childhood (DIEEC) professional development standards in response to the need for childcare providers to be equipped to support children with autism at their centers. The training content went through a rigorous quality assurance (QA) process and received DIEEC QA status in FY2020. Childcare staff from DIEEC accredited centers will be able to begin taking the training in FY2021.

Updated Training Content

Existing statewide trainings were updated to reflect current best practice and advancements in the field. All training content was moved to universal templates (e.g., PowerPoints, handouts, resource guides) that include accessibility features consistent with Section 508 guidance, and structural components that align with best practice, such as universal design for learning. Additionally, popular trainings, such as *Success with Social Skills*, were updated to include updated scholarship and best practice in the field.

Statewide Trainings Offered

DNEA trainings have historically been offered in a face-to-face format across the three Delaware counties. However, COVID-19 necessitated that training content shift to a virtual platform in March 2020. The DNEA was able to continue offering regularly-scheduled trainings via Zoom; enrollment numbers were consistent with, and in some cases higher than, those offered in a face-to-face format. A summary of DNEA statewide trainings offered in FY2020 can be found in Table 1.

Table 1*DNEA Statewide Trainings Offered in FY2020*

Training title	Times offered	Total attendees
Existing training content		
Classroom management	3	31
PEERS for school professionals	1	12
Success with social skills	4	74
Understanding autism and classroom strategies	4	82
New training content		
Introduction to autism spectrum disorder	2	58
Introduction to evidence-based practices for autism spectrum disorder	1	20
Introduction to the principles of applied behavior analysis	5	173
Introduction to evidence-based instructional practices for autism	3	67
Advanced instructional practices for autism spectrum disorder	1	14
Introduction to visual supports for students with autism	2	50
Classroom data collection	3	72
FY2020 Total	29	653

Capacity Building Initiatives

In FY2020 the DNEA expanded its training and technical assistance to include intensive supports designed to build the internal capacity of organizations and local education agencies. The DNEA designed targeted content tailored to meet the unique professional needs of attendees. These initiatives focused on providing ongoing training, coaching, and technical assistance to a core set of staff members who frequently work with individuals with autism and are uniquely positioned in their organization to become a trusted resource of information about autism to their

colleagues. Capacity-building initiatives addressed *Blueprint for Collective Action* Improvement Area 1 (Training and Technical Assistance), and Area 7 (Systems Coordination) and were executed by CDS DNEA staff in collaboration with Nemours Swank Autism Center and other community organizations (e.g., Center for Start Services). In FY2020, the DNEA provided comprehensive support to *Appoquinimink School District*, and the *Division of Prevention and Behavioral Health*.

Appoquinimink School District. The DNEA piloted and refined a comprehensive training program designed to build the internal capacity of school districts to support students with autism. In collaboration with the Office of the Statewide Director (OSD) of Delaware Autism Programs, Appoquinimink school district was selected to engage in the training program due to its rapidly growing new autism program (i.e., RISE). An intensive series of monthly didactic and coaching sessions were provided to special educators who worked in RISE. Didactic sessions highlighted specific evidence-based practices and coaching sessions engaged RISE teachers in a structured cycle of planning, teaching, and reflecting called *Action Planning*. This recurring coaching and technical assistance activity allowed RISE teachers to practice designing and implementing evidence-based instructional plans with guidance from DNEA staff. The DNEA assisted district-based Board Certified Behavior Analysts (BCBAs) in supporting RISE teachers through monthly technical assistance calls. Student progress was shared with DNEA staff at monthly professional learning community (PLC) meetings so they could assist RISE teachers in making data-based instructional decisions, and model strategies for collaborating with professional peers. The DNEA led an additional training session with other school professionals who frequently interacted with students with ASD in order to introduce them to the core characteristics of autism and introductory practices for supporting this population of students. The larger training helped ensure a broader understanding of autism amongst the school community.

A total of 56 professionals engaged in training and technical assistance activities with DNEA staff during the first year of the pilot. A subset of five RISE teachers, supporting over 25 students with autism, completed the entire intensive training series. Intensive training with an additional subset of 12 special educators from the Foundations Program was initiated; however, this work ended at the onset of the pandemic due to the shift to virtual learning. Table 2 summarizes the training and technical assistance provided to the school district in FY2020.

Table 2*DNEA Training and Technical Assistance Activities in Appoquinimink School District*

Audience	Activity	Number of sessions
RISE teachers	Didactics	6
	Coaching and technical assistance	6
Foundations teachers	Didactics	2
	Coaching and technical assistance	1
BCBA coaches	Technical assistance calls	8
Other school professionals	District-wide training session	1

Division of Prevention and Behavioral Health. In FY2019 the DNEA worked with the Division of Prevention and Behavioral Health (PBH) to implement a comprehensive training and technical assistance program designed to systematically improve the internal capacity of identified units within PBH to support individuals with ASD with co-occurring mental health needs. Mobile Response and Stabilization Services (MRSS), Delaware’s youth mobile crisis unit, was the first unit identified to receive the training and technical assistance package; work with the unit began during the summer of 2019.

The DNEA provided a full day of training in each county to all MRSS clinicians and supervisors in collaboration with the Center for Start Services. A total of 75 professionals engaged in the training, which focused on understanding the core characteristics of autism, co-occurring mental health needs, and evidence-based supports. Seven leads were identified within the MRSS unit to engage in an additional four didactic sessions. Leads also received ongoing technical assistance through case consultation; the DNEA provided six case consultation sessions to MRSS leads and supervisors.

Training and technical assistance activities were modified in response to the pandemic in order to meet the current needs of clinicians and community members being served by MRSS and other PBH units. An additional two PBH units were identified to be targeted with the same comprehensive training package in autumn of FY2021.

Community Training and Technical Assistance Requests

The DNEA responds to training and technical assistance requests from Delaware organizations and community members. Unlike DNEA statewide trainings, these requests allow the DNEA to train a specific agency or organization on a training topic of their choice. The training can be part

of a larger didactic series or in response to single training or technical assistance request. These activities address *Blueprint for Collective Action* Improvement Area 1 (Training and Technical Assistance) and were executed by CDS DNEA staff in collaboration with Nemours Swank Autism Center and other community organizations. In FY2020, DNEA experienced a decline in these requests as a result of the pandemic; thus, the activities summarized below represent those completed between July 2019 and March 2020.

Autism Didactic Series

Nemours Swank Autism Center, as part of its subcontract with the DNEA, facilitated an eight-part didactic series on autism for 10 mental health clinicians who work with children and adolescents. Each didactic focused on a different topic related to supporting youth with autism; sample topics included functional behavioral assessments, family collaboration, and visual supports. The didactic series ran from January 2020 to March 2020.

Individual Training and Technical Assistance Requests

The DNEA also responds to stand-alone training and technical assistance requests from community agencies and organizations. In these instances, the DNEA provided training and/or technical assistance on a single topic. Table 3 summarizes the training and technical assistance requests provided in FY2020.

Table 3

DNEA Community Agency and Organization Trainings and Technical Assistance Requests

Agency	Times offered	Total attendees
Latin Center	1	30
Delaware Guidance Services	2	45
Prevent Child Abuse Delaware	2	47
Division of Substance Abuse and Mental Health	1	129
Rockford Fall Lecture Series	1	100
Technical assistance requests	7	n/a
FY2020 Total	14	351

Information Dissemination and Community Outreach

In FY2020 DNEA staff continued to conduct outreach to community organizations and leaders in order to increase awareness of the DNEA; gather information about the needs of individuals with autism, their families, and providers; and share available resources and training opportunities. Over the course of the year, presentations about the DNEA were conducted at meetings held by the Center for Disabilities Studies' Community Advisory Council (CAC), Delaware Department of Education (DDOE) Special Education Directors, and Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program. Additionally, the DNEA held information tables at conferences and events across the state. A complete listing of these events can be found in Table 4. It is important to note that COVID-19 caused many events to be cancelled in FY2020, so the DNEA was limited to those held between July 2019 and March 2020.

Table 4

DNEA Exhibitor Tables

Event	Date
National Alliance on Mental Illness (NAMI)	October 10, 2019
Outside the Box Conference	October 11 – October 12, 2019
Parent Information Center Fall Family Symposium	November 8, 2019
Division of Substance Abuse and Mental Health Conference	November 13, 2019
Transition Conference	December 13, 2019
LIFE Conference	January 29, 2020

Outside the Box Conference

The DNEA partnered with the Statewide Programs for the Deaf, Hard of Hearing, & Deaf-Blind, and the Division for the Visually Impaired to continue to expand the Outside the Box Conference to include topics related to autism. *Outside the Box* is a 2-day conference designed for families and professionals of children with low-incidence disabilities. The conference took place October 11-12, 2019 and was attended by 232 professionals and family members.

DNEA Digital Community Outreach

The DNEA launched a website and a quarterly newsletter in the autumn of FY2020. These digital resources serve as another means to increase awareness about DNEA initiatives and disseminate evidence-based information about autism.

The website highlights DNEA activities; offers information on autism and Delaware-specific processes and resources; and includes resources on evidence-based practices. Visitors can use the website to request training or technical assistance, and register for upcoming DNEA events. Because the DNEA supports ICA operations, the website also provides information about the *Blueprint for Collective Action*, ICA meetings, and contact information for other ICA agencies and organizations.

Similar to the website, the DNEA newsletter highlights DNEA activities and provides recipients with a mechanism for signing up for the DNEA trainings. Each quarter, the DNEA newsletter highlights a new evidence-based practice and provides a brief tutorial about how to implement the practice. The newsletter is distributed on a quarterly basis via the DNEA listserv and DNEA website.

Evidence-Based Practice Resource Guides

At the onset of the pandemic, the DNEA began work on evidence-based practice (EBP) resource guides to support professionals who work with children with autism. We received feedback from school districts and other professionals that it would be helpful for teachers to have family-friendly versions that they could use to support remote learning. In response, the DNEA created family resource guides. Some of these guides are directly aligned to COVID-19 resources, while others are more general strategies that families may find helpful. An accompanying planning tool allows professionals to individualize the evidence-based practice and discuss its use in conjunction with other practices. The planning tool is designed to facilitate teacher/family communication and learning in a home environment. It was developed with feedback from family members and professionals.

Family Supports and Services

Autism Delaware supports families of individuals with autism through multiple programs; one such program is its Family Navigation program. Family Navigators respond to requests for information about autism, Delaware supports, and available services. Fifteen percent of DNEA funds are directed toward Family Navigations services at Autism Delaware; this equates to approximately 1.5 family navigators.

Autism Delaware Family Navigators received 5,418 contacts in FY20, which constitutes a significant increase from FY2019 (n=3,273 contacts). Table 5 provides a summary of the contacts made during each quarter and the distribution of those contacts across different categories of need. DNEA-funded family navigation supports represented approximately 35% of all family contacts made each quarter.

The significant increase in family contacts made in FY2020 can be attributed to COVID-19. Quarterly summaries indicate an uptick in contacts received during the third and fourth quarters from families who were seeking support in response to needs specific to COVID-19. Indeed, anecdotal reports indicate a shift in the supports and questions that families were seeking during these quarters. While each category of family need (e.g., connections and support, education, evaluation and diagnosis) remained relatively stable across each quarter, family navigators reported the nature of these requests shifted to include topics such as assistance with basic needs (information and referral).

Table 5*Autism Delaware Family Navigation Activities*

Family Need	Quarter 1	Quarter 2	Quarter 3	Quarter 4
Connections and support	23%	23%	27%	30%
Education	19%	27%	20%	19%
Evaluation and diagnosis	9%	6%	4%	3%
Information and referral	16%	16%	18%	15%
Mental health	1%	1%	2%	3%
Recreation and activities	5%	3%	5%	4%
Respite	5%	4%	3%	3%
Adult services and transition	8%	5%	3%	5%
Social services	8%	7%	7%	8%
Childcare	6%	2%	4%	3%
Therapies and treatments	0%	6%	7%	7%
Total number of contacts	1144	1191	1550	1533

Family navigation remains an integral part of the supports and services provided by Autism Delaware to families. The significant increase in contacts received in response to the COVID-19 crisis underscores Autism Delaware's role in the autism community as a trusted source of support for families.

Delaware Network for Excellence in Autism Operations

DNEA Staffing

In August 2019, the DNEA welcomed a new University of Delaware special education faculty member, Sarah Mallory (FTE 28%), to its Center for Disabilities Studies team. Given Dr. Mallory's expertise in autism and professional training, she was identified as a future contributor to the DNEA. After consultation with ICA members and based on her leadership experience and abilities, Dr. Mallory was also named the new DNEA interim director in September 2019.

The DNEA continued to be supported by Kellene Copeland (trainer and coach; 88% FTE) and Kara Downey (100% FTE) in FY2020. Ms. Copeland developed and conducted education and mental health trainings and activities, while Ms. Downey continued in her role as coordinator for DNEA activities. DNEA training activities were also supported for a portion of the year by Susan Veenema (trainer and coach; 100% FTE) and one day a week by Annie Doordan (trainer and coach). Brian Freedman (FTE 6%) served as interim director in July and August of 2019; supported the transition of Sarah Mallory into the position of interim director; and continued to serve as a trainer and coach on topics related to mental health and autism.

The DNEA strategically partners with subcontractors to broaden its collective expertise. As described in the original legislation creating the DNEA, Autism Delaware has a subcontract for offering family services. The DNEA also subcontracted with Nemours Swank Autism Center staff with backgrounds in school psychology, clinical psychology, and applied behavior analysis. These professionals contributed to DNEA activities such as coaching, technical assistance, training, and the development of new content.

DNEA Financial Report FY2020

In FY2020, the DNEA relied on remaining funds from previous years to conduct its training and technical assistance activities. Those funds were exhausted in June 2020 and the DNEA was not funded for the current year (FY2021). DNEA activities have halted, except those funded by external subcontracts. A summary of the FY2020 financial report can be found in Table 6.

Table 6

DNEA Financial Report (FY2020)

Item	Cost
Personnel	\$239,011.14
Travel	\$2,323.13
Training supplies and expenses	\$15.50
Advertising	\$940.00
Conference fees and expenses	\$2,147.40
Printing	\$6,383.03
Professional speaker fees	\$9,802.88
Other material and supplies	\$7,440.67
Sub-awards	\$115,125.95
Overhead	\$53,630.34
Total	\$436,820.04

Summary and Next Steps

Autism spectrum disorder remains a critical public health issue, with the CDC recently reporting an increased prevalence rate of 1 in 54. Years of stakeholder discussions in Delaware identified a lack of expertise in autism among almost all professional groups. In response, Senate Bill 93 established the DNEA to enhance Delaware's state- and system-wide capacity to improve outcomes across the lifespan for individuals with autism through high quality, evidence-based technical assistance and training for professionals and families. Since its launch in FY2017, the DNEA has exponentially increased the number of professionals trained each year. To date, the

DNEA has trained over 4000 professionals across the state, with FY2019 marking a 94% increase in professionals trained from FY2018.

In FY2020, the DNEA continued to exceed the number of professionals trained from previous years while expanding its training, technical assistance, and supports available to the community. Led by the University of Delaware Center for Disabilities Studies, the DNEA nearly tripled the number of statewide training topics available to the community by adding eight new trainings to its library. The DNEA also launched two capacity-building initiatives with Appoquinimink School District and the Division of Prevention and Behavioral Health (PBH). The DNEA maintained its existing technical assistance and outreach activities, while establishing a new website and community newsletter. Further, the DNEA created a number of evidence-based resource materials for professionals and families. When COVID-19 reached Delaware, the DNEA rapidly pivoted to providing its high-quality trainings in a virtual format while continuing to support professionals and families in the community with COVID-19 resources and technical assistance, and family navigation services.

The DNEA was not funded for the current year (FY2021); therefore, DNEA-funded activities were discontinued. Autism Delaware continues to support families at the same level, utilizing their own internal resources. The Center for Disabilities Studies also continues to support the autism community through other funded projects and activities; for example, work with PBH continues through a subcontract. However, there is a significant void in the autism community. This comes at a time when people with autism of all ages are facing new struggles and their families are especially challenged. Now more than ever, our state needs professionals who understand autism and who can confidently implement scientifically-based interventions. The DNEA resubmitted an application to the Health Fund Advisory Council (HFAC) for funding in FY2022 and is hopeful they will be able to continue their work at that time.

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