

Interagency Committee on Autism
Legislative Report on 2016-2017 Activities

Developed by:

Brian Freedman, Ph.D.

Interim Director, Delaware Network for Excellence in Autism

Associate Director, University of Delaware Center for Disabilities Studies

Annalisa Ekbladh

Director of Family Services

Autism Delaware

With additional contributions from other members of the Interagency Committee on Autism

The following report describes activities conducted by the Interagency Committee on Autism (ICA) and the Delaware Network for Excellence in Autism (DNEA) during FY2016-2017.

Background

The U.S. Centers for Disease Control and Prevention (CDC) have labeled autism spectrum disorder (ASD) an urgent public health concern as prevalence rates have significantly increased across the country over the past 30 years. Nationally, one out of every 59 children has an ASD. In Delaware, 8.4% of children enrolled in special education in Delaware public schools during the 2015-2016 school year were classified with autism – a more than *three-fold* increase since 2004. Without early intervention, the cost to care for a person with an ASD over his or her lifetime will range from \$1.4 to \$2.4 million. The total cost of ASD to society is estimated to be \$35-90 billion annually. Access to appropriate screening, treatment, education, vocational training and life skills training is critical for ensuring that all individuals with ASD have the opportunity for a full and productive life. Yet, national and state-level studies document the alarming unmet need for providers across disciplines and service delivery systems who have specialized expertise in serving individuals with ASD.

In 2011, Delaware was awarded a federal planning grant to improve services for children and youth with ASD. Following an extensive statewide community assessment, workgroups consisting of service providers, family members and representatives of state agencies met for several months to discuss the results of the assessment and other systems improvement issues. Long-term goals, objectives and activities were developed and compiled into the comprehensive 2013 Delaware Strategic Plan for ASD entitled the *Blueprint for Collective Action* (https://www1.udel.edu/cds/Autism_Final_Report.pdf), which included the following recommendations:

- All stakeholders will dedicate fiscal and other resources for the purposes of achieving the stated outcomes.
- An Interagency Committee on Autism (ICA) will be charged with identifying the needs of the community and leveraging resources across membership organizations and agencies.
- An autism resource center, later named the Delaware Network for Excellence in Autism (DNEA) will address the provision of training and technical assistance identified within the Blueprint for Collective Action.

Prospective members of an Interagency Committee for Autism (ICA) began meeting on a regular basis shortly after the release of the Blueprint for Collective Action. Initial members included leaders from the Department of Education, the Delaware Autism Program, the University of Delaware Center for Disabilities Studies (CDS), Autism Delaware, Nemours/A.I. duPont Hospital for Children, Division of Public Health, Division of Developmental Disabilities Services, Division of Vocational Rehabilitation, and Delaware Family Voices, as well as family members of children and adults with autism. Initially funded by the Department of Education and facilitated by CDS, ICA members gathered information regarding pressing needs of families and professionals, shared existing resources on evidence-based practice, and identified next steps

for addressing the most pressing community needs. Some of this work resulted in the creation of a comprehensive resource for families and professionals, also funded by the Department of Education, describing the medical diagnosis and educational classification of autism. This new resource, which has subsequently been widely distributed in multiple languages, describes in plain language the similarities and differences between diagnosis and classification, shares what is required in order to receive access to different types of services in Delaware, and offers next steps and resources for families and professionals.

Under the leadership of Senator Margaret Rose Henry and Representative Earl Jaques Jr., the Interagency Committee on Autism (ICA) and the Delaware Network for Excellence in Autism (DNEA) were formally established by Senate Bill 93, which was passed on June 30, 2016. Governor Jack Markell signed the bill into law on September 14, 2016. The passage of Senate Bill 93 was a direct result of passionate advocacy led by organizations like Autism Delaware that included countless families and individuals impacted by autism spectrum disorders, and was informed by multiple organizations and agency leaders.

The following report reflects ICA and DNEA activities during fiscal year 2016-2017, with additional notes on activities that are expected to take place during 2017-2018.

Interagency Committee on Autism (ICA)

The Interagency Committee on Autism (ICA) is tasked with implementing the recommendations from the Blueprint for Collective Action, identifying existing gaps or overlaps in services, overseeing the development of goals and priorities for the DNEA, and advising the general assembly on recommendations for legislation. Voting members of the ICA, as established in Senate Bill 93, include:

- 1) The Statewide Director of the Delaware Autism Program;
- 2) A representative appointed by the Department of Education;
- 3) A representative appointed by the Division of Developmental Disabilities Services;
- 4) A representative appointed by the Division of Vocational Rehabilitation;
- 5) A representative appointed by the Center for Disabilities Studies at the University of Delaware;
- 6) A representative appointed by Autism Delaware;
- 7) A representative appointed by the Nemours network;
- 8) A representative appointed by the Division of Public Health;
- 9) A representative appointed by the Delaware Association of Rehabilitation Facilities;
- 10) A representative appointed by the Division of Substance Abuse and Mental Health;
- 11) A representative appointed by Family Voices;
- 12) A representative appointed by the Parent Information Center of Delaware;
- 13) A representative of Part C/Birth to Three System;
- 14) A representative appointed by the Division of Prevention and Behavioral Health Services;
- 15) A parent or caregiver of a child or adult with ASD from each county in Delaware;

16) An individual with ASD.

ICA meetings were held on the following dates during 2016-2017: 8/10/16, 11/9/16, and 5/30/17. Those ICA meetings included representation from the majority of voting members, with several organizations (e.g., Autism Delaware, Department of Education, and Nemours) sending multiple representatives. Those organizations that did not participate continued to be included on information related to meetings and other happenings in the ASD community.

Delaware Network for Excellence in Autism (DNEA)

Senate Bill 93 established the Delaware Network for Excellence in Autism (DNEA) as a training and technical assistance center for state agencies, organizations and other private entities operating in the State of Delaware who provide services and support to individuals and families affected by ASD. The DNEA is housed at the University of Delaware Center for Disabilities Studies (CDS) and has an established subcontract with Autism Delaware. CDS largely oversees the provision of professional training through the DNEA and Autism Delaware oversees training for families, as well as family navigation services. In addition, by establishing itself as a network, the DNEA can leverage the additional expertise and resources from ICA members and others in order to offer far-reaching, more impactful training for all community members., Funding was received to start the DNEA on November 17, 2016 for Fiscal Year 2016-2017. Therefore, the activities outlined below largely reflect efforts put forth from November 17, 2016 through June 30, 2017.

Building Awareness

The DNEA took steps in 2016-2017 to inform the community of its purpose and begin to grow awareness of the availability of the resources it has to offer. Social media platforms, individual meetings with state leaders, presentations to organizations, conference talks and advertising were all used to help raise awareness about the DNEA.

An introductory video (https://www.youtube.com/watch?v=OHL_E5uJ4PA) was developed by the University of Delaware Center for Disabilities Studies (CDS) that included DNEA staff, the Executive Director of Autism Delaware and a parent of a child with ASD. The Center for Disabilities Studies also produced a blog post (<https://blog.cds.udel.edu/altering-autism-landscape/>) that introduced the DNEA and other new autism initiatives to the community. CDS, Autism Delaware and other organizations used social media accounts such as Facebook and Twitter to announce and describe the DNEA and share these resources widely.

DNEA staff also conducted outreach to community organizations and leaders. Over the course of the year, presentations were conducted with the following organizations:

- Special Education Leadership Meeting (9/14/16)
- State Council for Persons with Disabilities (9/19/16)
- Delaware Family Voices, Inc. Family Leadership Advisory Council (9/28/16)
- State Board of Education (10/13/16)
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- Governor's Commission on Building Access to Community-Based Services - Health Care Committee (11/18/16)
- Brandywine Specialized Autism Program - Parent Action Committee (4/27/17)

The DNEA also held information tables either as a stand-alone or in conjunction with other CDS or Autism Delaware programs at the following conferences: Autism A-Z Beyond the Puzzle Conference (9/30/16), LIFE Conference (1/25/17), Inclusion Conference (3/15/17), and the Statewide Transition Conference (12/7/16). In addition, DNEA staff and ICA members conducted a presentation at the LIFE Conference about the DNEA and other new autism initiatives with approximately 40 people in attendance.

Production on a dedicated website also commenced and will be launched during 2017-2018. The site will contain resources and links related to evidence-based practices and Delaware-specific policies and support systems, such as information about the “birth mandate”, early intervention services, and family support. The website will include a multimedia platform that will contain videos, pictures, articles and other formats. The website will also include methods for requesting DNEA training and information on services and training for families.

Professional Training

The DNEA is responsible for training professionals supporting people with autism and their families across the lifespan. The DNEA has a particular focus on promoting evidence-based practices, i.e., services shown by scientific research to be more effective. Led by the Center for Disabilities Studies (CDS), the DNEA commenced training for professionals and families during this past year. Some trainings were individually requested while others were identified based on needs as outlined in the Blueprint for Collective Action. Different evaluations were used for each training based on the training topic and venue (in future years a standard instrument will be used across all DNEA professional trainings). A summary of trainings and highlighted evaluation responses are outlined below:

1. *Autism Spectrum Disorder (ASD) Education: Clinical Skills and PEERS for Clinicians* (11/10/16) – A full-day training offered to outpatient mental health therapists with Delaware Guidance Services. It included an introduction to ASD, as well as information on: adolescence and transition-to-adulthood, family engagement, therapeutic approaches, and an evidence-based treatment model for improving social skills. The training was held across multiple sites and was conducted live and via video feed. Trainers included DNEA staff and an ICA member.
 - Total attendees: 27
 - Post-training: On a scale of 0 to 5, clinicians rated their confidence level in conducting the evidence-based social skills intervention as a “4.1”.
2. *Anxiety and Stress-Related Disorders in Individuals with Autism Spectrum Disorder* (12/12/16) – A half-day training for mental health providers and adult service providers that described the transition to adulthood, common challenges faced by adults with ASD and their families, and treatment strategies for mental health challenges. The training was

delivered in collaboration with the Delaware Division of Substance Abuse and Mental Health (DSAMH).

- Total attendees: 32
 - Percentage of attendees who were satisfied with the training: 100%
3. *Multi-Day Technical Assistance on Building Clinical Models, Training Systems and Early Childhood Evaluation/Intervention Systems (3/9-3/10/17)* – The Clinical Director of the Vanderbilt Kennedy Treatment and Research Institute for Autism Spectrum Disorders (TRIAD), Pablo Juarez, M.Ed., BCBA, provided two days of training and technical assistance for clinicians, educators and agency and organizational leaders. Topics included early childhood evaluation and intervention, designing clinical interventions, establishing training systems in schools, utilizing telehealth, and organizing a statewide system of support in ASD.
- Total attendees: 60
 - Percentage of attendees who were “highly satisfied” with the event: 80%
4. *STAT-MD Training Workshop: Early Identification of ASD for Pediatric Health Care Providers (6/14-6/15/17)* – A 2-day training on early screening and assessment of ASD and the STAT (Screening Tool for Autism in Toddlers & Young Children), an empirically derived, interactive measure that has been developed to screen for autism in children between 24 and 36 months of age. Attendees included pediatricians, speech-language pathologists, educators, early childhood specialists, psychologists, and others representing a variety of organizations (Delaware Autism Program, Child Development Watch, Nemours/A.I. duPont Hospital for Children, Easter Seals, Autism Delaware and University of Delaware).
- Total attendees: 40
 - Percentage of trainees who:
 - “Strongly agree” they would use the information in their practice: 85%
 - Overall were “Satisfied” or “Highly Satisfied” with the training: 97.5%

Resource Dissemination

The DNEA continued to disseminate resources related to needs of the ASD community. A detailed brochure describing the differences between a medical diagnosis and educational classification of ASD was disseminated to school professionals, clinicians and other community members. This brochure was developed by CDS in collaboration with the Department of Education and other ICA members, and was funded by the Department of Education prior to the passage of SB93. A total of 890 English brochures and 140 Spanish brochures were disseminated in 2016-2017. Agencies receiving brochures included Caesar Rodney School District, Milford School District, Red Clay School District, Delaware Autism Program Brennen School, Christina Early Education Center, Autism Delaware, and both the North and South Child Development Watch clinics. To date, the Department of Education has funded and facilitated brochure translation, which is available in nine different languages, including Arabic, Cantonese,

English, Haitian Creole, Hindi, Mandarin, Spanish, Telugu, and Vietnamese. Additional translation requests are filled by the Department of Education as they are received.

Collaborative Activities

The DNEA developed collaborative relationships with additional in-state and out-of-state partners in order to build a strong foundation for future training:

Additional In-State Collaborators

1. *Delaware Statewide Programs for Children with Deaf-Blindness* - Staff members from Autism Delaware and CDS, including DNEA staff, commenced discussion with the Delaware Statewide Programs for Children with Deaf-Blindness regarding expansion of the Outside the Box Conference, a 3-day conference designed for families and professionals of children with low incidence disabilities. Additional collaborators for the conference include the Delaware School for the Deaf and the Division for the Visually Impaired. An agreement was made to expand the 2017 conference to include topics on evidence-based practice in ASD and include professionals and family members impacted by ASD, and that the DNEA would support funding for the conference.
2. *Delaware Positive Behavior Support* – The Delaware School-wide Positive Behavior Support (PBS) program supports teachers and other professionals in Delaware school districts through training and coaching on a multi-tiered system of support that promotes positive behaviors across all students, including students receiving special education services. PBS is housed at the Center for Disabilities Studies and is funded by the Delaware Department of Education. The Delaware PBS program currently has multiple initiatives related to training of school staff in evidence-based practice for supporting students with disabilities including ASD, although ASD is not the project’s primary focus. Planning for several collaborative ventures were discussed including the sharing of resources and a staff member (funded equally by both programs), facilitating connections to the DNEA for schools strongly connected to PBS, and the expansion of training for school staff to providers outside of the school.

National Collaborators

1. *Ohio Center for Autism and Low Incidence (OCALI)* - Collaboration was established regarding the use of OCALI’s ASD training modules. These widely-used modules offer user-friendly formats to share information about autism and evidence-based practices and can be delivered to wide-ranging audiences. The use of these modules with Delaware audiences will begin in 2017-2018.
2. *Vanderbilt Kennedy Treatment and Research Institute for Autism Spectrum Disorders* - Collaboration was established regarding the use of evidence-based evaluation and treatment strategies developed through their center. Vanderbilt provided manuals and consultation on short-term early intervention treatment modules that will be implemented in multiple early childhood settings in Delaware, such as Nemours/A.I. duPont Hospital for Children and Child Development Watch in the Delaware Division of Public Health.

3. *UCLA Semel Institute for Neuroscience and Behavior* - Collaboration was furthered with UCLA on their Program for the Education and Enrichment of Relational Skills (PEERS®), an evidence-based social skills intervention for people with ASD. The DNEA provided funding for two Autism Delaware staff members to receive training on social skills interventions for adults. They also provide on-going support for CDS staff supporting school teams conducting PEERS.

National Meetings & Conferences

The DNEA was represented at national meetings and conferences dedicated to professionals supporting people with ASD and their families:

- The Ohio Center for Autism and Low Incidence Annual Conference
November 16-18, 2016; Attended by Annalisa Ekbladh
- The Association for University Centers on Disabilities (AUCD) Annual Conference
 - December 4-7, 2016; Attended by Brian Freedman
- The International Meeting for Autism Research
 - May 10-13, 2017; Attended by Brian Freedman and Brittany Powers

Staffing

The DNEA began identifying and hiring CDS-based staff in 2016-2017, beginning with the director. A search committee was established for hiring the position of director that included the director of CDS, the interim director of the DNEA, the executive director of Autism Delaware, a psychologist from Nemours/A.I., and a CDS staff member who leads a school-based training initiative. A national search was conducted for the director position, with advertisements being placed with a variety of well-known organizations and periodicals. As of the end of the 2016-2017 year, efforts to hire a director had been unsuccessful. After an extensive review of applications, three applicants were interviewed by the search committee. Unfortunately, none of these interviews yielded a candidate that was approved by the search committee. As a result, the DNEA and ICA are re-examining outreach efforts and the scope of the position itself in order to determine the best process for establishing long-term leadership for the DNEA.

CDS provided interim staffing for start-up activities while a more expansive DNEA staffing plan was developed. Brian Freedman, Ph.D., Associate Director of CDS, is functioning as the DNEA Interim Director (10% FTE). DNEA coordination was provided by Annalisa Ekbladh (25% FTE), and then Brittany Powers, MPH, following Annalisa's departure from CDS to Autism Delaware.

Toward the end of 2016-2017, in the absence of a full-time Director, CDS put forth stronger efforts to hire other DNEA staff members. Richard Lytton, CCC-SLP, a speech-language pathologist and specialist in augmentative and alternative communication, was hired as a DNEA Coach and will be providing training, consultation and coaching for the community with 30% FTE. Additional efforts are underway to hire trainers with specific expertise in those areas identified as high priorities for the DNEA

Family Training

The following sections highlight areas where DNEA funding has enhanced Autism Delaware’s abilities to serve and support families across Delaware. Family Support services have historically been and continue to be a core service for Autism Delaware. DNEA funding represents approximately 15% of the total Family Support services budget.

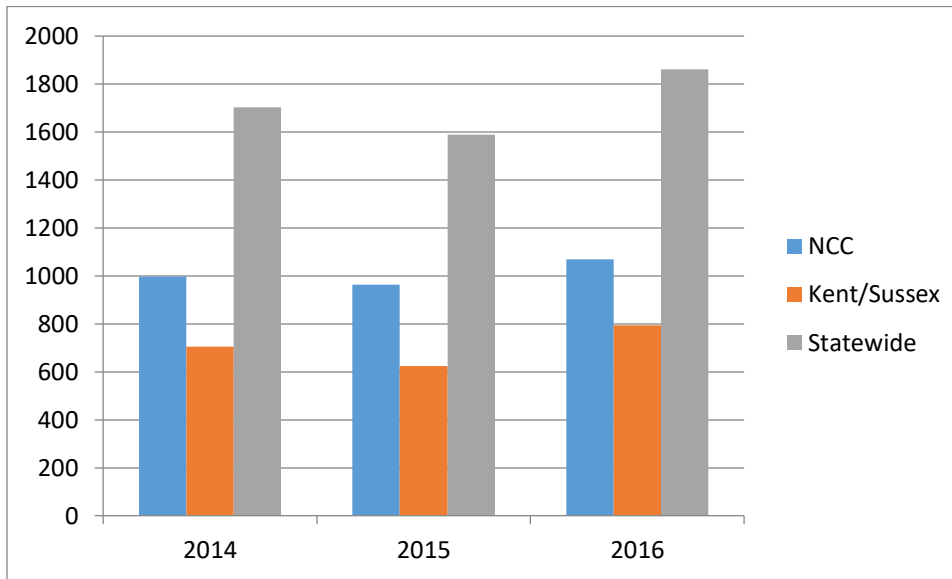
A. Enhance information and referral and personal support through Family Navigation

This year, the Family Support team has increased its capacity through the addition of a Family Support Program Manager and two new Family Navigators, both of whom are bi-lingual. Thus, the number of parent contacts has increased by almost 20% from 2015 (See Fig.1)

Fig.1

Total Number of Individual Family Supports Contacts 2014 - 2016, by Location

(As reported by FileMaker, Methods: phone, email, mail, or face to face)



	2014	2015	2016
<i>NCC</i>	998	963	1068
<i>Kent/Sussex</i>	705	625	794
<i>Statewide</i>	1703	1588	1862

With new bilingual Family Navigators on staff, Autism Delaware expanded services for and improved outreach to Spanish-speaking families, individuals, and community groups. These efforts included:

- Interviews with bi-lingual staff in “Hoy” and “El Tiempo”
- Purchased a half-page advertisement in “El Tiempo” for the 2017 calendar year

- Developed and enhanced existing English and Spanish language materials to reflect the diversity of services being offered through Autism Delaware’s Family Support Department
- Succeeded in scheduling and meeting face to face with leaders in the Hispanic communities of Wilmington and Sussex County (La Esperanza, La Red, Latin American Community Center, various faith-based organizations and others)

As a result of increased outreach and in order to remain responsive to families, community supporters, and funders, Autism Delaware implemented the use of FamCare, an electronic case management system that captures data reflecting the work happening within Delaware communities. Currently, the new software system is in use by all Family Navigators.

B. Provide parent education seminars/workshops

The number of parent education programs offered by Autism Delaware increased from 4 to 10 this year.

“Autism 101” Workshops

Autism Delaware also introduced a quarterly “*Autism 101*” program in NCC and Kent/Sussex locations. This newly offered program was designed for families of newly diagnosed children. This program includes an overview of the functional areas affected by autism and common approaches designed to help families within the home and community environments. Participants that have completed program evaluations are reporting a high level of satisfaction with the content averaging 4.9 out of 5 over the 3 offered events. One common comment being shared by participants is that families desire more time for questions and answers. As a result, in Fiscal year 2017-2018, we will increase session lengths by ½ hour.

Fall 2016 Workshops

- Seizure Recognition and Management (collaboration with the Epilepsy Foundation)
- Special Needs Trusts and Guardianship

Spring/Summer 2017 Workshops

- Navigation 101 – Pizza & Paperwork
- Apps for Autism
- Autism, Anxiety & Depression
- Behavior How-To At Home
- *Evaluation:* Participants reported a high level of satisfaction with the content averaging 4.5 out of 5.

Increased utilization of technology as a tool for engaging more people

Many parent education programs are now utilizing videoconferencing or Facebook Live. Videoconferencing has allowed for simultaneous workshops in Newark and Lewes office locations. Additionally, families can participate from their home environments. Utilizing this technology ensures a consistent message is shared with families across the state. The following represents the participation of families in offered workshops using Facebook Live. (See Fig.2)

Fig.2 Speaker Series In-person and virtual workshops attendance is as follows:

Face-to-Face only sessions

- September: Seizure Recognition & Management – 8 attendees in person
- January: Special Needs Trust, Guardianship – 17 attendees in person
- March: Autism 101 – 8 attendees in person

Face-to-Face & Video conferencing/Facebook Live Sessions

- April:
 - Apps & Autism (5 in person/ 1,000 views on FB Live)
 - Autism, Anxiety & Depression (12 in person/ 1,900 views on FB live)
- May: Behavior How To At Home (2 in person/ 896 views on FB Live)
- June: Autism 101 – 10 attendees in person / 5 via video conference

C. Staff Training:

A key requirement of the DNEA is the provision of evidence-based services. Through DNEA funding, Autism Delaware provided training in evidence-based programs such as Sib-Shops and PEERS. In addition, staff were provided with Wrightslaw Special Education training to assist families with navigation in the area of IDEA/education.

D. Overview of core Family Navigation and Support activities

Support Groups/Coffee Hours: On-going group intervention supports are offered in multiple locations in each county in the state. Parent Coffee Hours in NCC, Kent and Sussex have been successful and mostly well attended. Grandparent groups have continued across the state. In NCC, attendance has fluctuated but a core group remains active contributors in the helping process. Similarly, the Lewes grandparent group has been successful, as evidenced by the consistent number of attendees.

Programs:

- **Kent/Sussex Counties:** Summer beach camp serving up to 30 participants, and Jr. golf programming remain core southern activities.
- **New Castle County:** Social Lego sessions were offered to two age groups (8-12 and 13-17). The younger age group had lower attendance and merged with the older group for a total of 5 participants. PEERS Social Skills training was offered for the first time. The PEERS Curriculum was originally developed at UCLA. It offers a 16-week evidence-based social skills intervention for motivated adolescents in middle school or high school who are interested in learning ways to help them make and keep friends. The program was very successful and 8/8 participants graduated from the first cohort.

Individual/family advocacy: Autism Delaware regularly supports families and individuals with a variety of issues impacting their lives. On a daily basis, Autism Delaware responds to requests for information and addresses concerns within the special education system that conflict with family desires. Family engagement at all levels provides knowledge and experience that aids in all advocacy efforts. As a result of being a consistent resource for the community, Autism

Delaware had a record number of parent contacts including phone consultations, in-person meetings, and in-person support to parents in IEP meetings. (See Fig.1)

Community Engagement: Autism Delaware staff members are engaged in many local and state committees and collaborations that assist in providing families with the most current and appropriate information. Family Support staff are represented on the following committees or groups:

- The Governor’s Commission on Community Access: Inclusive Health Promotion workgroup
- Interagency Committee on Autism
- Statewide Special Education Strategic Planning Committee
- Delaware Oral Health Care Coalition
- Governor’s Advisory Council for Exceptional Citizens
- Emergency Medical Services for Children Advisory Committee - collaboration among statewide medical providers, such as the major hospitals, to promote the health and safety of Delaware’s children through research, education, advocacy, and collaboration with established and new partnerships
- Family SHADE - supporting families of children and youth with special health care needs through information and referral, roadmap to services, transitions app
- Several educational councils and committees to improve IEPs, access to the general education curriculum, etc.
- Support local PTA/PTO/PACs by attending, presenting about services offered at Autism Delaware, bringing a speaker, or sharing information whenever possible.

Recreation activities: Recreational offerings for families vary throughout the state based on demand by participant, location and activity of choice. The following events are consistently offered in each part of the state.

- Kent/Sussex: Movies, skating parties, bounce house nights, art club and other recreational events for families continue. Family annual parties are also well attended (holiday party, fall festival, etc.).
- New Castle County: A consistent group of adults with autism remain committed to participating in monthly bowling. Movies and bounce events continue. Additional events include Caring Santa, train rides, skating events, and annual parties; which are all well attended.

Additional Training from Leveraged Funds

DNEA staff and ICA members have also offered training for professionals and families through the cultivation of additional funding streams beyond state funds:

1. *HRSA State Implementation Grant for Autism Spectrum Disorders* – Delaware was one of four states to receive a federal grant to enhance screening, identification and early intervention systems in ASD. Through this grant, statewide leaders and family members are bridging resources and filling gaps in the early childhood system for children at-risk for ASD and their families. Although the project encompasses statewide needs and

services, there is a particular emphasis on improving services for families that live downstate, as well as Spanish-speaking families in Delaware.

- a. Project Partners: University of Delaware (CDS and other departments), Autism Delaware, Nemours/AI duPont Hospital for Children, Department of Education, Division of Public Health/Birth-to-Three/Child Development Watch, Family Voices
 - b. Funding: \$1,260,000
 - c. Start/End Date: 9/1/16-8/31/19
 - d. Trainings offered and other notable outcomes:
 - i. Monthly stakeholder meetings among state leaders, officials, educators, clinicians and family members, which facilitates a collaborative process for refining the early childhood system. The open forum allows all parties to give feedback as new systems are developed.
 - ii. The creation of a family member council that provides feedback on all elements of the project and has a voice in the development of new systems to ensure that family perspectives and experiences are considered.
 - iii. The creation and pilot of a new 6-8 week parent training service offered through telehealth.
 - iv. The creation and pilot of a new case management system to support better coordinated care for newly diagnosed families.
 - v. The creation of resources designed to reinforce the “birth mandate” system in order to improve professionals’ and families’ understanding and promote a more fluid process.
 - vi. Assessments of pediatric ASD screening, early intervention, and family self-efficacy, in order to promote the creation of future training that can target particular needs.
2. *Leadership Education in Neurodevelopmental Disabilities (LEND)* – Delaware joined a national network of training programs that focuses on ASD and other disabilities.
- a. Project Partners: University of Delaware (CDS and other departments) and Nemours/A.I. duPont Hospital for Children (and several organizations and state agencies)
 - b. Funding total: \$2,500,000
 - c. Start/End Date: 7/1/16-6/30/21
 - d. Trainings offered and other notable outcomes:
 - i. A year-long intensive (300+ hour) training program for eight (8) graduate and postdoctoral trainees from multiple disciplines (clinical psychology, nutrition, physical therapy, speech-language pathology, special education and families) in interdisciplinary, family-centered, culturally competent care for children with ASD and their families. Training program included didactic sessions, clinical/community observations, clinical practicum, supervisory mentoring, mentoring from a family, and a leadership project.

- ii. A training for professionals on the role of Occupational Therapists and Physical Therapists in treating children with ASD (100 attendees).
 - iii. A training for professionals on identification and treatment of ASD (41 attendees).
 - iv. A training on classroom strategies for working with children with ASD (25 attendees).
3. *Delaware Clinical & Translational Research ACE Award (NIH)* – A program designed to support greater use of evidence-based social skill interventions by community providers. Laura Dewey (ICA member) under mentorship from Brian Freedman (ICA member and DNEA interim director) provided training and on-going consultation to mental health providers from Delaware Guidance Services as they developed and provided social skills interventions at multiple locations.
- a. Project Partners: Nemours/AI, Delaware Guidance Services, Center for Disabilities Studies
 - b. Funding total: \$20,000
 - c. Start/End date: 10/1/16-9/30/17
 - d. Trainings offered and other notable outcomes:
 - i. Full-day training provided to 25 mental health counselors on ASD, adolescence, family engagement, and social skills interventions (also mentioned in DNEA Professional Training section above).
 - ii. Long-term follow-up and consultation with 10 mental health counselors from two clinic locations.

DNEA Financial Report 2016-2017

The following totals reflect funds utilized during the time of funding for 2016-2017, which ran from November 17, 2016 – June 30, 2017.

Personnel Costs	\$21,391.94
Travel Costs	\$4,818.35
Materials & Supplies	\$29,435.97
Sub Awards	\$75,039
Overhead	\$16,129.10
<i>Total</i>	<i>146,814.36</i>

The unspent \$353,185.64 will be carried over into the 2017-2018 year, in order to supplement 2017-2018 funding identified for the DNEA (\$500,000). This new total of \$853,185.64 is closer to the originally estimated budget amount (\$866,708) that was projected for the DNEA in Year 2 on the original Fiscal Note for Senate Bill 93.

Priorities for 2017-2018

At the end of 2016-2017, the ICA initiated a process for establishing priorities for the DNEA for 2017-2018. All ICA members were asked to identify priorities among those areas of need

identified in the Blueprint for Collective Action. ICA members were asked to consider areas of high need as well as areas that they believe require less or more intensity. The results identified four target priorities that will guide DNEA efforts in the upcoming year:

- All medical professionals charged with diagnosing “autism” will use empirically-supported evaluation protocols.
- All students with ASD who are eligible for special education will be classified for the provision of appropriate educational services and support including and beyond the academic assessment areas.
- All LEAs have the skills and ability to provide high quality and equitable services and supports for individuals with ASD.
- All individuals with ASD will receive appropriate mental health services and crisis support services when they need them and where they need them.

Summary and Next Steps

The significant rise in prevalence of Autism Spectrum Disorders (ASD) and the substantial needs faced by children and adults with ASD and their families necessitates a community of informed family members and highly trained, dedicated professionals. A substantial, sustained effort by the community has resulted in a shared voice that brought forth a plan for creating a better system in Delaware for those impacted by ASD. This plan led to the creation of two important entities: a) the Interagency Committee on Autism (ICA), an organization comprised of dedicated leaders from state agencies, organizations and family members impacted by ASD; and b) the Delaware Network for Excellence in Autism (DNEA), a statewide training and technical assistance center that promotes evidence-based practice for professionals and support for families impacted by ASD.

The ICA and DNEA officially launched in 2016-2017. Following the start of funding in November 2016, the DNEA took its first initial steps to raise awareness, develop processes, disseminate resources, and commence training. Trainings on evidence-based practice, overseen by the UD Center for Disabilities Studies, were provided to 159 professionals from a variety of disciplines across the state. An additional 174 professionals received training developed through additional funds cultivated by the ICA and DNEA. Family support and training, overseen by Autism Delaware, resulted in a substantial increase in families of children with ASD receiving family navigation services through Autism Delaware - an almost 20% increase from 2015. Family trainings and workshops also reached almost 3,000 people between in-person attendance and Facebook Live viewings.

Substantial first steps were taken in 2016-2017 to develop the staffing and processes for the DNEA, as well as to begin to offer training to professionals and support to families. Although some areas required more time and resources than expected (e.g., identifying a DNEA Director), these were considered critical for the long-term success of the DNEA and ICA. The membership organizations in the ICA, as well as the DNEA staff, remain committed to furthering all aspects of this critical training initiative in Year 2 and beyond, as we continue to build a stronger system

across the lifespan in Delaware for those impacted by and supporting people with autism spectrum disorder.

-- Brief Update on 2017-2018 Activities --

Several notable steps and accomplishments have taken place in 2017-2018. The following represent highlights and brief updates that will be expanded upon in a full report upon conclusion of the 2017-2018 year.

- Conducted outreach with multiple school districts to assess needs and establish next steps in training.
- Collaborated on the development and execution of the Outside the Box Conference, which was attended by 125 professionals and 33 family members. DNEA funding sponsored multiple talks on a variety of topics.
- Conducted introductory trainings at district-wide meetings and early intervention settings.
- Established an interdisciplinary training series on Communication Interventions for delivery at multiple locations across the state.
- Autism Delaware conducted expanded versions of its Autism 101 sessions and workshops on “Sexuality and Sensory Considerations” and “Evaluations: What the Numbers Mean.” Regularly scheduled workshops continued through 2018.
- The DNEA sponsored multiple trainings at the Delaware Association of School Psychologists annual conference. Over 100 school psychologists will be in attendance.
- ICA subcommittees on “mental health services” and “afterschool/day care services” were established. These subcommittees have begun to identify and develop resources and training.
- Several ICA members and DNEA staff members have participated in a Department of Education workgroup examining the standards for classification of students with autism by Delaware school districts.