

Interagency Committee on Autism
Legislative Report on 2017-2018 Activities

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The following report describes activities conducted by the Interagency Committee on Autism (ICA) and the Delaware Network for Excellence in Autism (DNEA) during FY2018.

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 ASD. In Delaware, 8% of children enrolled in special education in Delaware public schools during the 2016-2017 school year were classified with autism – a more than *three-fold* increase since 2004 (based on DOE statewide enrollment data). The cost to care for a person with an ASD over his or her lifetime will range from \$1.4 to \$2.4 million (Buescher, Cidav, Knapp, & Mandell, 2014). The total cost of ASD to society is estimated to be \$11.5- 60.9 billion annually (Lavelle, et al., 2014; Buescher, Cidav, Knapp, & Mandell, 2014).

The 2013 Delaware Strategic Plan for ASD, entitled the *Blueprint for Collective Action* (https://www1.udel.edu/cds/Autism_Final_Report.pdf), resulted in increased collaboration and advocacy from multiple stakeholders. All stakeholders will dedicate fiscal and other resources for the purposes of achieving the stated outcomes.

In 2016, under the leadership of Senator Margaret Rose Henry and Representative Earl Jaques Jr., Senate Bill 93 was passed which resulted in the creation of:

- An Interagency Committee on Autism (ICA) - charged with identifying the needs of the community and leveraging resources across membership organizations and agencies.
- The Delaware Network for Excellence in Autism (DNEA) – a statewide training and resource center designed to address the training and technical assistance needs as outlined in the Blueprint for Collective Action.

The following report reflects ICA and DNEA activities during fiscal year 2018 with additional notes on activities that have already occurred or are expected to occur in fiscal year 2019.

Interagency Committee on Autism (ICA)

The 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 (DAP);
- 2) A representative appointed by the Department of Education (DOE);
- 3) A representative appointed by the Division of Developmental Disabilities Services (DDDS);
- 4) A representative appointed by the Division of Vocational Rehabilitation (DVR);

- 5) A representative appointed by the Center for Disabilities Studies (CDS) at the University of Delaware;
- 6) A representative appointed by Autism Delaware (AD);
- 7) A representative appointed by the Nemours network;
- 8) A representative appointed by the Division of Public Health (DPH);
- 9) A representative appointed by the ABILITY Network (formally known as the Delaware Association of Rehabilitation Facilities (DelARF));
- 10) A representative appointed by the Division of Substance Abuse and Mental Health (DASMH);
- 11) A representative appointed by Family Voices (DEFV);
- 12) A representative appointed by the Parent Information Center (PIC) 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 (DPBHS);
- 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 2017-2018: 8/30/17, 12/6/17, 3/28/18 and 6/6/18. Quarterly 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. Organizations who attended at least three of the four quarterly meetings included: CDS, AD, Nemours, DOE, DAP, DVR, DEJV, Part C/Birth to Three, and the parent advocate from New Castle County. Currently there is no parent/caregiver representative from Kent County, parent/caregiver representative from Sussex County, or self-advocate representative on the ICA. All organizations received prior notice about meeting dates and an opportunity to participate via video was offered for all meetings. Those organizations that did not participate continued to be included on information related to meetings and other happenings in the ASD community.

ICA Workgroups

The ICA formally established three workgroups in FY2018: education, childcare, and mental health. Workgroups were formed in order for ICA members and other invitees to focus on particular areas of need. Workgroups are tasked with assessing needs, identifying existing resources, conducting outreach with potential collaborators outside of the ICA, and developing a plan or recommendations for the ICA. In addition to ICA member participation, DNEA staff attend workgroup meetings in order to participate in planning for training-related needs, record meeting minutes, and facilitate dissemination of information to the entire ICA. Workgroups provide reports on each of their activities at ICA quarterly meetings.

Education Workgroup

The ICA education workgroup was established in June 2018. Due to continued family requests to Autism Delaware for education-related issues, school-based training requests to the DNEA, and the passage of Delaware House Bill 292, which allocates additional resources toward training on ASD in schools, ICA members felt a workgroup was needed to coordinate available resources and build internal school capacity for supporting students with ASD. In FY2018, the workgroup met two times and discussed the development of a needs assessment for school districts and charters, a system of tiered support and technical assistance, as well as training topics and content development. The workgroup will continue to meet in FY2019 to implement the needs assessment and training plan. ICA representatives who attended Education Workgroup meetings included: CDS, DOE, DAP, and AD.

Childcare Workgroup

The ICA childcare workgroup was established in September 2017. Sustained reporting from ICA members, including AD, indicated a substantial need for providers to be trained in supporting children with ASD in childcare settings. In FY2018, the childcare workgroup met three times and discussed areas of need, available resources, and potential training opportunities. The workgroup will continue to meet in FY2019 to develop a sustained plan to support childcare providers. ICA representatives and other organizations participating in Childcare Workgroup meetings included: AD, DOE (including the Office of Early Learning and 619), Part C/Birth to Three System, Delaware Stars, and the Delaware Institute for Excellence in Early Childhood (DIECC).

Mental Health Workgroup

The ICA mental health workgroup was established in September 2017 as a committed effort to address the identified DNEA priority ensuring appropriate mental health services and crisis supports are received, as detailed below. In FY2018, the mental health workgroup met two times to discuss the training needs of mental health providers, available resources and expertise, and a plan to build provider capacity in supporting individuals with co-occurring ASD and mental health concerns. The use of evidence-based practices by outpatient clinicians was identified as a need and will continued to be explored in FY2019. ICA representatives attending Mental Health Workgroup meetings included: CDS, AD, Nemours, PBH and DSAMH.

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. The summary below largely reflect efforts put forth from July 1, 2017 – June 30, 2018.

Priorities for 2017-2018

In Fiscal Year 2017, the ICA initiated a process for establishing priorities for the DNEA, to be reassessed annually. All ICA member agencies were asked to identify and rank five 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. For Fiscal Year 2018, the ICA established four priority areas, which are listed below.

- All medical professionals charged with diagnosing “autism” will use empirically-supported evaluation protocols.
- All LEAs have the skills and ability to provide high quality and equitable services and supports for individuals with ASD.
- 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 individuals with ASD will receive appropriate mental health services and crisis support services when they need them and where they need them.

Building Awareness

The DNEA took steps in 2017-2018 to inform the community of its purpose and to grow awareness 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.

A webpage on the CDS website was launched (www.cds.udel.edu/dnea) that describes the ICA and DNEA, as well as offers information on autism, Delaware-specific processes, and evidence-based practice. The website includes methods for requesting training/technical assistance and a training calendar with opportunities to register. The website also provides information on the Blueprint for Collective Action. The website will grow over time to include additional video testimonials from individuals with ASD and family members, information and videos about evidence-based practice and Delaware-specific processes, and updates and progress on the Blueprint for Collective Action.

In addition to the launch of the aforementioned website, the DNEA adds information to the public calendar on the state Public Meeting Calendar platform, which features each ICA Quarterly Meeting. The ICA Quarterly Meetings are open to the community and rotate throughout the three Delaware counties.

DNEA staff also conducted outreach to community organizations and leaders in order to increase awareness of the DNEA, gather information about the needs of individuals with ASD and their families, and providers, and to share available resources and training opportunities. Over the course of the year, presentations were conducted with the following organizations:

1. Delaware Developmental Disabilities Council (09/30/17)
2. The Ability Network of Delaware (03/10/18)
3. Statewide Transition Council (01/18/2018)
4. Behavioral Health Task Group - Sussex County Health Coalition (05/18/2018)

The DNEA also held information tables either as a stand-alone or in conjunction with other CDS programs at the following conferences: LIFE Conference (01/24/18), Inclusion Conference (03/14/18), Aspire Conference (05/02/18), Sussex County Early Educator Conference (02/10/18), and the Statewide Transition Conference (12/05/17).

The DNEA also developed a logo and marketing materials. DNEA staff worked with a web-based vendor and solicited ideas for the logo. ICA members then gave feedback. A wide variety of marketing materials were purchased at the end of the fiscal year and began to be distributed this past summer.

The interim director of the DNEA authored an update in the Summer 2018 issue of Autism Delaware's newsletter, describing the DNEA and sharing upcoming opportunities to participate in training.

Professional Training

The DNEA is responsible for training professionals supporting people with autism and their families across the lifespan, with a particular focus on promoting evidence-based practices. 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. A standard model of an evaluation form was used (see example in Appendix A) to evaluate the majority of training sessions. In a few cases, a different evaluation was used due to the parameters of the training. A summary of trainings, highlighted evaluation responses, and the priority and/or strategic plan

area covered through each training are outlined below. More detailed evaluations for each training can be found in Appendix B.

1. Western Sussex Summit: Many Faces of Autism (12/1/17)

Presenters: Brian Freedman, Richard Lytton, Brittany Powers, Dafne Carnright

Summary: A half-day training for educators in Sussex County to offer introductory information about ASD and guided discussion with facilitators from the DNEA. The session utilized video modules designed by the OCALI that include contributions from people with ASD, family members and professionals about the characteristics of ASD as they share experiences, perspectives, and dispel common misconceptions. Content areas included social communication, restricted interests and patterns of behavior, sensory, cognition and information processing, and emotional regulation. Facilitated group discussions supported participants in applying information and developing strategies for their classrooms and schools, applying evidence-based practices, and considering how they can work collaboratively with families.

Strategic Plan Area(s) addressed:

- Improvement Area II: Outcome B: All LEAs have the skills and ability to provide high quality and equitable services and supports for individuals with ASD. (DNEA priority area)
- Improvement Area II: Outcome C: School administrators, teachers and para-educators have access to an array of on-going professional development activities reflecting the education of students with ASD.

Participants included general educators, special educators, paraprofessionals, and aides.

- Number of attendees: 20
- Average satisfaction rating: 2.8 (out of 3)
- Average percent change in Understanding of Content: +38.6%
- Average percent change in Understanding of Application: +44.1%

2. UD Early Learning Center Professional Development Day: Many Faces of Autism (01/12/18)

Presenters: Brian Freedman, Richard Lytton, Brittany Powers

Summary: A half-day training for staff at the University of Delaware Early Learning Center to offer introductory information about ASD and guided discussion with facilitators from the DNEA. The session utilized video modules designed by OCALI. Facilitated group discussions supported participants in applying information and developing strategies for identifying risk factors for autism in young children, Delaware-specific referrals processes for suspected autism (including information on Delaware's birth mandate), working with young children in their classrooms, applying evidence-based practice, and working collaboratively with families.

Strategic Plan Area(s) addressed:

- Improvement Area II: Outcome B: All LEAs have the skills and ability to provide high quality and equitable services and supports for individuals with ASD. (DNEA priority area)
- Improvement Area II: Outcome J: All early childcare and preschool educators will demonstrate the skill and knowledge necessary to appropriately include and support children with ASD.

Participants included teachers, early intervention specialists, aides, and undergraduate students.

- Number of attendees: 60
- Average satisfaction rating: 2.7 (out of 3)
- Average percent change in Understanding of Content: +44.9%
- Average percent change in Understanding of Application: +51.9%

3. Making A Difference Conference: Many Faces of Autism (04/13/2018)

Presenters: Kellene Copeland, Brittany Powers, Heidi Mizell

Summary: A half-day training for staff at the 2018 Making A Difference Conference for early childhood professionals to offer introductory information about ASD and guided discussion with facilitators from the DNEA. The session utilized the video modules from OCALI. Facilitated group discussions supported participants in applying information and developing strategies for working with young children, as well as considering how they can work collaboratively with families toward successful outcomes.

Strategic Plan Area(s) addressed:

- Improvement Area II: Outcome B: All LEAs have the skills and ability to provide high quality and equitable services and supports for individuals with ASD. (DNEA priority area)
- Improvement Area II: Outcome C: School administrators, teachers and para-educators have access to an array of on-going professional development activities reflecting the education of students with ASD.
- Improvement Area II: Outcome J: All early childcare and preschool educators will demonstrate the skill and knowledge necessary to appropriately include and support children with ASD.

Participants included teachers, teaching assistants, day care owners, project managers, and other professionals.

- Number of attendees: 27
- Average satisfaction rating: 3.5 (out of 4)
- Average percent change in Understanding of Content: +55.1%
- Average percent change in Understanding of Application: +68.1%

- Conference Evaluation: 100% of participants who completed the conference evaluation (24/24) reported presenters were knowledgeable, information was applicable, and the presentation was engaging.

4. Early Intervention Provider Training: Using Visual Supports (05/31/2018)

Presenters: Kellene Copeland, Nicole Lehman

Summary: A full-day training for early intervention providers across the state conducted by DNEA Coach, Kellene Copeland, and Child Development Watch Assessor and Speech-Language Pathologist, Nicole Lehman. The training focused on the use of visual supports and evidence-based strategies for implementation with young children with developmental disabilities, including ASD. Content included understanding the steps to providing intervention, how to create visual supports, and the implementation of visual supports for increasing learning and decreasing maladaptive behaviors with children. The training included presentation, facilitated discussions, and opportunities for interactive case study workshops to create visual supports. This training was conducted in collaboration with the state's federally funded early childhood grant (Building Bridges).

Strategic Plan Area(s) addressed:

- Improvement Area II: Outcome B: All LEAs have the skills and ability to provide high quality and equitable services and supports for individuals with ASD. (DNEA priority area)
- Improvement Area II: Outcome E: All medical providers, mental health providers and support staff will have access to information, knowledge and training to effectively serve individuals with ASD.
- Improvement Area II: Outcome K: All early childcare and preschool educators will demonstrate the skill and knowledge necessary to appropriately include and support children with ASD.
- Improvement Area II: Outcome J: All early intervention providers and early childcare/preschool educators will demonstrate the skills and knowledge necessary to appropriately transition children with ASD from early intervention programs to preschool and/or from preschool to school.

Participants included speech-language pathologists, registered nurses, physicians, social workers, early childhood educators, and other disciplines of early interventionists.

- Number of participants: 28
- 100% of participants reported the training was engaging and kept their attention.*
- 100% of participants reported better understanding of content.*
- 100% of participants reported better understanding of application.*
- 96.3% of participants reported feeling very or moderately confident to apply the information learned.*

*Note: Evaluation format varies from other reported DNEA trainings due to external Building Bridges evaluation.

5. *Communication Series*

Presenters: Dick Lytton, Kellene Copeland

Summary: This series consisted of three training sessions. Each session was presented once in Newark and once in Dover for a total of six sessions. The topics of the sessions were complementary but independent; that is, participants could come to one or two without feeling lost because they did not have information from the other(s). Only one participant participated in all three.

Strategic Plan Area(s) addressed:

- Improvement Area II: Outcome B: All LEAs have the skills and ability to provide high quality and equitable services and supports for individuals with ASD. (DNEA priority area)
- Improvement Area II: Outcome C: School administrators, teachers and para-educators have access to an array of on-going professional development activities reflecting the education of students with ASD.
- Improvement Area II: Outcome E: All medical providers, mental health providers and support staff will have access to information, knowledge and training to effectively serve individuals with ASD.
- Improvement Area II: Outcome H: All agencies and human service providers will have access to adequate training to support life skills, employment, public safety and emergency management on behalf of individuals with ASD.

Each of the three training sessions are described below:

A. Understanding Autism & Communication Skills (4/18/2018 & 4/24/2018)

The first session utilized the video modules from OCALI that include contributions from people with ASD to focus on the “Understanding Autism” content of this session. Content presentation and facilitated discussion supplemented each the module topics to emphasize the effects each issue can have on the speech, language, and communication skills of people with ASD.

Participants included educators (including an early interventionist), a parent, a nurse, a group home manager, and a health insurance case manager.

- Number of attendees: 6
- Average satisfaction rating: 3.6 (out of 4.0)
- Average percent change in Content: +41.3%
- Average percent change in Application: +100.8%

B. Social Skills and Communication Skills for People with ASD (5/16/2018 & 5/21/2018)

The second session included an overview of the characteristics and components of language and communication for participants. The use of both symbolic (verbal) and non-symbolic (non-verbal) communication techniques were covered with symbolic including oral speech, writing and typing, sign language, low-tech communication boards and books, and high tech speech output communication devices. The role visual supports can play in helping to organize the attention and the joint attention of people with ASD was also presented.

Participants included educators (including an early interventionist), parents, a nurse, a family support specialist, a health insurance case manager.

- Number of attendees: 5
- Average satisfaction rating: 3.46 (out of 4.0)
- Average percent change in Content: +16.7%
- Average percent change in Application: +34.1%

C. Independence and Interdependence: Goals for People with ASD (6/12/2108 & 6/18/2018)

The third session focused on people with ASD as members of communities (local communities, educational communities, recreational communities, work communities, etc.). Participants learned how people with ASD can be supported in becoming more active participants in day-to-day activities and how communication devices can support increased independence and interdependence. Attendees also discussed the value of including speech-language pathologists (SLPs) as a part of a treatment/education/support team and the important emphasis for SLPs on interdisciplinary collaboration.

- Number of attendees: 4
- Average satisfaction rating: 4.0 (out of 4.0)
- Average percent change in Content: +50.0%
- Average percent change in Application: +33.3%

6. Incorporating Developmental & Autism-Specific Screening Into Practice

Contributors: Brittany Powers and Karen Avino

Summary: The American Academy of Pediatrics Delaware Chapter (DEAAP) developed an online training for medical providers on developmental and autism-specific screening. A DNEA staff member collaborated with an DEAAP staff member to design the training, adding particular focus on information regarding the use of the Modified Checklist for Autism in Toddlers-Revised (M-CHAT-R). The training offers an overview of best practices and standardized tools for developmental and autism-specific screening, referral processes, state resources, and workflow. The training is publicly available on YouTube and is now available on the DEAAP's website. Continuing medical education units (CME's) are offered to providers who complete the online training video and quiz. The original content was developed using leveraged funds from

the aforementioned Building Bridges grant and was converted into a web-based training by DNEA staff. Future work will be sustained by DNEA funds.

Strategic Plan Area(s) addressed:

- Improvement Area I: Outcome D: All medical professionals charged with diagnosing "autism" will use empirically-supported evaluation protocols. (DNEA priority area)
- Improvement Area II: Outcome E: All medical providers, mental health providers and support staff will have access to information, knowledge and training to effectively serve individuals with ASD.

7. Autism 101

Contributors: Autism Delaware Staff

Summary: Autism Delaware offered a quarterly program in NCC and Kent/Sussex locations called, "Autism 101". This training is designed for professionals serving individuals with ASD and their families. *Autism 101* includes an overview of the functional areas affected by ASD and common approaches designed to help professionals in supporting individuals with ASD. A separate *Autism 101* training was developed for parents and caregivers of newly diagnosed children with ASD. Participants that have completed program evaluations report a high level of satisfaction with the content averaging 4.85 out of 5 over the 4 offered events. In 2016, participants expressed a desire for more time for question and answering. As a result, in Fiscal year 2017-2018, Autism Delaware increased session lengths by ½ hour and revised content. In addition, this year Autism Delaware offered 2 sessions in Spanish. DNEA funding represents approximately 15% of the total Family Support services budget, including Autism 101 trainings for professionals and families.

Strategic Plan Area(s) addressed:

- Improvement Area II: Outcome E: All medical providers, mental health providers and support staff will have access to information, knowledge and training to effectively serve individuals with ASD.
- Improvement Area II: Outcome H: All agencies and human service providers will have access to adequate training to support life skills, employment, public safety and emergency management on behalf of individuals with ASD.
- Improvement Area IV: Outcome C: All individuals with ASD and their families will understand identify and support skills of self-determination.
- Improvement Area VI: Outcome A: All families will have an understanding of the attributes and characteristics of ASD and the manner in which it affects human development and learning.

Below is a list of Autism 101 trainings conducted by Autism Delaware on behalf of the DNEA:

<u>Date</u>	<u>Audience</u>	<u>Number of Participants</u>
July 2017		
07/12/2017	La Red Pediatrics	8
September 2017		
09/16/2017	Nemours Nursing Staff	40
09/20/2017	Dover Behavioral Health	30
09/25/2017	Dover Behavioral Health	36
October 2017		
10/12/2017	Delaware Technical & Community College Disability Supports	12
10/16/2017	La Red Health Center	15
10/26/2017	Grand Opera House Staff	15
November 2017		
11/13/2017	Wesley Occupational Therapy Program	23
11/15/2017	OSHER Program	25
January 2018		
01/19/2018	Western YMCA Staff	18
01/16/2018	Tower Hill School	120
March 2018		
03/05/2018	Grand Opera House Staff	15
03/10/2018	Crisis Intervention Team	50
03/29/2018	United Cerebral Palsy Camp Staff	12
April 2018		
04/09/2018	Bear/Glasgow YMCA Staff	10
04/17/2018	Appoquinimink Family Council	12
May 2018		
05/02/2018	Delaware Adolescent Program	10
05/22/2018	Lombardy Elementary	40

DNEA Facilitated/Sponsored Trainings

Outside the Box Conference – The DNEA partnered with the Statewide Programs for the Deaf, Hard of Hearing, & Deaf-Blind, the Division for the Visually Impaired and Autism Delaware to expand the Outside the Box Conference, a 3-day conference in Rehoboth Beach designed for families and professionals of children with low incidence disabilities. This year the conference expanded to include topics related to autism and audiences impacted by autism. The intention is for the conference to become a state and regional leader (and perhaps eventually national leader) in conferences for professionals and families impacted by children with autism and low-incidence disabilities.

The Outside the Box Conference took place on October 6-8, 2017 and was attended by 125 professionals and 33 family members. Training strands were offered in disability-specific areas (e.g., autism) as well as broader areas impacting the entire population (e.g., Communication; Individualized Education Plans (IEPs); Teaming and Behavioral Strategies). A broad range of professionals attended the conference including: Administrators, Audiologist, Educational Diagnosticians, Early Intervention Specialists, General Educators, Nurses/Medical, Occupational Therapists, Paraprofessionals, Psychologists, Speech-Language Pathologists, Special Educators, Teachers of the Deaf, and Other.

Strategic Plan Area(s) addressed:

- Improvement Area II: Outcome B: All LEAs have the skills and ability to provide high quality and equitable services and supports for individuals with ASD. (DNEA priority area)
- Improvement Area II: Outcome C: School administrators, teachers and para-educators have access to an array of on-going professional development activities reflecting the education of students with ASD.
- Improvement Area VI: Outcome A: All families will have an understanding of the attributes and characteristics of ASD and the manner in which it affects human development and learning.

As members of the conference planning committee, DNEA staff were involved in all aspects of planning, including supporting site logistics, securing speakers, marketing, and managing conference activities. DNEA funding also supported fees and associated costs for speakers on topics related to autism specifically and general evidence-based practices used with children with autism. The conference planning committee continued to meet on an on-going basis in order to evaluate the 2017 conference and begin planning for the 2018 conference.

Delaware Association of School Psychologists (DASP) Annual Conference – The DNEA sponsored two speakers on autism-related topics at the DASP Annual Conference, which was held on May 10-11, 2018. Over 100 attendees received training on evidence-based evaluation and treatment methods related to supporting children with autism in the schools. At the conference, DNEA staff also conducted a survey of 76 school psychologists and other attendees

– identified by district - in order to understand their level of competence and training needs. Survey information was shared with the ICA and is informing future trainings that are offered statewide and with individual districts.

Strategic Plan Area(s) addressed:

- Improvement Area I: Outcome B: All infants, children and adults, regardless of classification, are known to the school and service providers (with parent’s informed consent) when ASD is present and provided reasonable considerations.
- Improvement Area I: Outcome C: 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. (DNEA priority area)
- Improvement Area I: Outcome E: The standard for diagnostic practice for all categories of ASD will include an array of therapeutic recommendations.

The training sessions sponsored by the DNEA are included below:

Marilyn Monteiro, Ph.D., led a 6-hour session entitled “Autism Evaluations: Individualizing the Diagnosis Using the MIGDAS-2 Process.” Dr. Monteiro described procedures for diagnosing and classifying autism. In particular, she focused on evaluations for children with more verbal skills and identifying innovative ways of discerning autism characteristics that may not be readily apparent.

Emily Bernabe, Ph.D., BCBA (Clinical Director of the Swank Autism Center at Nemours/AI duPont Hospital for Children) led a 3-hour session entitled, “Classroom and Behavioral Consultation Strategies for Students with Autism Across the Lifespan.” Participants learned about behavioral consultation and methods for supporting students with autism across different age groups and levels of functioning. Emily focused on strategies for working effectively with teachers, other classroom staff, as well as families in creating positive environments and understanding and reducing challenging behavior.

Technical Assistance Sessions

In Spring 2018, the DNEA began offering technical assistance and resources for requests from professionals that were individualized or would not be covered in an upcoming training. The following represent examples of technical assistance provided:

- Contact: Seaford School District teacher (3/28/18) - Provided coaching via phone on general evidence-based practices and implementation based on student needs. Discussed preventative behavior strategies to bring back to the school to in order to plan and implement supports for transitions with a specific student. Provided follow-up with additional resources to support implementation of practices.
- Contact: Seaford School District IEP team (5/4/18) - Participated in IEP review with Niki Roberts with PBS for an on-site coaching session. Followed up via email after

observation in classroom with two special education teachers on strategies for individuals displaying sensory and attention seeking behaviors. Created and shared visual schedules with movement opportunities built in and choice board with exercise options.

- Contact: Student Teacher in Appoquinimink School District (5/1/18) - Provided coaching in person around supporting a student with behavioral challenges in the classroom. Discussed the importance of data, overview of ABC data, reinforcement, and satiation. Followed up with resources which included reinforcement profiles and assessments.

Strategic Plan Area(s) addressed:

- Improvement Area II: Outcome D: School administrators, teachers and para-educators have access to technical assistance anchored to their individualized school needs.

Professional Contributions

- Several ICA members and DNEA staff members participated in a stakeholder group to provide the Department of Education with input on revisions to the eligibility criteria regulations for an educational classification of ASD.
- DNEA staff members participated in Sussex County Health Coalition meetings and workgroup meetings, including in the Behavioral Health Workgroup and the Early Childhood Workgroup.
- DNEA and Autism Delaware staff members participated in the 2017 National Autism Leadership Summit at the Ohio Center for Autism & Low Incidence Annual Conference. At this invitation-only event, leaders from training centers on autism from across the country share updates with each other on local activities, discuss areas of challenge, and work together to identify newly identified needs.
- DNEA staff participated in planning meetings for the Delaware Inclusion Conference
- DNEA staff participated in the Statewide Transition Council and monthly transition cadre meetings facilitated by the Department of Education and Division of Vocational Rehabilitation.

Resource Dissemination

An informational brochure for families describing the differences between a medical diagnosis and educational classification of ASD continued to be disseminated to school professionals, clinicians and other community members, and ICA members to help facilitate conversations around ASD. 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.

Strategic Plan Area(s) addressed:

- Improvement Area II: Outcome C: 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. (DNEA priority area)
- Improvement Area VI: Outcome C: Dissemination- The initiatives reflected in this statewide plan include a wide range of information and avenues to provide information. Therefore, there will be an appropriate dissemination plan for all the state initiatives.

The total number of brochures disseminated in response to requests for the 2017-2018 year is shown below.

English	850
Spanish	275
Arabic	75
Hindi	75
Telugu	75
Mandarin	50
Haitian Creole	50
Cantonese	50
Total	1,500

Staffing

The DNEA continued to put significant effort toward hiring CDS-based staff in 2017-2018. Two full-time staff were hired during 2017-2018 (Kellene Copeland and Susan Veenema). Susan was hired to oversee and deliver school-based trainings. Kellene serves as a full-time trainer/coach. Both have significant experience teaching students with ASD and providing training and coaching. Susan also has previously overseen statewide training initiatives and has led multiple statewide initiatives with the Delaware Department of Education (DOE).

We continue to search for a DNEA Director. The search committee consists of 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 2017-2018 year, efforts to hire a director had been unsuccessful. Of the applications for director, we have requested interviews with eleven applicants. We made offers to two candidates in 2018 and unfortunately, both turned us down after lengthy negotiations. We continue to review all new applications immediately and the search committee decides collaboratively whether applicants warrant a full interview. Prior to full interviews, informational meetings are held with the interim director in order to share more extensive information about the position. In Summer 2018, we began actively working with recruiters at UD to expand our efforts in order to pro-actively seek

new candidates. We also initiated a new advertising effort. In addition, we are engaging in discussions with UD administration about how we might adjust the nature of the position in order to attract more qualified candidates.

CDS continued to provide interim staffing for organizational activities as staff were hired. Brian Freedman, Ph.D., Associate Director of CDS, is functioning as the DNEA Interim Director (10% FTE). DNEA coordination was provided by Brittany Powers (25% FTE). Richard Lytton, CCC-SLP (20% FTE), a speech-language pathologist and specialist in augmentative and alternative communication, also continued to offer training and consultation.

The DNEA also benefits from working with subcontractors in order to enhance its services through organizations that offer expertise beyond what CDS-based staff can offer. As described in the original legislation creating the DNEA, Autism Delaware has a subcontract for offering family services. This year, Autism Delaware also offered some Autism 101 trainings through its DNEA subcontract in those situations when the request seemed to be a better fit for Autism Delaware's expertise. Expansion of the subcontract was also discussed to include employment training/coaching in 2018-2019.

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.

Key Strategic Areas:

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

This year, through DNEA funding, the Family Support team has increased its capacity to serve families statewide through two new Family Navigators, both of whom are bilingual. Additionally, Autism Delaware fully implemented their electronic case management system that captures data reflecting the work happening within Delaware communities (FamCare) and enables Autism Delaware to more accurately track parent contacts as well as the time spent with each parent contact. Thus, Autism Delaware has increased the number of parent contacts by almost 75% in 2017-2018 compared to the previous year's parent contacts. For the first time in Autism Delaware's history, they have more parent contacts in Kent/Sussex than New Castle County due to increased resources and outreach (see appendix C).

Autism Delaware focused on expanding our services to Spanish speaking families but remains vigilant to the role it plays within all communities and families impacted by ASD. This year, the following represents some action steps made towards improving Autism Delaware's overall outreach to families, individuals and community groups of Delaware's Spanish-speaking community:

- Interviews with bi-lingual staff in "Hoy" and "El Tiempo"

- Developed and enhanced existing English and Spanish language materials to reflect the diversity of services being offered through Autism Delaware’s Family Support Department
- Developed a formal MOU with La Red Health Center to provide onsite services to Spanish speaking families
- Representation on various councils and committees such as the Delaware Hispanic Commission, Latin Youth Committee, Delaware CAN, Heart of Good Health, La Esperanza, La Red, Latin American Community Center, Hispanic Mentor Association and others.

Under new leadership and with a focus on increasing evidence-based services, Autism Delaware’s vision of the work includes offering proactive family navigation throughout the state, increasing new community business collaborations and establishing funding streams for the continuation of services.

B. Provide parent education seminars/workshops

This year Autism Delaware has maintained the expansion of education programs and offered Autism 101 program in Spanish for the first time. In addition to the Autism 101 trainings for professionals discussed previously, AD provides Autism 101 trainings to families of children newly diagnosed with ASD.

This year, thanks to DNEA support, many of Autism Delaware’s parent education programs are now being offered utilizing videoconferencing or on Facebook Live. Videoconferencing has allowed Autism Delaware to offer simultaneous workshops in Newark and Lewes locations. Also, families can participate from their home environments. Utilizing this technology enables Autism Delaware to offer a consistent message to families across the state. The following represents the participation of families in offered workshops in-person and using Facebook Live.

Face-to-Face only sessions

- September: Autism and Sexuality – 8 attendees in person
- January: Autism 101 in English – 9 attendees in person
- January: Autism 101 in Spanish – 4 attendees in person
- June: Autism 101 in English – 5 attendees in person
- June: Autism 101 in Spanish - 8 attendees in person
- June: Autism 101 and Sexuality – 6 attendees in person

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

- October: Financial Planning for Special Needs (17 in person/ 605 views on FB Live)
- November: Know the Numbers (6 in person/641 views on FB Live)
- March: Sleep and your Child with Autism (5 in person/ 1400 views on FB Live)
- June: Understanding Down Syndrome & Autism (10 in person/ 3 via videoconference)

C. Staff Training

A key requirement of the DNEA is the provision of evidence-based services. Through DNEA funding Autism Delaware has been able to provide training in evidence-based programs and best-practice in Family Support.

D. Overview of core Family Navigation and Support activities

Support groups/Coffee Hours: Offered in multiple locations in each county, small group intervention support modalities are facilitated by Family Navigators and attended by families and other caregivers. In 2017-2018, Spanish-speaking and bilingual support groups were offered in New Castle and Sussex Counties. Autism Delaware has seen tremendous growth in Coffee Hour attendance in all counties. Grandparent groups have continued across the state and have a consistent number of attendees.

Individual/family advocacy: Autism Delaware regularly supports families and individuals with a variety of issues impacting their lives. Daily, Autism Delaware is addressing requests for information and discussing special education system issues that interfere with family desires. Participating in family engagement at all levels provides Autism Delaware with the knowledge to use during opportunities for individual/family and legislative advocacy. 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 as well as providing support to parents in IEP meetings (appendix C). The number of Spanish speaking families served has seen an enormous increase this year. Contacts with Spanish speaking families rose from less than 1% (2016-2017) of total contacts to 13% in 2017-2018 (420 total contacts).

Community Engagement: In order to best serve families, Autism Delaware's staff 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 - that focuses on health disparity

- Interagency Committee on Autism- statewide organization comprised of all agencies and organizations who touch the lives of people with autism and their families. Chair for Childcare Sub-Committee.
- Statewide Special Education Strategic Planning Committee – committee of stakeholder to develop a plan to improve special education in Delaware
- Delaware Oral Health Care Coalition - focuses on a few topics, but most importantly for our population is Medicaid coverage for dental procedures for adults. We assisted with a dental survey for adults with disabilities.
- Governor’s Advisory Council for Exceptional Citizens – the state advisory panel for IDEA and advises on the human service needs of exceptional persons
- 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
- Numerous different educational councils and committees - improving IEPs, access to the general education curriculum, etc.
- Local PTA/PTO/PACs by attending, presenting our services, bringing a speaker, or sharing information whenever possible.

DNEA Financial Report 2017-2018

The following totals reflect funds utilized during the time of funding for 2017-2018:

Personnel Costs	\$99,930.82
Travel Costs	\$6,671.77
Training Supplies & Expenses	\$1,374.94
Advertising	\$2,838.00
Conference Fees & Expenses	\$2,628.00
Printing	\$6,583.14
Computer Hardware & Supplies	\$7,037.36
Professional Speaker Fees	\$16, 372.00
Professional Development	\$249.00
Employee Recruiting	\$1,390.91
Other Material and Supplies	\$616.25
Sub Awards	\$106,686.00
Overhead	\$34,128.51

<i>Total</i>	<i>\$286,506.70</i>
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The unspent \$213,493.30 of the \$500,000 funding appropriated in 2017-2018 will be carried over into the 2018-2019 year. This amount, plus the \$246,911.60 in carryover from 2016-2017, will supplement the 2018-2019 funding. Expenditures are expected to be significantly higher in 2018-2019 given the recent staffing increases and subsequent increases in training and supply purchasing.

Priorities for 2018-2019

At the end of Fiscal Year 2018, the ICA reassessed the DNEA priorities using the previously established survey method. The same four priorities were recommended for 2018-2019 focus which are listed below.

- All medical professionals charged with diagnosing “autism” will use empirically-supported evaluation protocols.
- All LEAs have the skills and ability to provide high quality and equitable services and supports for individuals with ASD.
- 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 individuals with ASD will receive appropriate mental health services and crisis support services when they need them and where they need them.

The collective ICA members decided to focus on priorities for several years, rather than reassess annually, to allow sufficient time to measure progress and community outcomes. Additionally, the ICA did not want specific DNEA priorities to limit the scope of the DNEA work and felt a new method for identifying priority areas and terms would be beneficial for DNEA oversight. In 2018-2019, the ICA plans to create a set of rules and guiding policies for the decisions and reassessment of DNEA priorities.

Summary and Next Steps

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. In 2017-2018, the DNEA continued to build awareness of the needs of people with autism and their families, develop priorities to guide further activities, and expand its offering of training and technical assistance. Trainings on evidence-based practice, overseen by the UD Center for Disabilities Studies, were provided to 250 professionals from a variety of disciplines across the state. Autism 101 trainings for professionals, a portion which was funded through the DNEA, was conducted by Autism

Delaware with 491 professionals. An additional 278 professionals participated in training through supplementary grants cultivated by the ICA and DNEA. Family support and training, overseen by Autism Delaware and partially supported with DNEA funding, resulted in a substantial increase in families of children with ASD receiving family navigation services through Autism Delaware - an almost 75% increase from 2016-2017. Autism Delaware also increased family contacts in both Kent and Sussex Counties, as well as for families using Spanish as their primary language. Family trainings and workshops, including Autism 101s, reached approximately 3,200 people between in-person attendance and Facebook Live viewings.

Substantial steps were taken in 2017-2018 to develop the staffing and processes for the DNEA, as well as to increase our efforts in training professionals and offering support to families. Two full-time staff were hired during 2017-2018 a third full-time staff member was hired shortly after completion of the fiscal year. With three full-time staff and multiple collaborating partners, the DNEA has substantially increased its training capacity and will have an even greater impact in 2018-2019. Although hiring a DNEA Director has required more time and resources than expected, all collaborating partners agree that the selection must be done in a careful fashion in order to ensure 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 3 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 2018-2019 Activities --

Several notable steps and accomplishments have taken place already in 2018-2019. The following represent highlights and brief updates that will be expanded upon in a full report upon conclusion of the 2018-2019 year.

- A DNEA Coordinator, Kara Downey, was hired shortly after the completion of the fiscal year. Kara will serve as DNEA coordinator and will help facilitate the ICA and its workgroups, coordinate logistics for trainings, develop dissemination products and conduct training. Kara has a background in social work and adult services and is the sibling of an adult with ASD.
- The passage of HB292 – which brings additional resources toward training on autism in the schools - led to the initiation of a broader plan for providing training to school staff across the state. This plan, developed in a collaborative process by the DNEA, the Delaware Department of Education, the former Statewide Director of the Delaware Autism Program, and Autism Delaware has begun to be implemented with the creation of a needs assessment which was disseminated to all districts and charter schools on 11/19/18. Following completion of the needs assessment, a more comprehensive assessment will be conducted with districts and charter schools to establish a plan for systemic intervention.

- DNEA staff conducted five full-day statewide trainings for educators, special educators paraprofessionals, and other school staff during Summer 2018. A total of 230 participants attended the trainings, which provided introductory information on autism spectrum disorders as well as evidence-based practices.
- DNEA staff initiated discussions with the Division of Prevention and Behavioral Health Services (DPBHS) and the Division of Developmental Disabilities Services (DDS) on the needs of professionals in their agencies and their contractors.
- DNEA staff conducted two trainings on autism and evidence-based practices in Fall 2018 in conjunction with DPBHS for over 130 outpatient mental health therapists, inpatient psychiatric staff, case managers, and others. The success of these trainings has led to additional discussions with DPBHS about more extensive and targeted future upcoming trainings.
- The ICA will further define the ICA's responsibilities, working processes, and meeting rules during Fiscal Year 2019. This effort will be managed by an outside facilitator (Jerry Petroff) and will include a daylong retreat.
- The DNEA will be conducting outreach to identify needed ICA representatives including a parent/caregiver from Kent County, a parent/caregiver from Sussex County, and an individual with ASD to ensure full member presentation on the committee.
- DNEA staff will be developing content and conducting a variety of school-based trainings throughout 2018-2019. Topics include Classroom Strategies, Instructional Strategies, Social Skills, Understanding Autism and Classroom Strategies, Instructional Strategies and Evaluation and Classification.

APPENDIX A



Professional Development Evaluation Form

Training Title

Position: _____ *(specify general or special education)* **Date:** _____

CONTENT

Before the workshop

After the workshop

Read each of the statements and rate your understanding of the topics BEFORE the workshop. Next indicate the extent of understanding after the session.

How would you describe your understanding of the following?

	None	Little	Moderate	Extensive	None	Little	Moderate	Extensive
Different ways individuals with ASD process information								
Triggers that may cause emotional dysregulation for students with autism								
Communication is not just verbal communication								
Need for sensory built into the day								
Need for preparing students for what is coming next in the day/transitions								

APPLICATION

Before the workshop

After the workshop

Read each of the statements and rate how prepared you felt implementing the topics BEFORE the workshop. Next, rate how prepared you feel after the session.

How would you describe your preparedness to do the following?

	None	Little	Moderate	Extensive	None	Little	Moderate	Extensive
Accommodate students who process information at a different speed								
Identify the variety needs a students may have that may trigger emotional dysregulation								
Identify other communication strategies for students with ASD								
Strategies for integrating sensory into your students' day								
Preparing students for transitions throughout the day								

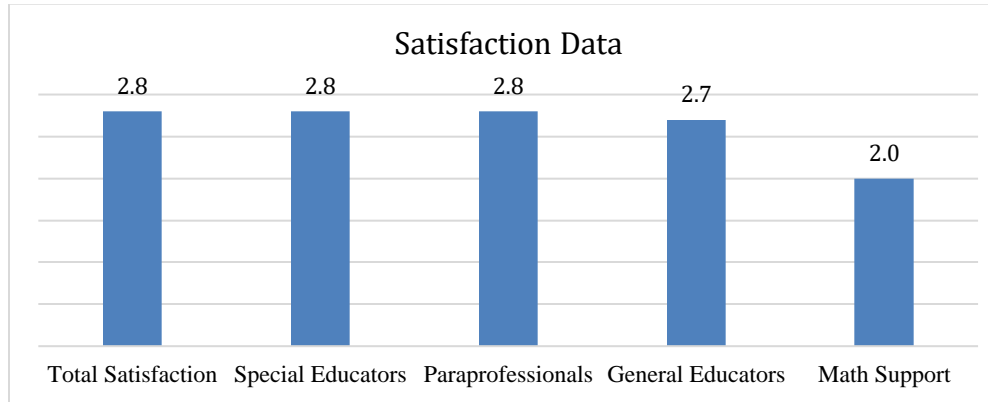
Training Satisfaction Rating (circle): 1 (1) Not at all satisfied (2) Partly satisfied (3) Satisfied (4) Very satisfied

Additional Comments:

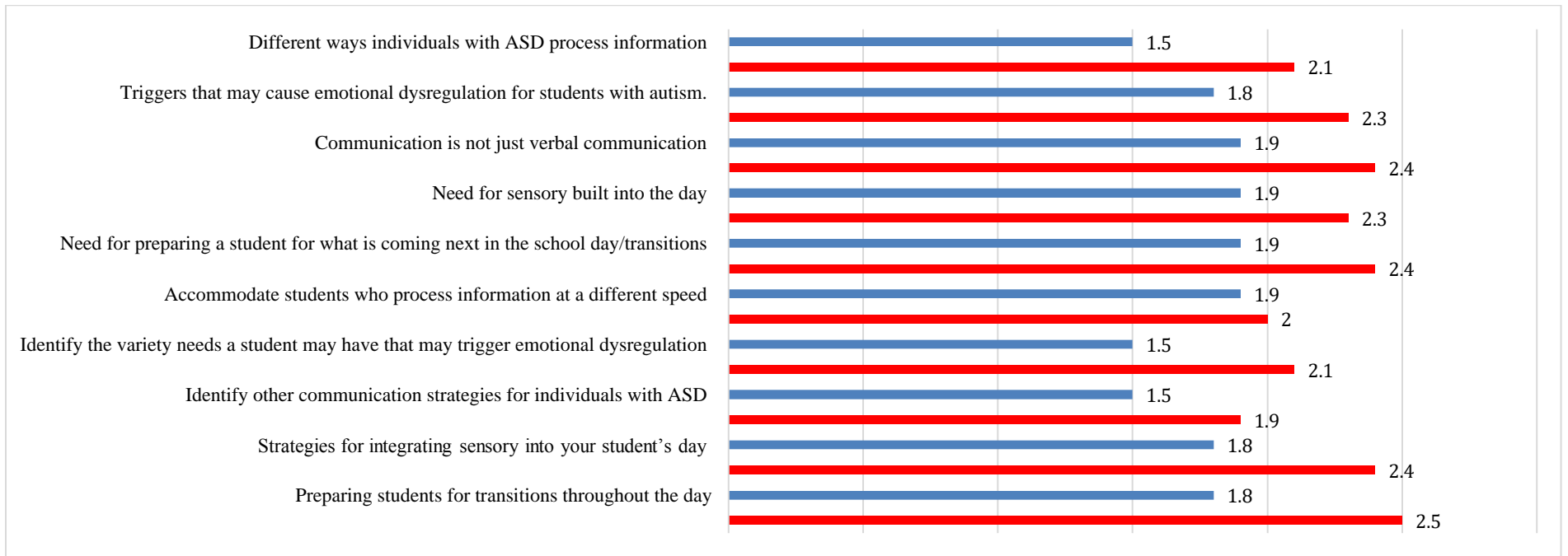
APPENDIX B

DNEA TRAINING EVALUATION DATA

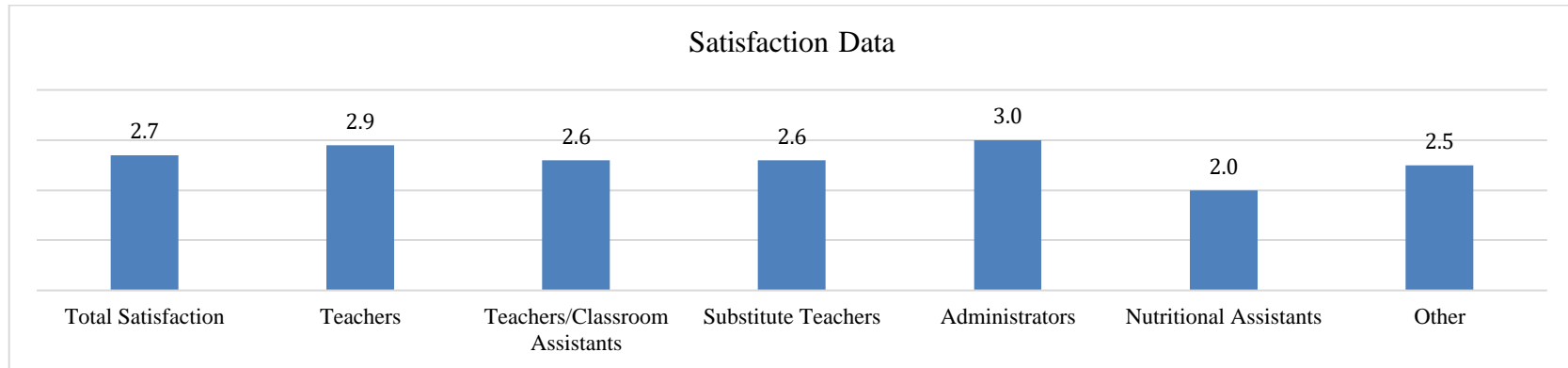
A. Western Sussex Summit: Many Faces of Autism



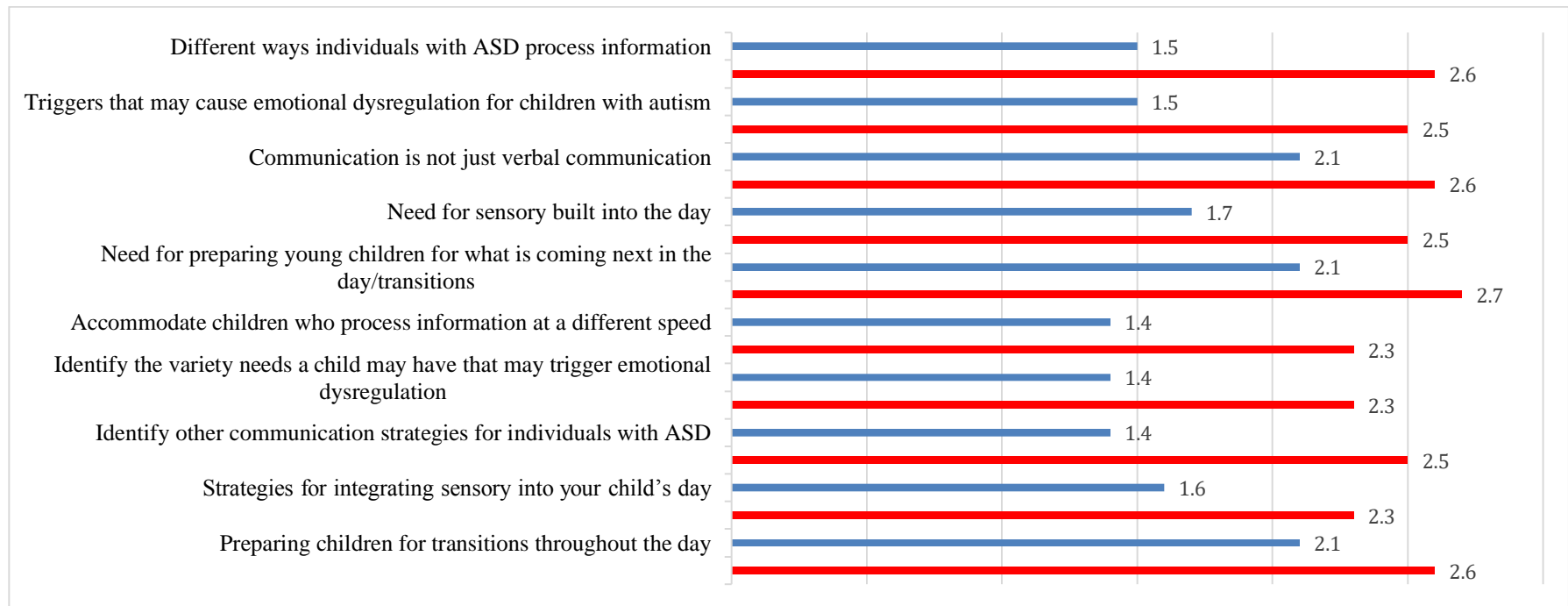
Training Satisfaction (0 - 3 Scale: 0- not at all satisfied; 1- partly satisfied; 2- satisfied; 3- very satisfied)



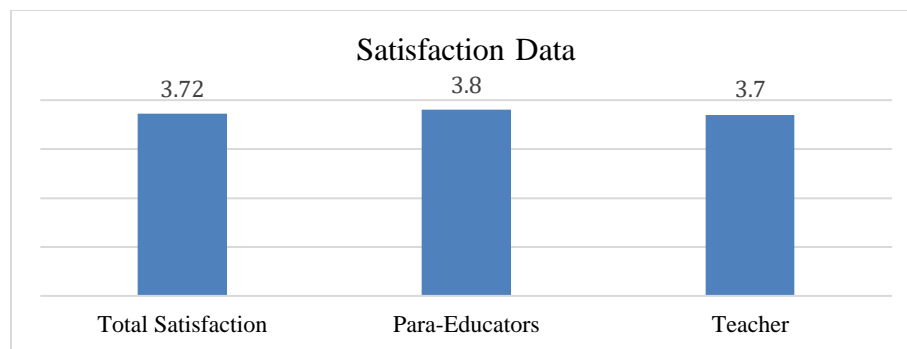
B. UD Early Learning Center Professional Development Day: Many Faces of Autism



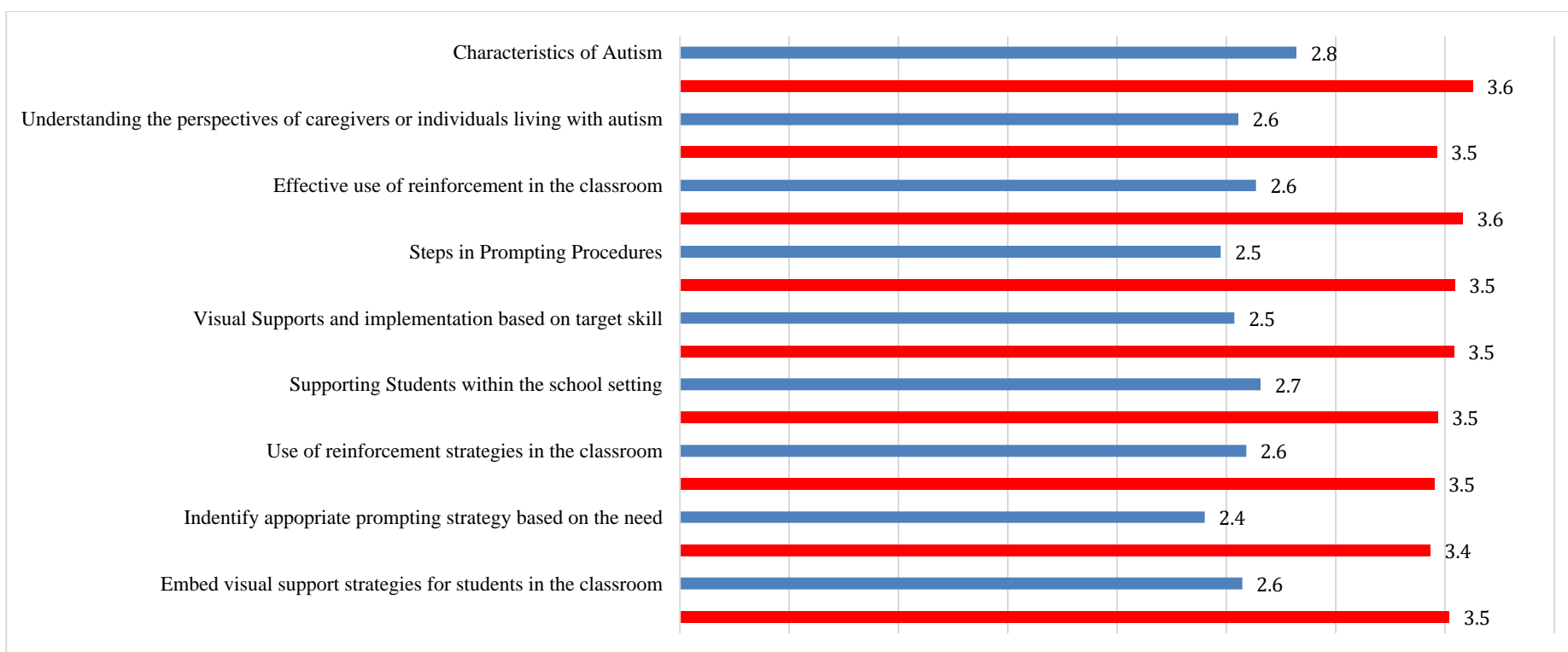
Training Satisfaction (0 - 3 Scale: 0- not at all satisfied; 1- partly satisfied; 2- satisfied; 3- very satisfied)



C. Making A Difference Conference: Many Faces of Autism



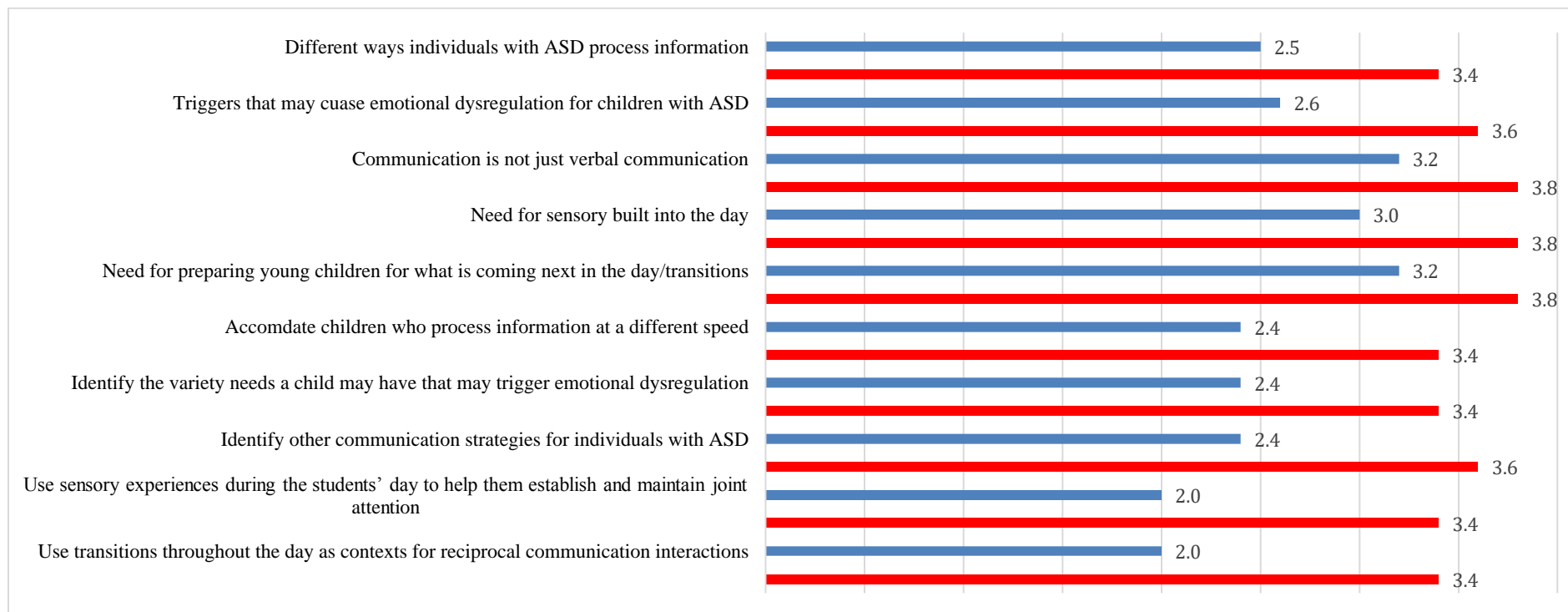
Training Satisfaction (0 - 3 Scale: 0- not at all satisfied; 1- partly satisfied; 2- satisfied; 3- very satisfied)



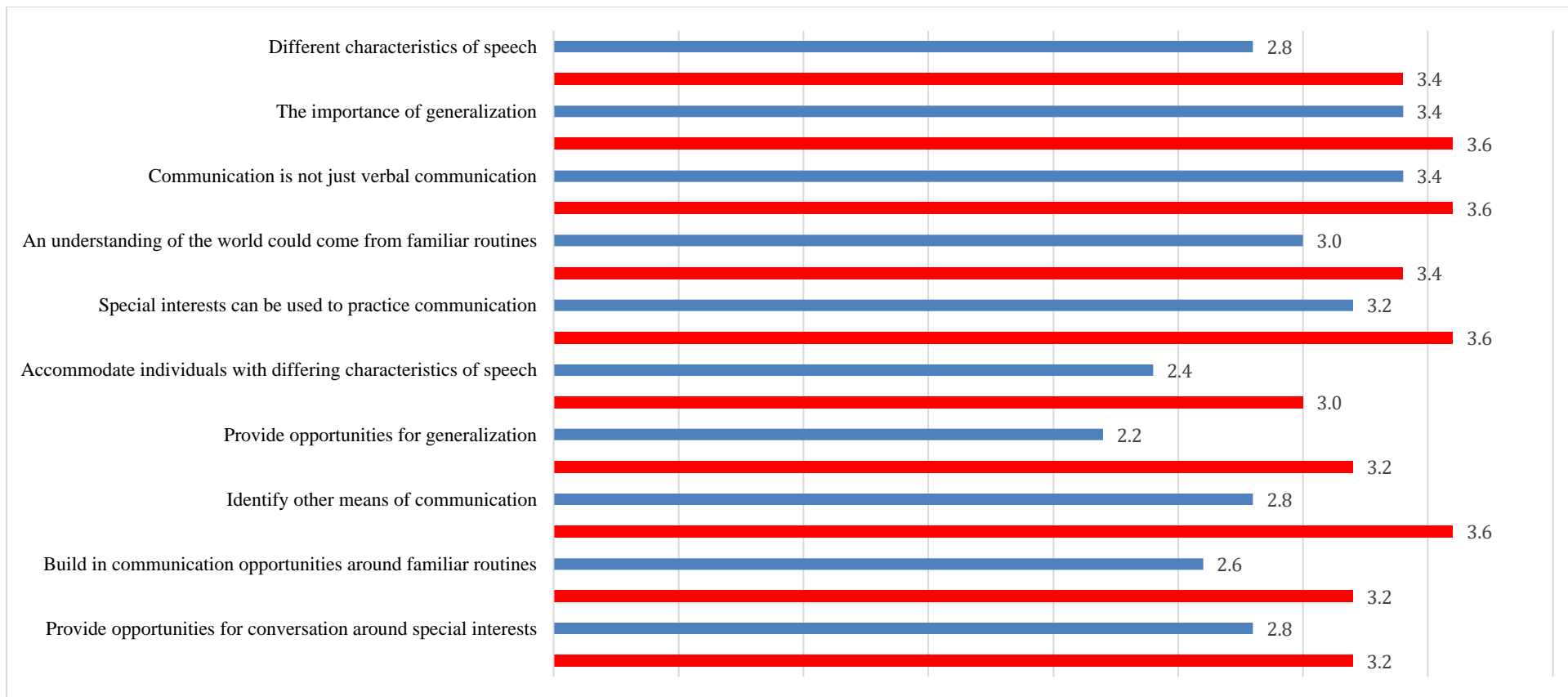
D. Communication Series: Understanding Autism and Communication Skills



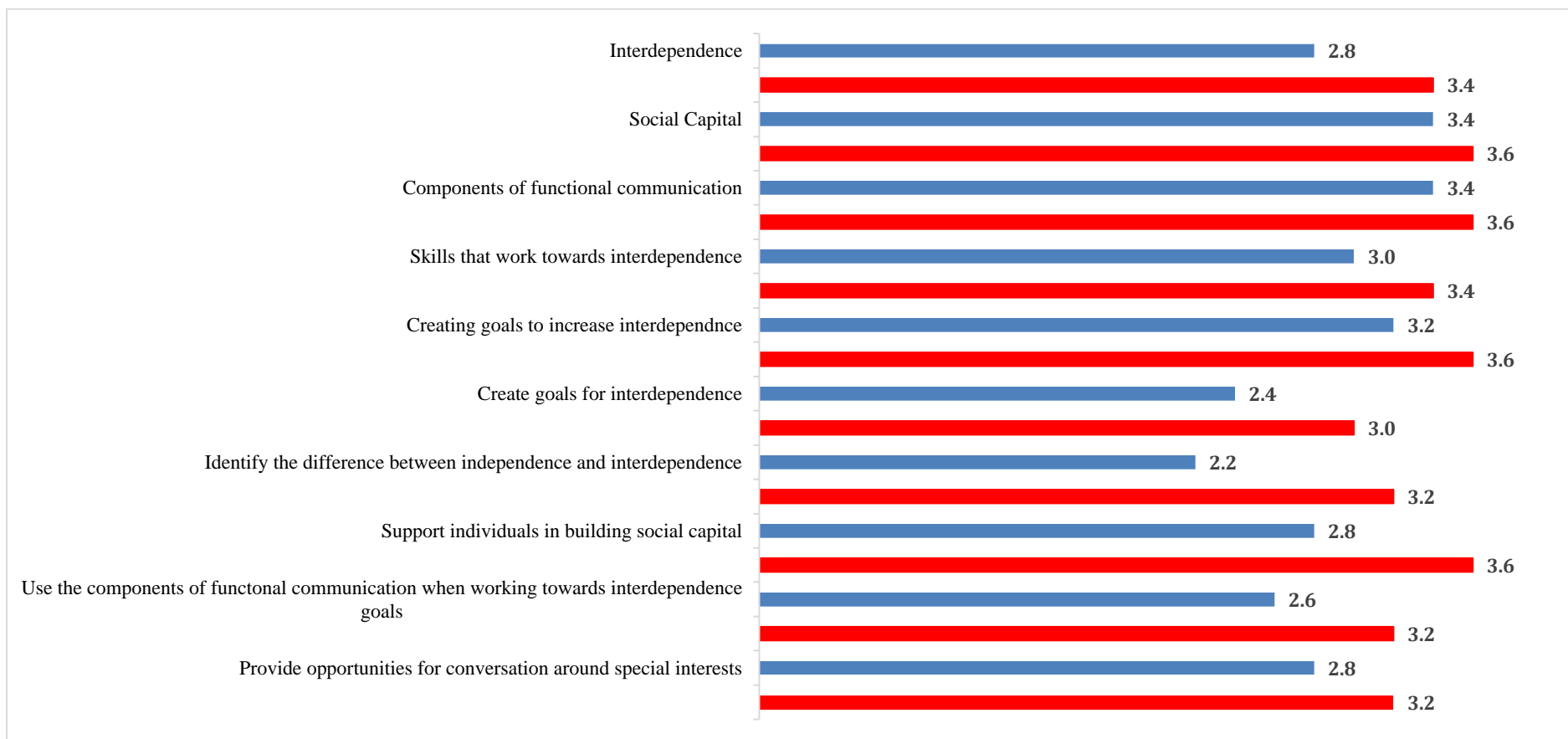
Training Satisfaction (0 - 4 Scale: 1- not at all satisfied; 2- partly satisfied; 3- satisfied; 4- very satisfied)



E. Communication Series: Social Skills and Communication Skills for People with ASD

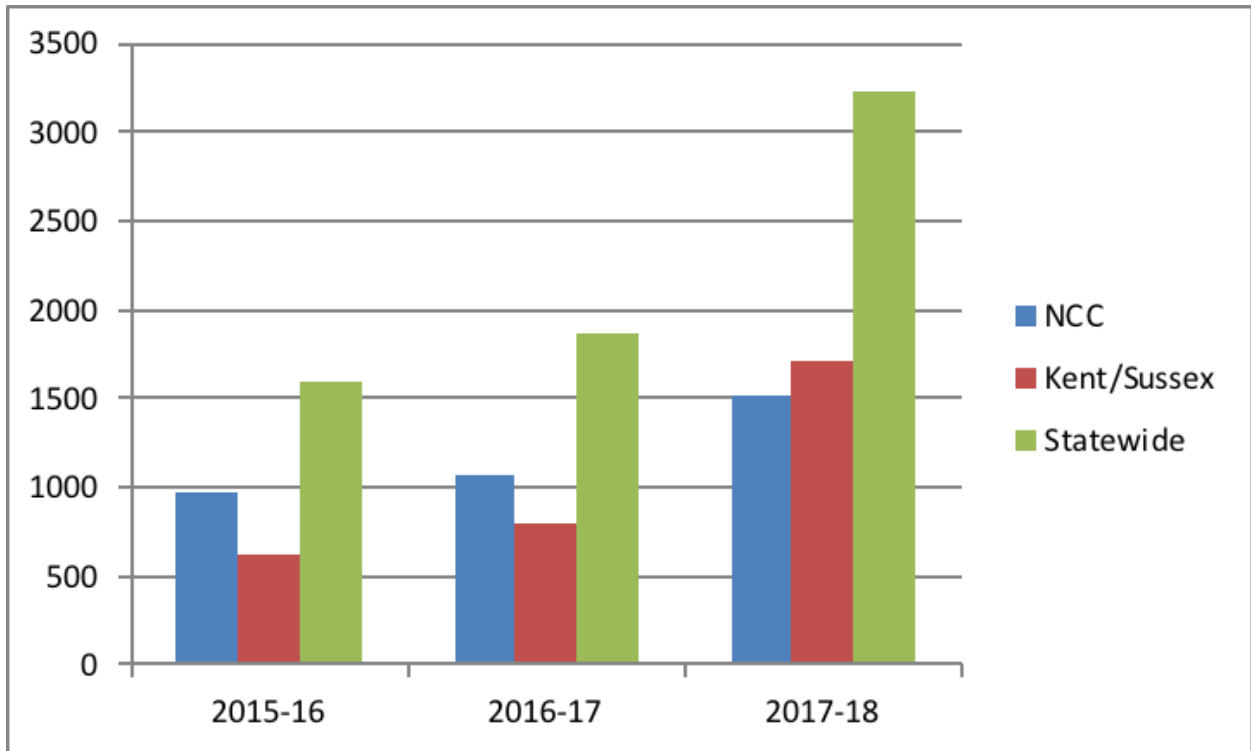


F. Communication Series: Independence and Interdependence- Goals for People with ASD



APPENDIX C

Total Number of Individual Family Supports Contacts 2014 - 2016, by Location
 (As reported by FileMaker, Methods: phone, email, mail, or face to face)



	2015-16	2016-17	2017-2018
NCC	963	1068	1522
Kent/Sussex	625	794	1705
Statewide	1588	1862	3227

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