

**Interagency Committee on Autism
Meeting 12/06/2017**

Agenda

- 1) Welcome & Introductions **Please sign in*
- 2) Family Needs Report
- 3) Committee Updates
- 4) DNEA
 - a) Staffing Update
 - i) Director Search & Status
DNEA Director Candidate Presentation
Thursday, December 7th, 2017
12:00 – 1:00 PM
Delaware Biotechnology Institute
15 Innovation Way, Newark, DE 19711
 - b) Training Update
 - i) Parent Training Series
 - ii) Western Sussex Summit
 - iii) Upcoming training opportunities
 - iv) Training Request Process
 - c) Website Update
 - d) DNEA Report
 - e) ICA Policies & Processes
 - i) Volunteer committee to develop draft for review (e.g., voting procedures)
- 5) Agency Updates

Next meeting: Wednesday, March 14th, 2017 @ 1:00 – 4:00pm; CDS Room 132A

ICA Priorities

- ❖ 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.

ICA Meeting Minutes

December 6, 2017

In attendance: Zoom – Brian Freedman (CDS), Brittany Powers (CDS), Dick Lytton (CDS), Dawn Maloney (Parent Advocate), Susan Veenema (DOE), Emily Bernabe (Nemours), Laura Dewey (Nemours), Vince Winterling (DAP), Annalisa Ekbladh (Autism DE), Shebra Hall (DHSS/Birth to Three), Brian Hall (Autism DE), Heidi Mizell (Autism DE), Erin Goldner (Hope Street DE; Sibling Advocate) Cindy Brown (DOE), Ashley Kavanaugh (DVR), Clay Watson (DSAMH), Vanessa Rodriguez (DEFV)

Condolences offered to Autism Delaware on the loss of Alex Eldreth, their Director of Policy, who recently died. This is a very sad loss for the entire ASD community.

Remembrance for Alex Eldreth on Monday, 12/11 at Easter Seals 4:30-6:30PM. Please RSVP to Autism Delaware if you plan to attend – Teresa.Avery@delautism.org.

Family Needs Report

- Autism DE – 729 parent contacts in the past quarter (almost double the number from last year), new Family Navigators on board so more parent contacts, new intakes (new families/clients for the first time) 60 (Sept), 61 (Oct), 78 (Nov); previously was averaging around 40-50/month
- Avg time spent in person with families is 73 min/family
- Avg time spent with Spanish speaking families is 120 min/family – Spanish families need a lot more background info, don't know as much coming in about services, etc.
- This quarter # of families Spanish served: 6 in NCC, 11 in Sussex
- A lot of families (including in the on-line support group) are struggling with crises and navigating the MH system
- Participated in a record # of IEP's across the state this quarter
- Shift for districts to keep their own students leading to the increase, non-DAP district families are needing more support

Committee Updates

- Last meeting, identified subcommittees
 - One related to day care issues, one related to MH
 - MH Subcommittee – has done outreach to see who could serve on the committee
 - Laura & Emily at Nemours, Dafne at AD, Chris Knox – at DSAMH
 - Diane Treadwell-Deering (new Director of Swank Autism Center at Nemours) has agreed to give a talk in the spring
 - Will be meeting next week (Wed at 2 PM)
 - Want to find quick ways to act whether looking at specific immediate resources, trainings, working with in-patient facilities
 - Will be meeting on a regular basis to get things moving immediately
 - At OCALICON, several states mentioned utilizing school-based MH programs in supporting students with dual-diagnosis
 - Consideration of having the following groups represented:
 - DOE– Susan will request at their meeting next week

- early childhood mental health (Mary Moore?)
 - PBH
- If interested in participating, contact Brian Freedman at brianf@udel.edu know
- Childcare Subcommittee is meeting tomorrow
 - Annalisa can email notes from tomorrow
 - Will talk about who else will be good to include in the conversation

DNEA Updates

- Staffing
 - DNEA Director candidate presenting to community tomorrow
 - Search committee includes: Brian Freedman, Beth Mineo, Emily Bernabe, Teresa Avery, Esley Newton
 - Candidate review process: initial app review by Brian & Beth; those that meet minimum standards – app goes to search committee, then committee decides if the person should receive an initial interview; following that references are checked and stronger candidates are invited for a second interview & to give a talk to the community
 - Tomorrow's candidate (Brenda Bassingthwaite)
 - Will be talking about school district programs in Iowa around challenging behavior
 - Post-talk Q&A – Brian or Brittany offered to share questions for those who couldn't be there (no questions were offered)
 - Brenda will also be meeting with other stakeholders:
 - Another candidate who will be interviewed before the holidays
 - Local to DE, works in the schools
 - There is DNEA funding for a Director, 4 trainers, and a coordinator
 - Currently Brian, Brittany, and Dick remain the funded staff, but only funded part-time by DNEA
 - Current DNEA staff will continue to work to identify trainers and a coordinator
 - One trainer with extensive ASD experience in Delaware received an offer, but decided not to accept.
 - Have a new candidate we are interviewing with next week
 - Have additional potential candidates with experience in supporting children/adults with challenging behavior.
 - If you know anyone who you think may be a good fit or have interest, connect them with Brian directly
 - Flexibility with funding and want to identify areas of expertise and fill areas of need
 - Likely specialty areas among trainers: Special Ed (especially ASD & EBP), Applied Behavior Analysis (using ABA as a way to support students in various ways, especially challenging behaviors), Experience with adults (supporting professionals in employment settings)
 - Want trainers across the lifespan, skills & willingness to train across settings
 - Want wide & varied expertise, also want engaging trainers

- Want combinations of didactic trainings, coaching and consultation, follow-through
 - Dick's training: Augmentative Communication in a broader approach of education and social communication
 - Concern: Going to be hard to create systems wide statewide change with this limited staff
 - Especially in school districts – need to look at an effective approach to create change:
 - Vince shared that in his experience it typically takes about 10 months to truly transform a classroom
 - Model that Brian & Susan had discussed was focused on working with certain teachers “tag-teaming” to create model classrooms, requires buy-in from districts
 - Do have two districts that were ready to go
 - Woodbridge & Lake Forest
 - Looking at how can we support them
 - Have begun with Woodbridge at the Western Sussex Summit
 - When selecting districts to train first, looked at prevalence of ASD, who's serving students in-district – also discussed with Mitch, Cindy, Maria, Susan
- Training Request Process
 - Request for training process drafted by AD, worked on by CDS staff, now being bounced back and forth.
 - Need to look at how we're marketing widely information about the DNEA and also how we're communicating back to ICA members
- Outreach Plans/Ideas
 - Consider plugging into statewide conferences with both tables and giving/sponsoring talks
 - Like presentation last year at the LIFE conference
 - Beneficial to have presence at the inclusion conference (specifically to reach spec ed directors) – serves 6-700 educators – use that opportunity to make announcements and spread the word (either at a table and/or making announcements at sessions)
 - Cindy & Susan will ask planning committee about DNEA having opportunity to speak about who they are, what's available
 - Critical to get special ed directors on board with the DNEA
 - Would be helpful to put out a training schedule to the community
 - Even if just a higher level training, get trainings out there to the community, increase awareness, get people talking
 - DAP ADOS Training – 80 people trained in total
 - Next training is 12/18 – will be tricky with timing to recruit other organizations
 - Currently open to all DAPs, all districts, all charters
 - Generally a mix of new people and people coming for retraining
 - DNEA to team with DAP in the future around ADOS trainings

Trainings

- Western Sussex Summit
 - Presented last week at the Western Sussex Summit
 - Hosted at the Woodbridge High School
 - Professional Development day for schools
 - Primarily Sussex County school professionals, but open to community
 - Used OCALI Many Faces of Autism modules (available free online)
 - Time in-between chapters to host facilitated discussions in small groups
 - Created facilitation questions specific to implementation in classroom and within the home
 - Kept a theme and focus of family-centered practices through thinking about how things may be different in home vs in school, how we can connect with families more and work together
 - Had participants complete a “Next Steps” action plan and self-address an envelope so that we can follow-up with participants after the holiday
 - Feedback
 - Group of 20 participants
 - Overall very positive feedback
 - Satisfaction rating 2.8/3 on scale 0-3
 - Sum of participants shows increases in self-rated knowledge in all content and application areas of the training
 - Especially large increases seen in general educators
 - Sign that this type of training is probably needed and helpful for gen ed
 - Still have the assessments to score and can share results once complete
- Parent Training Series (Autism DE)
 - Have line up of topics, Autism 101 (really successful, really good turnouts, good evaluations), Autism 101 also in Spanish, session on sleep, two sessions on transition (1 English, 1 Spanish), communication, benefits, nutrition/feeding, autism awareness month: parent panel of hope (successes, parents at different stages of life) – 10 months of the year skipping July and August
 - Will be releasing 2018 calendar soon
 - Others have reached out about doing more specialized topics, may add some more
 - Will again offer on FB Live & videoconferencing
 - Commentary that parent panels are so powerful; also important to have self-advocates talk on panels
 - Need for transition workshops – how can parents and schools work together and what are the skills students need in preparing for employment
- OTB Conference
 - Originally deaf and deaf/blind community
 - Annalisa connected with Mark Campano to set the stage for expanding conference to include the autism community
 - Joined this year, developed conference together

- Overall, conference was a success (data provided on conference expansion and evaluation)
- Growth over the years, partially attributed to the expansion of the community being served
- Thinking about the upcoming year & how we will have a follow-up process in place to work with professionals after the conference day
- Encouraged to explore CE's for conference
- Brought in a trainer from The Autism Program (from Rhode Island), Cheryl Cotter
 - Highly attended sessions
 - Presented on strategies to support children with ASD in general ed settings, and families working with school professionals
- Will increasing the advertising efforts this year
- Current process for moving forward on the recently developed strategic plan to improve spec ed:
 - One recommendation in the strategic plan is to have professional development days for all educators (3 per year dedicated to spec ed professional development)
 - Trying to get one of the PD days to correspond with the OTB conference
 - Also talked about having the inclusion conference being a PD day

Another suggestion/need: Getting common knowledge and basic needs information out to crisis workers and mental health field

Also have bigger venues to host events

- Will be submitting a presentation proposal for the Making A Difference Early Childhood Professional Conference, April 13-14th, 2018
 - Planning to propose a training similar to that used at Western Sussex
 - Many Faces of Autism with facilitated discussions, target early childhood in discussions and questions

Website Update

- Brian has gotten permissions to move the DNEA website off the CDS website and to move outside the CDS group that worked on the website
- Already have content, videos, request form templates that can be used for a new website – open to additional input from others on content and development
- Need to identify a website developer and request our own website
- Will still be information about DNEA on CDS website, which will then link to the DNEA website
- Decisions need to be made around the look and feel of the website
- Website developers looking for work? Anyone within POWR or within the community?
 - Erin may know someone who may be interested, part of ASD community, knows accessibility
 - Jason Cockerham : <https://jcock.rocks/>

Legislative DNEA Report

- Outline, draft will be complete next week and sent to ICA members
- Decision to have the report largely focus on activities from the past fiscal year, but also have a separate section that briefly summarizes additional activities to-date since 6/30/17.
- Questions and discussion regarding carryover:
 - We have previously been allowed to carry forward funding that was not spent in the first year
 - Have about \$300,000 carry-over and \$500,000 budgeted for year 2 – around \$800,000 for Year 2, which was the original amount budgeted for Year 2.

Processes & Policies

- Training request process being put in place
- Also want a process for ICA's procedures
 - Examples:
 - Voting procedures
 - Not having representation from all agencies
- ICA weighing in on and evaluating the DNEA Director.
- Future ICA agenda on having a discussion with Beth around criteria for DNEA Director
 - What is ICA's role in this?
 - Per legislation, ICA provides oversight for and development of the goals and priorities of the DNEA. Discussion whether this extends to oversight of director – differences of opinion on this.
 - Some ICA members felt that the ICA should receive a performance report/review from the DNEA director
 - Decision that these issues would be discussed at a future meeting.

Agency Updates

- DAP
 - Training on ADOS
 - 5 or 6 programs continue with intensive PD's
 - Look to be doing well, clear impact of training, maintenance looks good (some drift), clear line of demarcation in classrooms where training is occurring versus not
 - DAP is down critical numbers of staff across all disciplines
 - Brennen – caseloads of 50 kids, it's a tough load, recruiting all the time
 - Evaluating behavior interventions – overall number of kids requiring review is decreasing, kids being reviewed (small, persistent percentage) are not improving with treatments, DNEA should be thinking about the need to accommodate residential treatment programs & needs
 - No activity for recruitment of DAP Director, Vince will likely take a consultant position, but will move out of F/T in July
 - For lack of staff, is consultants an option? Ex – BCBA's
 - Discussion about the need for advocacy for a BCBA academic training program in Delaware, DAP and others could provide training experiences
 - Brian has developed a pre-proposal for a BCBA training program at the university, enthusiasm appears to wax and wane from UD leadership;

- Consider combining with other existing ABA programs
- Nemours
 - New Medical Director for Autism Center (Diane Treadwell-Deering - psychiatrist) started in October
 - Hired 3 new ASD psychologists, 2 of which are BCBA's
 - Psychology Director of Autism Program is still open position
 - Working to get more coordinated, do more recruitment
 - HRSA grant work – CDW and schools, telehealth
 - Behavioral health department has tripled, focus on responding to MH needs
 - Whole hospital looking to make care more autism-friendly
 - ED has a CI project around creating a sensory room in the ED and a streamlined process for children with sensory needs, has significantly decreased challenging behavior emergencies
- DOE
 - New committees to discuss 925 regs, eligibility criteria, federal & state guidelines
 - Will be done across all disability categories
 - Several ICA members participating on the committee (Brian, Annalisa, Dawn, Laura, Vince)
 - Inclusion Conference, March 14th, 2017 *will be moving ICA quarterly meeting
 - Consider an autism strand for spec ed and gen ed teachers, not just autism specialists
 - Consider DNEA sponsoring an autism strand of the conference
 - ICA members on planning committee will raise this when planning starts in January
 - 619 – doing major overhaul of the website for the OEL, hoping to launch in January
 - Portals for parents, portals for providers
 - Also revising “how to” manuals for coordinators
- Autism DE
 - Launching a new website very soon
 - Easier for families to request assistance from a family navigator
 - Much more user friendly
 - Upstate: really adding a lot of new social skills programs, sib shops in the works
 - Girls group: BRAVE – specifically for girls who are higher functioning, 9-19 years old, social recreational groups – place for teens to connect, will resume meetings in January, in-house for a little while
 - Boy group starting on Friday, was Lego group but now boys want to be more social, transitioning into more social group; will start a new Lego group
 - All social groups are held in Newark right now
 - Respite dollars could be used by families to help fund this.
 - Respite dollars recently increased to \$2700 per year but may be more difficult to access in the new system (Medicaid-based)
 - PEERS group; preschool PEERS is not available yet (will be available in a year) – Nemours also has a PEERS group going, DOE still has their PEERS groups going, DE Guidance in Lewes has a PEERS group going

- Hopefully offering young adult and adolescent groups soon
 - Collaborating with the new innovation library, sensory room was built there
 - Downstate: launching ACT program as part of HRSA grant – comprehensive care coordination program for families of young children with ASD, developing goals, follow along with families of young children, starting in the new year with just a few families
- CDS
 - Connecting UD Disabilities Studies Minor and Nemours Social Work
 - Use disabilities studies connections to find childcare for caregivers who come to Nemours
 - Having an easy process for communicating the caregiver’s needs to the disabilities studies program students (likely through online posts to the program with specific information about the family need – child’s needs, times, days, etc)
 - Informal process to connect families with available resource of college students
 - Have to be careful about labeling as “respite” because of the challenges related to reimbursement and what constitutes a “provider” of respite services.
- DEFV
 - Spanish MCO Call: 12/12/17 11am-1pm *Flyer attached, please share