Interagency Committee on Autism (ICA) Quarterly Meeting Minutes 6.3.20

Virtual via Zoom

ICA Representatives Present

Autism Delaware: Brian Hall

Center for Disabilities Studies: Beth Mineo

Delaware Autism Program (DAP), Statewide Director: Mary Whitfield

Department of Education (DOE): MaryAnn Mieczkowski

Division of Prevention and Behavioral Health Services (DPBHS): Meredith Tavani

Division of Substance Abuse and Mental Health (DSAMH): Wynne Hewitt

Division of Developmental Disabilities (DDDS): Cory Nourie

Division of Public Health (DPH): Isabel Rivera-Green

Nemours Network: Laura Dewey

Parent Information Center (PIC) of Delaware: Tina Andrews Parent/Caregiver for New Castle County: Dawn Maloney

Parent/Caregiver for Kent County: Andrea Creed Parent/Caregiver for Sussex County: Crystal Thawley

ICA Representatives Absent:

Ability Network: Thomas Cook

Delaware Family Voices (DEFV): Ann Phillips Part C/Birth to 3 System: Sue Gamel-McCormick

ICA Representative Substitutions:

Division of Vocational Rehabilitation (DVR): LaShonta Mitchell

Others Present:

Sarah Mallory (CDS/DNEA Interim Director) Brian Freedman (CDS) Kara Downey (CDS/DNEA) Kellene Copeland (CDS/DNEA) Maria Locuniak (DOE) Dafne Carnright (Autism Delaware) Brittany Powers (CDS)

1. Welcome and Introductions

a. Crystal Thawley was welcomed as the new ICA Parent/Caregiver Representative from Sussex County.

2. Exciting News and Upcoming Community Events

a. No updates

3. Family Needs Report

 Autism Delaware reported they have seen a dramatic increase in the number of family contacts made during the past few months. April and May contacts increased by 25% compared to the last quarter. High need areas included basic needs, social services, and childcare.

- Another area of concern noted was families experiencing behavioral and mental health challenges (some of which have escalated due to COVID-19).
 - i. Autism Delaware discussed the need for parents to understand what they should try first, how long they should try a particular intervention, and when to move on to a more intensive support. They also raised concerns about the lack of short- and long-term care facilities and difficulties with out of state placements.
 - 1. Cory Nourie discussed difficulties associated with reintegrating individuals from out-of-state placements when they return to Delaware.
 - 2. Brian Freedman will bring the concern to the ICA Mental Health Subcommittee meeting, which has already been working to address this issue. If anyone is interested in attending the next subcommittee meeting, please contact Kellene Copeland at kellene@udel.edu.
- c. The family needs report from Autism Delaware was shared with the committee. Please contact Annalisa Ekbladh with additional questions (Annalisa.Ekbladh@delautism.org).

4. ICA Updates

- a. ICA Co-Chair
 - Eight nominations were received for ICA co-chair by ICA representatives. Nominees were contacted by the DNEA Program Coordinator to determine their interest in serving in the co-chair role. At this point in time, no one was able to accept the position.
- b. ICA Annual Report
 - i. Feedback for the 2018-2019 ICA Annual Report is due on Thursday, June 4th. Please send 1 set of compiled feedback per rep/agency via track changes. For questions or extensions, please contact Kara Downey at kdowney@udel.edu.

5. DNEA Funding

- a. Sarah Mallory, DNEA Director, led a discussion concerning the current status of DNEA funding for FY21.
 - i. In all likelihood, the DNEA will not be funded during the upcoming fiscal year (starting July 1, 2020). Currently, the DNEA receives roughly \$500,000 a year. Its main activities include ICA coordination, training and technical assistance, and family navigation. A total of 15% of DNEA funding goes to Autism Delaware.
 - ii. Prior to Senate Bill 93, the ICA was run out of CDS and facilitated by Annalisa Ekbldah as part of her position at CDS. At that time, DOE funded 1 day a week of her time at CDS.
- b. The DNEA is working to find other sources of funding for individual projects, including federal grants and a contract with PBH; however, a base level of funding is ultimately needed to maintain the work. DNEA leadership expressed the budget could be reduced by 37% 40% (to

approximately \$315,000) and still maintain the current number of statewide trainings, provide district-level support to a new school district, maintain supports with the current target school district, provide management to the ICA, and continue to fund a similar percentage of family navigation.

- c. ICA members discussed potential ways of supporting DNEA activities:
 - i. Maryann Mieczkowski would like to see additional details about the scope of work completed by the DNEA.
 - ii. Mary Whitfield discussed DOSAP potentially providing professional development and training as part of her office's HB 292 work.
 - iii. School districts could assist in funding DNEA supports; it is important to note that some districts may not have enough funding to pay for such supports. The MOU for the current school district is coming to an end and can be restructured to reflect these changes.
 - iv. Autism Delaware indicated they do not have plans to reduce staff at this time. DNEA funds currently support 1.5 family navigators (about 200 family contacts each per month). Autism Delaware may need to look for outside funding.
 - v. Nemours indicated that they are investigating ways to continue to provide their expertise. A meeting is being set up with Sarah Mallory, Brian Freedman, and Diane Treadwell-Dearing from Nemours to discuss this further.
- d. The ICA indicated they would like more information about the activities and costs associated with ICA coordination.
 - The DNEA Coordinator will create a list of activities. It was noted that it is difficult to determine a specific financial amount for running the ICA since it is based on a percentage of DNEA staff members' salaries.
 - ii. CDS was asked if UD/CDS is able to commit funds for ICA coordination.
 - Beth Mineo (CDS Director) indicated that CDS does not rely on funding from UD; its projects and related staff are funded through external dollars. If the DNEA is not funded, the positions would no longer exist.
- e. The ICA discussed the work associated with the ICA, specifically its subcommittees and workgroups.
 - i. Brian Freedman indicated he is still prepared to meet with and lead the mental health subcommittee and ASD diagnosis subcommittee.
 - ii. Tina Andrews indicated PIC may be able to lead an Early Childhood Workgroup.
- f. Sarah Mallory explained that CDS and Autism Delaware DNEA members met to discuss if a letter of support from the ICA would be possible and/or beneficial. Potential letters of support could address funding to sustain ICA activities; a statement of support discussing the impact of the DNEA activities; or a request to sustain a minimal level of funding for the DNEA funding. A final decision was not made.

- g. Maryann Mieczkowski noted that the ICA is written into Delaware code and is obligated to continue.
- h. DNEA/ICA activities that would need immediate attention were discussed.
 - i. A request was made to ensure all materials and necessary documents are compiled and located centrally.
 - ii. The DNEA website will not have funding to continue; PBH indicated that they may have funding from a grant to support website maintenance.

6. COVID-19 Community Updates and Quarterly Strategic Plan Activities

Improvement Area I: Identification, Diagnosis, and Classification	
Lead Agency/Organization	Activity
CDS	With Building Bridges funding, support is
Nemours	being provided to CDW to conduct ASD evaluations. With COVID-19, the work has had to shift. Virtual evaluations are happening through Nemours via Tele-ASD-PEDS. Telehealth is continuing.

Improvement Area II: Training and Technical Assistance	
Lead Agency/Organization	Activity
DAP	Trainings were offered virtually at DAP
	sites. They received very positive
	feedback.
DNEA (CDS)	Statewide education trainings have
	moved online. Trainings were offered in
	April and May; June trainings were just
	announced and included Introduction to
	Autism Spectrum Disorder and
	Introduction to Strategies for Supporting
	Individuals with Autism.
DNEA (CDS)	DNEA has paused support with Appo. as
	its teachers moved to providing virtual
	support.
DNEA (CDS)	DNEA is developing parent and
	professional resource guides to facilitate
	educators' work with families. Some are
	COVID-19 related.
CDS	LEND trainees are developing a training
	on self-determination for the DNEA.
DNEA (CDS)	Training and coaching with mobile crisis
	have continued.
DNEA (CDS)	Planning for inpatient support at Terry
PBH	Center and Silver Lake in collaboration

	with PBH and the Center for START
	Services is continuing.
DSAMH	Grand rounds addressing ASD and
	assessment were cancelled due to
	COVID-19; hoping to reschedule.
CDS	The Project IMPACT April learning
	community meeting was cancelled. It was rescheduled for the week of June 8. They have developed online telehealth library and are in initial conversations regarding expanding trainings for Part C.

Improvement Area III: Pre-Professional Training	
Lead Agency/Organization	Activity
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Improvement Area IV: Self-Determination, Self-Advocacy, and Social Network	
Development	
Lead Agency/Organization	Activity
-	-

Improvement Area V: Transition to Adult Life	
Lead Agency/Organization	Activity
-	-

Improvement Area VI: Family Support and Stakeholder Engagement	
Lead Agency/Organization	Activity
-	-

Improvement Area VI: Systems Coordination	
Lead Agency/Organization	Activity
CDS	Learn the Signs, Act Early partnered with Help Me Grow in supporting WIC clinics in early identification and appropriate referrals.
DNEA (CDS)	ABA Reimbursement Workgroup is continuing to meet and are developing a survey for parents, providers, and school professionals
DPH	DPH is finalizing a needs assessment to identify priority areas. One priority area is supporting the identification of children with special healthcare needs

7. DNEA Updates

- a. See updates under Quarterly Activities update, Improvement Area II:
 Training and Technical Assistance

 Public Comment
- - a. None