



**GOVERNOR'S ADVISORY COUNCIL FOR EXCEPTIONAL CITIZENS (GACEC)
GENERAL MEMBERSHIP MEETING
7:00PM, February 21, 2023
MICROSOFT TEAMS MEETING**

MINUTES

MEMBERS PRESENT: Al Cavalier, Nancy Cordrey, Matt Denn, Bill Doolittle, Karen Eller, Ann Fisher, Cory Gilden, Tika Hartsock, Kristina Horton, Thomas Keeton, Jessica Mensack, Molly Merrill, Beth Mineo, Maria Olivere, Trenee Parker, Erika Powell, Jennifer Pulcinella, Stefanie Ramirez on behalf of Laura Waterland, Meedra Surratte

OTHERS PRESENT: Christina Farmer/Department of Health & Social Services (DHSS), Nicole Topper/DHSS, Amy Roe/Lead-Free Delaware, Sarah Bucic/Lead-Free Delaware, Madison Weir, Lillian McCuen, Hope Sanson/DHSS, Pam Reuther/Interagency Coordinating Council (ICC), Ann Woolfolk/ICC, Dale Matusевич/Delaware Department of Education (DDOE), Kenny Weir, Bruce Orr/ICC, Breana Kulesza, Shonetesha Quail/DHSS

STAFF PRESENT: Pam Weir/ Executive Director, Kathie Cherry/Office Manager and Lacie Spence/Administrative Coordinator

MEMBERS ABSENT: Genesis Johnson, Brenn  Shepperson and Erik Warner

Chairperson, Ann Fisher, called the general membership meeting to order at 7:02pm. It was announced that a quorum was present. Nancy Cordrey **made a motion** to accept the February agenda with Kristina Horton seconding the motion. The **motion was unanimously approved**, with Tika Hartsock abstaining. Maria Oliver made a **motion to approve** the January meeting minutes with Jennifer Pulcinella **seconding the motion**. The motion **passed unanimously**, with Tika Hartsock abstaining. Jennifer Pulcinella made a **motion to approve** the January financial report. Molly Merrill **seconded the motion**. The **motion passed unanimously** with Tika Hartsock abstaining.

PUBLIC COMMENT

There was no public comment for this month.

COMMITTEE REPORTS

ADULT TRANSITION SERVICES COMMITTEE

Meedra Surratte reported that Maureen Whelan is unable to present this year regarding prison education. The Adult Transition Services Committee is going to review the data from the prison education system in preparation for when they are able to meet. Dale Matusевич and George Tilson have agreed to meet with the committee, and they are still working on choosing a date.

CHILDREN AND YOUTH COMMITTEE

Committee Chairperson, Tika Hartsock, announced that the Children and Youth Committee had a presentation from Sarah Bucic and Amy Roe, from Lead-Free Delaware. They had a question-and-answer session and hope to bring the presenter back to speak to full Council.

INFANT AND EARLY CHILDHOOD COMMITTEE

Jennifer Pulcinella reported that Pam Reuther, the Chair of the Interagency Coordinating Council (ICC) joined the Infant and Early Childhood Committee this evening. They discussed the ICC letter opposing the transition of Part C to the Delaware Department of Education (DDOE). Jennifer stated that there was historical discussion on the intent of the letter as well as current legislative actions were very informative. The Committee **made a motion** to have a meeting that includes the Infant and Early Childhood Committee of the GACEC, Part C Transition Support Committee of the ICC and DDOE to initiate conversation around stakeholder engagement specific to the Part C Transition before April 15, 2023. Discussion ensued regarding the previous plan to hear from supporters on both sides of the transition of the Part C Program before a decision is made whether or not to support the letter of opposition written by the ICC. Molly Merrill clarified that this motion is separate from the discussion on supporting the letter from the ICC. This motion is to ensure that if the Part C transition does happen that stakeholders are involved and at the table for the discussions directly related to the transfer. The motion was **approved unanimously** with Matt Denn, Tika Hartsock, and Beth Mineo abstaining.

POLICY AND LAW COMMITTEE

Erika Powell reported that the Policy and Law Committee is recommending endorsing the actions in the Disabilities Law Program Memo. Erika added that there was rich discussion, and the Committee is recommending that Council look more into Prison Education. In regard to Senate Bill 24, the Policy & Law Committee would like to note that medication training should be added to all schools including the nurse and two additional staff in case of an emergency. They also recommended changing the wording from “suffering a seizure,” to “experiencing a seizure” for more current language. Molly Merrill asked if there was language in the Bill about not including children from a school because they have a seizure plan. Bill Doolittle and Stefanie Ramirez added that this topic is already covered in Federal and State Law. Dale

Matusevich recommended reaching out to DDOE to address an issue such as this immediately so it can be resolved in a timely manner. Matt Denn suggested contacting the bill sponsor directly before sending a formal letter about any concerns with the bill. Bill Doolittle agreed that this should be a standard practice for us moving forward. Beth Mineo stated that seems reasonable as long as the follow-up can be timely so that we can share more formally if need be. The Committee **made a motion to approve** adopting all the recommendations as written below in the Policy and Law Memo with the additional recommendations. The **motion passed** unanimously, with Tika Hartsock abstaining.

Proposed DDOE Regulation on 915 James H. Groves High School, 26 Del. Register of Regulations 657 (February 1, 2023)

The Delaware Department of Education (DDOE) proposes to amend 14 Del. Admin. C. § 901, which describes the operation of the James H. Groves High School (Groves), an adult education high school. DDOE is proposing to amend this regulation to add a defined term in Section 1.0, replace “State Director” with “Director of Adult and Prison Education Resources”, and to strike the standardized assessment requirement from subsection 2.1.1.1.2. DDOE also proposes additional non-substantive changes to ensure the regulation complies with the *Delaware Administrative Code Drafting and Style Manual*. These proposed regulations were first included in the November 1, 2022 Delaware Register of Regulations. Council submitted comments to DDOE, which are reprinted below. Any response from DDOE to a comment as well as any recommended follow-up action by Council is **in bold**.

First, proposed 14 Del. Admin. C. § 915.1.0 would add an additional definition for “In School Credit Program” which is described in existing 14 Del. Admin. C. § 915.2.2. The proposed language defines the In School Credit Program as an “alternative program operated by the James H. Groves High School that provides an opportunity for students who are age 14 or older and enrolled in their local day school to attain credits needed to fulfill high school graduation requirements.” Council may wish to recommend that DDOE include the word “education” between “alternative” and “program” so as to clearly identify this as an alternative education program and not an alternative program for students facing discipline.

DDOE RESPONSE: “[T]he Department decided to add ‘education’ to the definition of ‘In School Credit Program’ in Section 1.0[.]”

Council may wish to give thanks to DDOE for responding and incorporating its comments.

Second, proposed 14 Del. Admin. C. § 915.2.1.1.1.2 removes the standardized assessment requirement as part of the application for enrollment at Groves. Specifically, that section would be changed as follows (indicated by strikethrough): “Qualify as meeting secondary level skills, as determined by the Department, on a standardized assessment.” With the change, it is now unclear how DDOE would measure whether a student would qualify as meeting secondary level skills. Furthermore, it could lead to students being measured against different criteria, which can lead to inequitable outcomes. Council may wish to recommend that DDOE not remove this requirement or if it chooses to remove the specific requirement of a standardized test, that it identify other ways of meeting this secondary skill level.

DDOE RESPONSE: “[T]he Department decided to . . . not strike the standardized assessment requirement from subsection 2.1.1.1.2 and add additional language to the subsection.” The additional language added to subsection 2.1.1.1.2 allows for a student to demonstrate secondary level skills by *either* a standardized assessment *or* a review of high school credits attained.

Although this partly addresses the earlier-expressed concern, Council may wish to request that DDOE explain what it means by “high school credits attained” and whether there are specific instances where one measure is used over the other.

The additional proposed changes, including the change to the title of the Director of Adult and Prison Education Resources, are non-substantive.

However, there are additional concerns with the regulation outside of the proposed amendments that Council may want to address. First, the admission criteria do not contemplate those students in the prison education program specifically. Students in prison who are seeking their high school diploma or GED are automatically enrolled in Groves, yet there is no indication in 915 that there is an exception to the admission criteria for those students (or that students enrolled in prison education are enrolled in Groves). Therefore, Council may wish to recommend that DDOE include language in this regulation that identifies Groves as providing education to incarcerated students and that those students are otherwise exempt from the admission criteria.

DDOE RESPONSE: The Department decided not to make any further changes to the regulation that was published on November 1, 2022, as a result of [Council]'s written submittal.

Council may, again, wish to recommend that DDOE include language identifying Groves as providing education to incarcerated students and that those students are otherwise exempt from the admission criteria.

Second, current Section 2.3 disallows enrollment of students who have been expelled or are pending expulsion unless he or she receives a waiver from DDOE. Title 14 Del. C. § 4130(d) explicitly exempts Groves from the prohibition on enrolling expelled students. Council may wish to recommend DDOE reconsider its position on whether expelled students can enroll at Groves without a waiver. Council previously made this recommendation in 2006 (10 Del. Register of Regulations 988 (December 1, 2006) and 18 Del. Register of Regulations 561 (January 1, 2015)).

DDOE RESPONSE: The Department decided not to make any further changes to the regulation that was published on November 1, 2022, as a result of [Council]'s written submittal.

Council may, again, wish to recommend that DDOE reconsider its position on whether expelled students can enroll at Groves without a waiver.

Third, current Section 4.2 states that “[s]tudents enrolled in James H. Groves High School courses which have an attendance requirement, shall attend a minimum of 85% of the course hours to receive a unit of credit. No provision is made for excused absences.” DLP’s Policy and Law Memo to Councils in October 2006 had the following thoughts:

Although not a paragon of clarity, the last sentence could be construed as precluding credit if a student has less than 85% attendance regardless of good cause. This would have a disproportionate impact on students with disabilities, particularly those with chronic health conditions or frequent flare-ups of symptoms. A no-exceptions policy may violate Section 504 and unnecessarily limit the discretion of IEP teams to accommodate students with disabilities. For example, if a student with disabilities achieved A's in all tests and assignments, but attended only 84% of classes due to a hospitalization, Groves would have no discretion but to deny credit based on the strict regulation. Even on a practical level, Section 3.0 authorizes Groves to grant credit for a lengthy list of non-traditional work with no explicit attendance standards. In contrast, imposing a no-exceptions 85% attendance limit in Section 4.2 appears overly prescriptive.

Council may wish to recommend DDOE again consider whether having an outright “no excused absences” policy is appropriate in light of federal and state law and regulations regarding the rights of people with disabilities to be free from discrimination.

DDOE RESPONSE: “[T]he Department decided to strike the requirement that provision cannot be made for excused absences from subsection 4.2 because each Groves site has its own attendance policy and the requirement is not necessary.”

Council may wish to thank DDOE for considering its comments and removing the ban on excused absences.

Proposed DHSS DPH Regulation on 4459 A Childhood Lead Poisoning Testing, 26 Del. Register of Regulations 677 (February 1, 2023)

Previously under these regulations, health care providers were only required to test children for lead if they were between the ages of 22 and 26 months and if they were deemed to be “high risk.” These proposed regulations eliminate the high/ low risk determination made by a health care provider, making lead testing requirements universal. Additionally, the proposed regulations increase the number of times a child is required to be tested for lead before the age of 6. Under the new regulations, a medical provider must “administer or order a blood test for lead” at least twice:

when the child is between 9 and 15 months of age and again between 21 and 27 months of age. Further, tests conducted between 15 and 18 months of age shall be considered a 12-month test, and between 18 and 21 months of age shall be considered a 24-month test.

Additionally, the new regulations provide a set of requirements for when a child older than 28 months but younger than 6 must be tested again for lead.¹

1 3.2 A primary health care provider for a child who is 28 months old or older and younger than 6 years old shall administer a blood test for lead in the following circumstances:

3.2.1 If the child has not previously received a blood test for lead;

3.2.2 If the child's parent or guardian fails to provide documentation that the child has previously received a blood test for lead;

3.2.3 If the health care provider is unable to obtain the results of a previous blood lead analysis; or

3.2.4 If the child's parent or guardian requests that the child receive a blood test for lead regardless of the child's age.

The new requirements also require that “If a child is insured under Delaware's Medicaid program, the child's primary health care provider shall administer a blood test for lead to the child at the 12-month visit and again at the 24-month visit in accordance with Early and Periodic Screening, Diagnosis and Treatment (EPSDT) requirements.”

Recommendation: Council should support these changes, as they greatly increase the opportunities to screen for lead and remove subjective determinations of “high/low risk” as barriers to testing. Council should recommend clarity about circumstances when a child is tested between 9 and 13 months of age and whether/ when they needed to be tested again to count as a 12-month test for purposes of childcare or school lead testing documentation requirements.

Clarifying Type of Testing and Reference Levels

The proposed regulations also clarify when a capillary or venous lead blood test is appropriate. In general, a capillary blood lead test is less sensitive. In the new proposed definitions, the regulations distinctly define “screening” as a capillary blood test and “testing” as a venous blood test. Under these new proposed regulations, “[a] health care provider shall administer or order a blood test for lead, by venous methodology, if the results of capillary screening indicate blood lead level result greater than or equal to the reference level in a child younger than 6 years old.” The new proposed regulations ensure that “reference level” is defined as “the current blood lead reference level as determined by the Centers for Disease Control and Prevention.”

Recommendation: Council should support these proposed changes because they clarify blood testing requirements and ensure that the process is standardized, and adequately sensitive testing is used to confirm blood lead levels.

Religious Exemption

The proposed regulation states that “A certificate of blood lead testing exemption for religious *beliefs* shall be signed and dated by the child’s parent or guardian, notarized, and kept in the child’s medical chart.” Previously, the regulations allowed an exemption for religious “reasons” rather than “beliefs.”

Recommendation: It would be useful to have “beliefs” defined, particularly because the drafters of the new proposed regulations indicate that “beliefs” are distinct from “reasons.” Additionally, regulations regarding childcare and school requirements for lead testing documentation should align with any new regulations.

Blood Testing Documentation and Reporting Requirements

The proposed regulations provide detailed information about the data that must accompany a blood test from the doctor’s office to the lab. These detailed requirements for data collecting are new.

The proposed regulations also specify that in addition to reporting blood lead level tests to the health care provider and the Division of Public Health, the results should be reported to “[a]nother entity as required by State, federal, or local statutes or regulations, or in accordance with accepted standards of practice.”

Recommendation: Council may wish to support these new requirements that help ensure that lab tests are properly stored, tested, and reported. However, Councils may wish to recommend further discussion and proposed regulation regarding data privacy and data sharing between agencies (for example, parties have discussed data sharing between Department of Health and Department of Education to address early intervention, etc.) It is potentially concerning that the language the language surrounding data sharing with other entities is left vague in these proposed regulations. While there may be benefits to data sharing to ensure provision of services, child and parent privacy is a critical issue. Recently, there has been a high-profile case of data sharing

between New Jersey’s Department of Health and law enforcement involving universal blood lead testing which raised serious ethical and constitutional rights issues.

(<https://newjerseymonitor.com/2022/07/13/newborn-screening-program-used-to-aid-criminal-investigation-public-defender-says/>; <https://newjerseymonitor.com/2022/07/13/newborn-screening-program-used-to-aid-criminal-investigation-public-defender-says/>) .

Proof of Documentation Requirements Prior to Child Care or School Enrollment

Proposed regulations update and clarify the requirements for reporting blood lead level testing to childcare and to schools.

Recommendations: As noted above, clarification about earlier testing and whether it counts toward the 12-month visit testing for school/childcare reporting purposes. Additionally, further clarity and consistency between childcare regulations and Division of Public Health regarding when a test needs to be on file. (In this proposed language, “the blood test may be done within 60 calendar days of enrollment” but “certified documentation of the child’s blood lead analysis... in connections with the 12-month visit and 24-month visit” shall be provided no later than “30 days from the 12-month visit or 24-month visit” or “30 calendar days from first entry into the program or system.” While this accounts for different ages of young children entering day care of school settings and different timelines for routine check-ups, clearer language regarding timelines for reporting (possibly broken down by age group) may assist childcare settings and parents in ensuring they are compliant.

Final Regulations:

Final DMMA Regulation, 26 Del. Register of Regulations 677 (February 1, 2023)

Early, Periodic, Screening, Diagnosis, & Treatment Coverage in the Delaware Healthy Children’s Program,

Delaware Health and Social Services (Department)/Division of Medicaid and Medical Assistance initiated proceedings to amend Title XIX Medicaid State Plan regarding Early, Periodic, Screening, Diagnosis, & Treatment coverage in the Delaware Healthy Children's Program, specifically to align services provided to children under the Title XXI CHIP State Plan with services provided to children under the Title XIX Medicaid State Plan. The Department's proceedings to amend its regulations were initiated pursuant to 29 Del.C. §10114 and its authority as prescribed by 31 Del.C. §512.

DMMA acknowledged GACEC comments related to not using the APA process for amending provider manuals by sticking by its position that internal policies do not require public comments. It thanked GACEC for its general endorsement.

Legislation:

SB32- Amendments to Title 14, Section 1703, Eligibility for 12 month School Year

SB32 proposes to amend 14 Del. Code 1703 to add “visual impairments including blindness” to the list of disabilities that qualify children for a 12 month school year. The 12 month school year should not be confused with Extended School Year (ESY). ESY is required under IDEA for students who qualify, and cannot be restricted by diagnosis. Students who are in the 12 month program are also eligible for ESY. The 12 month school year program is a creature of state law.

While the amendment in SB32 is certainly essential to students with visual impairments,² DLP suggests that this is an opportunity to refine the list of eligible disabilities, first to make it more inclusive, and second, to remove some extremely arcane and offensive terms from the statute that are not consistent with terminology used today either by DOE, by diagnosticians or by the public in general.

The current list of qualified disabilities in Section 1703 includes “severe mental disability” and “trainable mental disability” and restricts orthopedic impairments to specific conditions that would certainly exclude students who have functionally equivalent diagnoses. “Severe mental disability and trainable mental disability” are classifications that are antiquated and are not used today. In 2010, the federal government passed legislation (“Rosa’s Law”) that required federal programs to eliminate the use of “mental retardation” and to use “intellectual disability” instead.³ This statute amended IDEA terminology, language in Section 504 regulations, and also prompted SSA to change its disability-related terminology as well.

The Delaware Department of Education in its regulation uses the terms “severe intellectual disability” and “moderate intellectual disability.” These are defined in DDOE Regulation 925.6.12. Apparently, DOE also uses the term “orthopedic impairments” and does not restrict it to certain diagnoses. See DDOE Regulation 925.6.13 for the DOE definition of orthopedic impairments. The IEP form has a tick-off box for the 12-month program that uses the terms moderate and severe intellectual disability and orthopedic impairment.

Council should consider asking the legislature to take this opportunity to amend the statutory language listing eligible students to make it consistent with federal law, state practice, and to remove outdated and frankly offensive terminology.

HB 55, Bill of Rights for Persons Experiencing Homelessness

HB55 creates a Homeless Bill of Rights in Titles 31 and 6. It establishes a new Chapter 45A in Title 6. HB55 protects individuals who are experiencing homelessness by creating rights related to:

1. Non-discrimination in use of public spaces
2. Non-discrimination from state, county or local agencies
3. Non-discrimination in housing due to status, lack of address
4. Non-discrimination while seeking temporary shelter
5. Non-discrimination in medical and dental care based on housing status
6. Non-discrimination in registering to vote and voting
7. Protection of private information
8. Reasonable expectation of privacy in personal property
9. Right to occupy a motor vehicle

² DVI has indicated support for this bill provided there is a correction to the number of teacher days to reflect actual practice. One also wonders why children with diagnoses other than autism do not receive the same level of educational service as those with autism.

³ <https://content.govdelivery.com/accounts/USED/bulletins/1a93caf>

10. Right to religious practices in public spaces
11. Right to eat, drink share or accept food in public spaces

The statute also prohibits political subdivisions from enacting any policy, regulation or ordinance that is contrary to the prohibitions and rights. The bill empowers the State Human and Civil Rights Commission to enforce the law and develop a complaint apparatus. The bill creates the right to file a complaint for violations of the law. The bill creates a very short statute of limitations of 90 days. Complaints related to law enforcement personnel are referred to the Department of Justice. This strikes the DLP as being a potential conflict of interest for the DOJ. Fees, damages and penalties are available under the statute. The Division of Human Relations can take prompt judicial action pending administrative action on the complaint, if appropriate. Rhode Island was the first state to pass a “Homeless Bill of Rights,” in 2012. Other states and municipalities have also developed bills of rights, including Illinois, Puerto Rico and Connecticut. ⁴ According to a report from the Office of the UN High Commissioner for Human Rights, titled “The Right to Adequate Housing,” local attempts to deal with homelessness by making homeless people disappear from sight are gross civil and human rights violations. “When local governments use “lock 'em up” strategies to criminalize homelessness, homeless people are caught in a long-term cycle of poverty and stigmatization.”⁵

The City of Wilmington has arguably engaged in a systematic campaign to drive out homeless individuals by moving transportation hubs, closing shelters and designing parks so that individuals have no place to sit. ⁶This bill will address this and other efforts by municipalities to try to drive homeless individuals from their communities. Another goal of enacting a Homeless Bill of Rights is to educate policy makers about how homeless individuals face pervasive discrimination. It is also a step away from the criminalization of homelessness. ⁷ Upwards of 25% of homeless individuals have a disability of some kind. Individuals with mental illness or intellectual disability are especially at risk. ⁸ For these reasons stated above, Council may wish to endorse this legislation.

SB 33- DFS Treatment Caseloads

SB33 proposes to reduce Division of Family Services (DFS) treatment caseloads from 18 to 12 cases per fully functioning caseworker. In order to adequately support children and parents interacting with DFS, including those with disabilities, and to prevent the future occurrence of disabilities, it is essential to attract and maintain a sufficient number of high quality DFS staff members. This proposed change to 29 Del. Code §9015, would decrease the number of families assigned to each protection treatment workers, from 18 down to 12. In its review of the Child and Family Services Reviews, the Government Accountability Office (GAO) noted that, in the majority of states, one or more workforce deficiencies (such as high caseloads) were cited as affecting achievement of results: “For example, workforce challenges were reported to delay the timeliness of investigations, limit the frequency of worker visits with children and families,

4 <https://www.samhsa.gov/homelessness-programs-resources/hpr-resources/rhode-island-homeless-bill-rights>

5 <https://wraphome.org/wp-content/uploads/2020/07/HBRRight2RestFactSheet-07162020.pdf>

6 <https://www.delawareonline.com/story/news/2019/02/12/wilmington-delaware-gentrification-poor-social-services-mayor-mike-purzycki/1422192002/>

7 <https://www.cambridge.org/core/journals/european-constitutional-law-review/article/homeless-bill-of-rights-as-a-new-instrument-to-protect-the-rights-of-homeless-persons/9F3980856738486AB50DE6F014393B2B>

8 <https://jphmpdirect.com/2019/07/24/homelessness-among-individuals-with-disabilities/>

negatively impact the achievement of permanency goals and inhibit the level of involvement of children and families in case planning.”⁹

Children and parents with disabilities often require increased time and planning to adequately address the unique challenges associated with their disabilities. Due to the complications that may arise related to disability, the potential need for accommodations or non-standard services or service delivery, these parents and children are put at an increased disadvantage by an overloaded caseworker. This disadvantage in turn interferes with their ability to achieve permanency goals. Indeed, the National Council on Disabilities review of multiple studies found that parents with disabilities have higher rates of termination of parental rights (TPR) and involvement with child welfare.¹⁰ One study found that, compared to peers without disabilities, parents with disabilities were over three times more likely to have a TPR, and that parents who had a disability were more than twice as likely to have child welfare involvement.¹¹ Children, parents and prospective parents with disabilities interacting with DFS should be provided full and equal services, which may involve increased time and effort on the part of the DFS worker. Federal law, including Section 504 of the Rehabilitation Act of 1973 (Section 504)¹² and Title II of the Americans with Disabilities Act of 1990 (ADA)¹³, protects children, parents/guardians, and prospective parents/guardians with disabilities from unlawful discrimination in the administration of DFS programs, activities, and services.¹⁴ In fact, in recent years, the U.S. Health and Human Service’s Office for Civil Rights (HHS OCR) and U.S. Department of Justice’s Civil Rights Division (DOJ CRD) have received rising numbers of complaints of discrimination from individuals with disabilities involved with the child welfare system.¹⁵ HHS OCR and the DOJ CRD have issued findings of discrimination for the failure of a child welfare system to implement services and supports appropriate to afford a parent with disabilities a full and equal opportunity to seek parental/child reunification.¹⁶ Therefore, in order to ensure that Delaware is properly affording appropriate, full and equal services, and non-discriminatory treatment, to children, parents, and prospective parents with disabilities, it is essential that DFS be properly trained on disability accommodations, and staffed so that caseloads can be maintained at or below statutory limits. Council may wish to support this bill since lower caseloads could facilitate more time and flexibility on the part of the child welfare system, when working with individuals with disabilities.

9 Children’s Defense Fund. (2006). Components of an Effective Child Welfare Workforce to Improve Outcomes for Children and Families: What Does the Research Tell Us?. Retrieved from https://www.childrensrights.org/wp-content/uploads/2008/06/components_of_effective_child_welfare_workforce_august_2006.pdf.

10 National Council on Disability, Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children at 76-84 (2012), at www.ncd.gov/publications/2012/Sep272012/

11 *Id.* at 77-78.

12 29 U.S.C. § 794.

13 42 U.S.C. §§ 12131-12134.

14 See also: U.S. Department of Justice and the Department of Health and Human Services joint technical assistance: “Protecting the Rights of Parents and Prospective Parents with Disabilities: Technical Assistance for State and Local Child Welfare Agencies and Courts under Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act” (August, 2015), available at https://www.ada.gov/doj_hhs_ta/child_welfare_ta.html.

15 *Id.*

16 US DOJ and HHS OCR Joint Letter of Findings, Investigation of the Massachusetts Department of Children and Families (January 2015), available at https://www.ada.gov/ma_docf_lof.pdf

SCR 3- DSAMH to study feasibility of replacing Delaware Psychiatric Center

Senate Concurrent Resolution 3 has already passed. It charges DSAMH with studying the feasibility of replacing DPC. The extensive preamble language noted that DPC is over 50 years old, that replacing DPC was part of a master plan to redesign the Holloway campus over 20 years ago and work was halted on that project in 2007. The Preamble also notes that: “a growing body of scientific evidence suggests that the design of mental health care facilities plays a significant role in staff safety and satisfaction, client outcomes and cost reduction.”¹⁷ Finally it notes that the state has federal money to study the feasibility of replacing DPC. A report is due to the legislature by late December 2023.

It is true that DPC is old and needs to be overhauled. DLP suggests that Council consider reaching out to DSAMH to ask for updates and to be part of this process. This is an opportunity to address community needs for quality acute psychiatric care of a variety of individuals, including individuals with co-occurring disorders. It is critical that the voices of those with lived experience and their advocates be consulted as part of this process.

SB 24- Seizure Safe Schools Act

SB 24 is a “Seizure Safe Schools Act” which requires that:

- all schools with a student diagnosed with a seizure disorder to train at least two employees in the administration of rescue medication or prescribed treatment to treat a student with a seizure. Training would include how to administer a manual dose of prescribed electrical stimulation with a Vagus Nerve Stimulator magnet. One of the two required employees may be the school nurse, who is not required to undergo additional training.
- all school employees, bus drivers and other school personnel with direct contact and supervision of students to be trained every two years in administering first aid to a student suffering from a seizure.
- schools provide age-appropriate seizure training to students.
- an annual “seizure action plan” be created, which is a collaboration between parents and the school including written authorization to administer seizure rescue medication or treatment and specific instructions for administering.
- the Delaware Department of Education to develop regulations regarding the above, and training programs for staff consistent with programs and training guidelines developed by the Epilepsy Foundation of Delaware or similar not-for-profit.

The act also contains a “Good Samaritan” clause that protects individuals who assist a student suffering from a seizure, from criminal or civil action, unless their behavior is willful or grossly negligent.

“Seizure Safe Schools” is a national legislative agenda for the Epilepsy Foundation. Their website elaborates:

The Epilepsy Foundation has launched a nationwide initiative to pass Seizure Safe Schools legislation in all states. The model bill has five key components: requiring school personnel to complete a seizure recognition and first-aid response training; mandating that the Seizure Action

17 There is some truth to this. See “A New Tool in Treating Mental Illness: Building Design,” <https://www.nytimes.com/2021/01/05/business/mental-health-facilities-design.html>; “The Role of Healthcare Facility Design on the Mental Health of Healthcare Professionals: A Literature Review,” <https://pubmed.ncbi.nlm.nih.gov/35975284/>

Plan is made part of the student's file and made available for school personnel and volunteers responsible for the student; ensuring that any FDA-approved medication prescribed by the treating physician is administered to the student living with epilepsy; educating and training students about epilepsy and first-aid response; and a Good Samaritan clause.¹⁸

Of the Epilepsy Foundation's five key components, SB 24, Delaware's proposed bill, requires (1) staff seizure recognition and first aid training; 2) Seizure Action Plans; 3) training of students; and 4) a Good Samaritan clause. The legislation appears to be missing an assurance that schools will "ensur[e] that any FDA-approved medication prescribed by the treating physician is administered to the student living with epilepsy," which is a significant omission. Additionally, in the present draft the requirement to have at least two staff trained in the administration of rescue medication or prescribed treatment is limited to schools with students with known seizure conditions. Given that students may transfer or move into a new school at various points in the year, and that it can take time to set up training and school protocols related to medication administration, already having staff in all schools who are annually trained in seizure rescue medication and prescribed treatment could be critically important.

Council support of this legislation would be consistent with the goals of promoting the health and safety of students with disabilities, as well as community integration. Council may wish to consider urging that the medication related training requirement be expanded to all schools, and that the bill add a requirement that schools ensure that approved medication is administered by students living with epilepsy.

MEMBERSHIP COMMITTEE

Al Cavalier stated that their high priority is to review new member applications. Al added that we will have applicants fill out a questionnaire and interview them. The Membership Committee will be modifying their questionnaire based on the unexpected news from Boards and Commission that the Membership Committee is not permitted to review the applications. Once the questionnaire is updated, the committee will begin to schedule interviews with applicants. They will prioritize applicants that will fill vacancies in IDEA categories first. The Committee hopes to tie up the Biographical Sketches within the next month.

PERSONNEL COMMITTEE

There was no Personnel Committee report for February.

ICC LETTER DISCUSSION

Pam Reuther, Chair of the ICC, provided a history of the letter from ICC opposing the transition for the Part C Program to DDOE. Pam Weir added that she thinks part of the confusion about the conversation during the Infant and Early Childhood Committee report is that some members

18 See: <https://www.epilepsy.com/advocacy/priorities/seizure-safe-schools>. Nineteen States have passed Seizure Safe Schools legislation, including our neighbors, New Jersey and Maryland. Two states have passed bills or resolutions that raise awareness about Seizure Safe Schools and/or encourage epilepsy and seizure-related training, including our neighbor, Pennsylvania. *Id.*

of the Committee met with the ICC and had discussions between the last GACEC meeting and the current GACEC meeting. Pam requested that those individuals fill in full Council on what was discussed. Pam read a statement that she received from Senator Sturgeon stating that she has agreed to give a 2-year extension for the transition. She is working on getting a director position at DDOE funded to work with the ED associate that was funded in last year's budget to ensure the transition goes smoothly with hopefully no negative impact on services. Senator Sturgeon plans to have the position and extension written into the budget epilogue language so it will be written as part of the operating budget bill. She will not know for sure if the Director position will materialize until we get to budget markup is completed in May but is confident that the Joint Finance Committee will agree to it. Bill Doolittle added that the biggest thing he saw was that the legislators repeatedly asked the departments to give their rationale for requesting it not be moved and nothing substantive was supplied. Bill is pushing for stakeholder engagement to be codified as part of the agreement for the extension of the transition. Bill suggested that if the ICC and GACEC has a certain number of seats that they would like on a stakeholder group, that would be good to express. Jennifer Pulcinella added that she is just finding out about this information from Senator Sturgeon tonight. Jennifer was unsure about what Pam was talking about when she referred to a discussion that happened between the January meeting and now. Jennifer was surprised to hear about how this letter was solicited. She added that the only thing we really can do is to hear next month from people who supported the transition. Bill stated that there is work being done but he cannot go too deep because it is on the decision of the legislators involved. Bill added if anyone has specific questions, he will answer them if he can and let us know if he cannot. Jennifer added that the lack of legislator transparency has made everything more difficult than it needs to be. Pam Weir added that after meeting with Representative Williams and Senator Sturgeon, she was able to understand their point of view in that they can only work with what is brought to them. Pam thinks this is more of a stakeholder issue and that stakeholders need to do a better job working together and sharing information with each other and legislators so we can ensure the best outcome. Bruce Orr asked if this extension would come before the legislature before the end of June and the answer was yes. Bruce stated that we need to recognize who is not being transparent. Pam Reuther added that it is about getting invited to the table first. Pam Weir said that there have been many times that she has come to the table and there are people there that should have brought other groups in sooner. This is why she thinks stakeholders need to do a better job at bringing each other to the table. Bruce Orr asked who is responsible for making those invites. Bill answered that is generally the department or the legislators. Pam Reuther stated that the legislators are not always aware of everyone that should be involved. Pam Reuther added that if this is going to work and be successful there has to be transparency and when you hear statements saying there are things happening, but I cannot talk about it, that does not evoke trust. Bruce believes that it is about the people who are doing the inviting. Al Cavalier asked Bruce if he was invited to the table moving forward, would his position on the move change. Bruce said his position would not change. Based on what is being done now, they are still not ready. Pam Reuther agreed with Bruce and added that she has not seen a concrete plan for success, so it is hard to endorse. If the transition does happen, the focus is on the success of the program. Molly Merrill noted that there is a disconnect for her because to her knowledge, the only stakeholder engagement she has received was the letter from the ICC which has gone unacknowledged. Molly wonders how in such a short time period, Senator Sturgeon was open to the idea of stopping the transition from happening, to now saying the transition will be happening in two years. Molly clarified that she,

Kristina Horton, Jennifer Pulcinella, and Bill Doolittle reviewed the letter from the ICC to clear up concerns that Bill had with their letter. Al Cavalier asked Molly if she would want the GACEC to take the position to support the transition but want to proposed legislation modified to a longer period of time. Molly answered no because nobody is telling us anything. We cannot make decisions when nobody can be transparent with us. The Departments are not even sharing their position or information with the legislator. Shonetesha Quail, Associate Deputy Director for the Division of Public Health, stated that DHSS does not believe that a transition is needed because they have made significant improvements. With that being said, they will follow the law because that is what they have to do as a State Agency. Shonetesha would like to have the opportunity for DHSS to state what their position is with Senator Sturgeon, and they have not been given the opportunity. Pam Weir stated that regardless of the outcome of the legislation and the discussion tonight, she will work very hard to make sure that the GACEC and ICC work collaboratively with all agencies to make sure that subject matter experts are at the table to help aid this transition. Bill Doolittle agreed with most of what is being said. He stated that the operation has been incredibly siloed. The strongest position that we can take now to break that down is to say that both Councils expect extensive and comprehensive stakeholder engagement during the transition process. Stefanie Ramirez stated that this bill has not yet been introduced, so there still may be time to talk to Senator Sturgeon about this. Molly stated that we still need to consider voting on the letter from the ICC at the next GACEC meeting. Pam added that we still need to hear from someone who is arguing in favor of the transition and asked Council who they would like to hear from. Pam is working on reaching out to people that are for the transition to speak at the next GACEC meeting. Bill volunteered but Pam stated that it is challenging with him being a GACEC member and being deeply engrained in this work but to not have the information. Bill replied that if you want to be successful with legislators, you honor their confidence. If you do not, you will not be a part of it again. Molly asked if it would be okay with Bill, Jennifer, and Kristina to share the notes from when Bill reviewed the ICC's letter with them. Bill is open to that idea and added that when negotiations are going on between legislators and departments, you do not want to upset them, and that is what he was referring to earlier. Pam added that she appreciated Molly bringing that up because she thinks the information that was discussed may have been helpful to inform Council on making decisions. Molly added that the conversation between the group was in her role as the ICC because Bill informed them of errors in the letter last month. They had a productive conversation, and that information was shared with the Executive Committee of the ICC. Molly thinks it would be helpful for Bill's suggestions to the letter to be shared with full Council if everyone agrees.

DDOE REPORT

Dale Matusevich, Director of the Exceptional Children's Resource Workgroup (ECR) of DDOE, presented to the GACEC. Dale apologized for not supplying information ahead of time due to being short-staffed and several unforeseen circumstances that happened. Dale reviewed some of the improvement activities since the stakeholder update was shared in November. ECR recently met with a national expert, Dr. Eddie Fergus, regarding suspension and expulsion for local education agencies (LEAs) who have been identified for not meeting the targets for indicator 4. They have had great conversations with LEAs who have been reaching out to do a better analysis of that data and the root cause analysis. There were 21 people who participated in that meeting. ECR has offered this training to folks who were identified and are attempting to be proactive.

The have two methods for identifying LEAs around indicator 4. Those LEAs who have been identified in at least one area for three consecutive years were invited to participate, but it was also opened to all LEAs to receive some training. Dr. Fergus will also be assisting with Indicators 9 and 10- Disproportionate Representation. An application has been submitted to the Swift Center at the University of Kansas. They currently have a grant from the U.S. DOE around looking at creating four State model demonstration sites across the country. ECR had their first interview with the Swift Center on Monday where they answered questions and spoke about the collaborative work that they do across workgroups and agencies. The Swift Center is looking at four State Education Agencies that would then have two model demonstration sites around inclusive practices and be working with up to eight buildings across the two LEAs. OSEP will be part of the selection process and could decide by March 15. There could be a second interview, but Dale is hopeful that they will be successful. That will also incorporate some work around the implementation of multi-tiered systems of support (MTSS). If selected there will be four years of intensive technical assistance. If not selected, there is a lower tier to do some targeted assistance through the same process. Dale added that they are always soliciting efforts for assistance in getting parents to engage in the survey in how they feel coming out of IEP meetings. Tomorrow will start the next round of schools in the pipeline to career success for students with disabilities. Yesterday, the next round of Employment Bootcamp opened, and the modules were released. Dale announced that Kathy Stephen has been hired to fill the transition role. Dale shared information about the IDEA Grant Application. They usually get the application in mid to late January. The due date is typically the beginning of May so Dale will ensure that everyone has time to give input as they are writing the grant. Dale wants to spend more time receiving input for the application. There are 24 to 26 assurances that have to be signed off on. Dale added that he will share this PowerPoint with Council and it will also be on the DDOE website on the ECR page. Dale encouraged everyone to reach out with questions. Council agreed that it would be better to review the information and set up a time with Dale in the next few weeks to have the discussion. Thomas Keeton **made a motion** to table the discussion with Dale and set up additional times to discuss and ask questions. Bill Doolittle **seconded the motion**. The **motion passed** unanimously with Tika Hartsock abstaining. Beth Mineo asked that Dale flag any areas that he would like the most input on.

DIRECTOR'S REPORT

Pam shared that she and Kathie Cherry attended the Joint Finance Committee (JFC) hearing on February 14. She announced that our Disability History and Awareness Month Poster Contest Celebration is this Friday. We will continue to work on the implementation of Microsoft Teams. Pam encouraged anyone who needs help to reach out to GACEC staff. Pam shared that we have obtained three laptops to share with new or existing Council members who do not have access with technology.

OUTSIDE COMMITTEE/ADHOC COMMITTEE REPORTS

Bill Doolittle shared that he is part of the Disability workgroup with DHSS that is working on Purchase of Care funding for children with disabilities. They are making progress, but the topic came up that we should possibly be doing this for all children with disabilities.

CHAIR REPORT

Chairperson, Ann Fisher, announced the absent members for the evening and thanked our guests for attending. Ann asked for volunteers for the By-laws Implementation Committee. Reach out to GACEC staff if you are interested. Ann reminded members to contact GACEC staff if they would like to see any of the letters written by the GACEC or responses. Jennifer Pulcinella **made a motion** to adjourn the meeting. Thomas Keeton **seconded the motion**. The **motion passed** unanimously, and the meeting adjourned at 9:15pm.