



GOVERNOR'S ADVISORY COUNCIL FOR EXCEPTIONAL CITIZENS (GACEC)
GENERAL MEMBERSHIP MEETING
7:00PM November 19, 2024
HYBRID MEETING

MEMBERS PRESENT: Al Cavalier, Nancy Cordrey, Matt Denn, Bill Doolittle, Karen Eller, Ann Fisher, Cory Gilden, Tika Hartsock, Kristina Horton, Jessica Mensack, Molly Merrill, Beth Mineo, Trenee Parker, Erika Powell, Jennifer Pulcinella, and Stefanie Ramirez.

OTHERS PRESENT: JoAnn Curley, Harley Doolittle, Mindi Failing, Fern Goldstein, Dale Matusevich/Department of Education (DOE), Cassandra Pierce, Peg Stewart, and Samantha Wooten.

STAFF PRESENT: Pam Weir/Executive Director, Kathie Cherry/Office Manager, Lacie Spence/Administrative Coordinator and Theresa Moore/Administrative Support Specialist.

MEMBERS ABSENT: Thomas Keeton, Maria Olivere, Breneé Shepperson, Meedra Surratte, and Erik Warner.

ADMINISTRATIVE ACTIONS: Ann Fisher called the meeting to order at 7:02pm. There was a quorum of members present. The motion to approve the November agenda was made by Jennifer Pulcinella and Trenee Parker seconded the motion. The motion passed unanimously. Jennifer Pulcinella made a motion, seconded by Molly Merrill to approve the September meeting minutes. The September minutes were approved. Jennifer Pulcinella made a motion to approve the September financial report. The motion was seconded by Beth Mineo. The motion passed unanimously.

PUBLIC COMMENTS: There were no public comments tonight.

HOUSE BILL 23: Council member Trenee Parker presented an update on House Bill No. 23 tonight. House Bill 23 passed recently and was signed by Governor Carney. It's really an expansion of House Bill 123, which was enacted several years ago. It affords children who have experienced foster care the opportunity to attend Delaware Technical and Community College, the University of Delaware, or Delaware State University on a tuition waiver program. This program allows them to not pay tuition, to have access to year-round free housing and year-round free food services. The modification that was made recently expanded some of the money that is used to support these programs. So, for some of you who are familiar with the

Office of the Child Advocate, they are now the administrator of these funds. For many years we've worked collaboratively with them around the application process for the tuition waiver program, and then also for a number of other programs that exist that support children who have experienced foster care. So, some of our youths don't want to attend college just like some of the students that you know, that you may interact with during the day, but they want other opportunities. There are opportunities for education in trade and vocational programs. The modification that was made now allows these funds to be utilized for those programs as well. Unfortunately, that doesn't include the element of the housing and the meal plan type of program, because the programs that we operate in the State are not residential, but nonetheless it affords the opportunity of these funds, which also include a number of scholarship funds that exist to be accessed by these youth to be able to utilize these programs. It also made a change that this is not something that a youth has to do when exiting high school. They can continue to access these funds up until the age of 26. Now, so that is also a change. It used to be that the opportunities didn't last for quite as long. One of the things that we recognize is we've tried to mirror some of what is in this legislation with what exists at the Federal level around support that exists for housing and for youth that are in foster care. A lot of those programs extend to the age of 26. So, we are hoping that by extending the support here that it will provide additional support for these youth, so that they have better outcomes. You know, I think. One of the things that everyone probably knows is that when there is any discussion about youth that have experienced foster care, there are typically discussions about them, not achieving academic success as well as their peers about them, being more involved in the criminal justice system about them, suffering from housing, insecurity, food, insecurity, so hopefully. A lot of the changes that have happened in our State are going to change the narrative around that and give our youth and young adults a better opportunity to be successful, to be measured the same as their peers, and not be viewed so much as a statistic. That's 1 of the messages that we try to give our youth and young adults in the independent living program kind of to incentivize their own desire to change their trajectory and to beat the odds. The number of youths in foster care who graduate from high school is lower than their peers. That number is far less than their peers when you talk about going to college and decreases even further when you talk about graduating from college. So, this is yet another step that thankfully our State has taken to support this group and to move them forward so they can be the people years from now that are sitting in these meetings and leading our state and making a difference. So that's kind of just a really quick synopsis of what it was. But it's another piece of legislation that we're really pleased to see moving forward so that we can support the children that we serve. I obviously had my complete and total hat on being the director of The Department of Services for Children, Youth & Their Families (DSCYF) talking tonight about HB 23.”

POLICY AND LAW COMMITTEE: The Policy and Law Committee reviewed and discussed the legal memo tonight. The members of the committee who were present concurred with all the recommendations noted in the Policy and Law memo and recommend endorsement by the full Council. Full Council voted and the motion passed to support the endorsement of the recommendations.

The Policy and Law Committee also recommended that the GACEC sign on to the letter being circulated by the Autistic Self Advocacy Network requesting that the FDA move forward implementing the ban on electric shock devices. A motion was made by Beth Mineo and Seconded by Bill Doolittle that GACEC sign on in support of the letter from Autistic Self-Advocacy Network requesting the FDA move forward implementing the ban on electric shock devices. The motion passed.

Date: 10/14/2024

Re: October 2024 Policy and Law Memo

➔ Proposed DOE Regulation on 14 DE Admin. Code 1596 Charter School Leader 28 DE Reg. 269 (10/01/24).

The Professional Standards Board (“Board”) and the Delaware Department of Education (“DOE”) proposes amendments to 14 **DE Admin. Code** 1596 Charter School Leader. The proposed amendments include defining and subsequently adding the role of “Instructional Administrator in Sections 1.0 and 2.0; revising the definition of “Regionally Accredited” based on U.S. Department of Education changes in Section 2.0; adding reciprocity language in Section 3.0; revising requirements in Section 4.0; adding Section 5.0 regarding reciprocity; and revising the application requirements in Section 6.0.

The proposed amendment replaces the word “leader(s)” in Section 1.0 with “Instructional Administrators.” Section 1.0 also amends the need for a leader to hold an additional Standard Certificate and instead states that an Instructional Administrator may hold one of several Standard Certificates in lieu of a Charter School Leader Certificate.

Section 2.0 defines “Instructional Administrator” as “a charter school administrator who supervises and evaluates educators, instructs students by means of designing and implementing curriculum, or instructs, trains, mentors, or coaches teachers.” It amends the definition of “regionally accredited” as “institutional accreditation from an agency that was designated as a regional accreditor before July 1, 2020, and is currently recognized by the U.S. Secretary of Education as a reliable indicator of the institution’s educational quality.”

Section 3.0 includes several grammatical changes. Section 3.1.2 amends the requirements for issuance of a Charter School Leader Certificate to include a that a Charter School Leader may hold valid and current license from a “jurisdiction whose requirements are substantially similar to the requirements in Section 4.0 of this regulation[.]” to be eligible for certification. Section 3.1.3 adds that eligibility for certification requires a Charter School Leader to meet “the requirements for an educator’s license in Delaware and meets the requirements set forth in Section 5.0 of this regulation.”

Section 4.0 adds that an applicant for certification must have “satisfactorily completed an alternative routes (sic) for licensure or certification program for Charter School Leaders as provided in 14 **Del. C.** §§1260-1266 and 14 **DE Admin. Code** 291.” Newly added Section 4.1.3 states that the applicant must have completed at least 4 years in one of several experience requirements in subsections 4.1.3.1 through 4.1.3.6, including: Experience as an Educator in a Charter School; Leadership experience in an educational or other setting; Related services in a Charter School; Military leadership experience; Teaching experience in a public school, independent or private school, or postsecondary institution and; Any combination of the experience options outlined in subsections 4.1.3.1 through 4.1.3.5 for a minimum of 4 years of experience altogether.

Section 5.0, on reciprocity, states that if an applicant is licensed or certified in a jurisdiction with requirements that are not substantially similar to the requirements in Section 4.0, the applicant must hold a valid and current license or certificate as a charter school teacher, have completed a preparation program for charter school leaders, and have earned a bachelor's degree from a regionally accredited college or university.

Section 6.0 adds what documentation is required for an certificate applicant, including an official copy of a valid and current license, official college transcripts, proof of completion of a preparation program for charter school leaders, and additional documentation as required by the Department.

Councils may wish to consider recommending that applicants seeking a Charter School Leader Certificate should be required to have or undergo training in special education legal requirements.

Instructional Administrators will have ultimate authority and responsibility in ensuring the delivery of a Free Appropriate Public Education (“FAPE”) to students with disabilities. Charter schools must follow all federal laws that apply to public schools.¹ Under the Individuals with Disabilities Education Act (“IDEA”), all public schools have the responsibility to provide FAPE to students with disabilities; charter schools are public schools and thus bear the same responsibility.² Students with disabilities are more likely to experience punitive discipline than students without disabilities in charter schools.³ The most recent report by the Center for Learner Equity found that students with disabilities in charter schools were secluded 2.11 times more than their peers without disabilities.⁴ The chart below depicts the discrepancy in suspension rates in charter schools between students with and without disabilities.

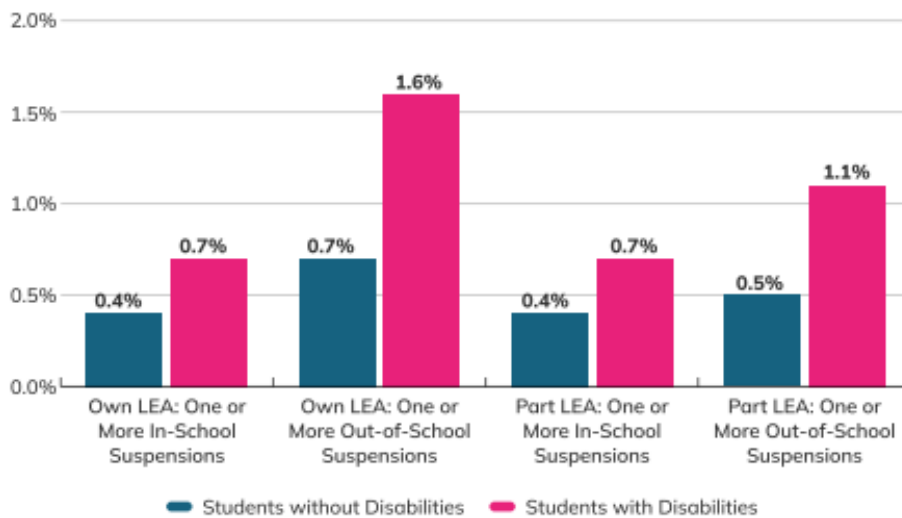
¹ Elaine Mulligan, The Facts on Charter Schools and Students with Disabilities, National Dissemination Center for Children with Disabilities, https://www.parentcenterhub.org/wp-content/uploads/repo_items/charterschools.pdf.

² *Id.*

³ Students with Disabilities, School Discipline and Engagement of Law Enforcement, The Center for Learner Equity (October 8, 2024), https://www.centerforlearnerequity.org/wp-content/uploads/CLE-crdc2024_brief4_climate.pdf.

⁴ *Id.*

Figure 3. Percentages of Suspensions by Students without Disabilities and Students with Disabilities by Type by LEA and by Student Group



Source: U.S. Department of Education, Office for Civil Rights, 2020–21 Civil Rights Data Collection, released November 2023, available at <https://civilrightsdata.ed.gov>.

The Center for Learner Equity’s report also found that charter schools have failed to “consistently address the needs of students with disabilities or, perhaps more importantly, close the gap in educational outcomes between students with disabilities and their peers.”⁵

To tackle these discrepancies, it is vital that Instructional Administrators are provided with current special education legal requirements and understand that a charter school is responsible for providing students with disabilities FAPE.

Recommendation: Councils should consider supporting this amendment with the addition of a requirement for special education legal /regulatory training requirements for applicants seeking Charter School Leader Certification.

➔ **Proposed Department of Health and Social Services (DHSS), Division of Public Health (DPH) Notice Regarding Inherited Metabolic Disorders, 28 DE Reg. 276 (10/01/24).**

With this notice, the Department of Health and Social Services (DHSS), Division of Public Health (DPH) is proposing to repeal Regulation 4103 Inherited Metabolic Disorders. Public comments are due by the close of business on November 1, 2024.

Before discussing why the DPH is seeking to repeal this regulation, a brief digression into inherited metabolic disorders is helpful. “Inherited metabolic disorders are medical conditions caused by changes in specific genes that affect metabolism. Different gene changes cause different types of inherited

⁵ Kara Arundel, Charter schools struggle to meet special education needs: A study by the Center for Learner Equity uncovers pain points and suggests ways to improve practices, K-12 Dive (July 24, 2024), <https://www.k12dive.com/news/charter-schools-special-education-students-with-disabilities/721926/>.

metabolic disorders. These gene changes are most commonly passed down from both parents. These disorders also are called inborn errors of metabolism.”⁶

Although there are numerous inherited metabolic disorders, one implicitly included in Regulation 4103 is Phenylketonuria (PKU).⁷ PKU “causes an amino acid called phenylalanine to build up in the body. PKU is caused by a change in the phenylalanine hydroxylase (PAH) gene. This gene helps create the enzyme needed to break down phenylalanine. Without the enzyme necessary to break down phenylalanine, a dangerous buildup can develop when a person with PKU eats foods that contain protein or eats aspartame, an artificial sweetener. This can eventually lead to serious health problems. For the rest of their lives, people with PKU — babies, children and adults — need to follow a diet that limits phenylalanine, which is found mostly in foods that contain protein.”⁸ If left untreated, PKU can lead to “[i]rreversible brain damage and marked intellectual disability,” and “[n]eurological problems such as seizures and tremors.”⁹ Regulation 4103 also recognizes the dire consequences that can result from untreated, inherited metabolic disorders, namely “severe mental retardation, and possibly death, in infancy.” (1.0). “If a child diagnosed with an inherited metabolic disorder amenable to dietary treatment is not able to maintain a strict dietary regime throughout life the individual will likely be developmentally delayed.” (1.0).

Regulation 4103 recognized that for children with inherited metabolic disorders (such as PKU) that can be treated with dietary management, having access to physician prescribed powdered formula that is low in protein is essential. Regulation 4103 also recognized that insurance coverage for specialty formulas was not all inclusive and families had financial difficulties paying for the necessary but expensive dietary treatment.¹⁰ (1.0).

As a result, the General Assembly created the specialty formula fund and provided funds to the DPH to cover the costs of the “specialty formula for women of childbearing age and children with inherited metabolic disorders.”¹¹ (2.0). Assistance under the fund is dependent upon and limited to the General Assembly appropriation. (6.3). Regulation 4103 set eligibility guidelines (3.0) and established a Case Review Panel to review each case and make recommendations to the DPH to help it determine the assistance that would be provided to eligible women and children. (5.0).

⁶ Mayo Clinic website inherited metabolic disorders; <https://www.mayoclinic.org/diseases-conditions/inherited-metabolic-disorders/symptoms-causes/syc-20352590>.

⁷ Although not mentioned by name in regulation 4103, the medical treatment for PKU includes dietary restrictions (low protein formulas for infants). Along with other inherited metabolic disorders, PKU is specifically mentioned and coverage is provided in the Insurance Code. It is included in Health Insurance Contracts, 16 *Del. C.* §3355, and Group and Blanket Health Insurance Contract, 16 *Del. C.* §3571.

⁸ Mayo Clinic website Phenylketonuria (PKU); <https://www.mayoclinic.org/diseases-conditions/phenylketonuria/symptoms-causes/syc-20376302>.

⁹ *Id.*

¹⁰ See Insurance Coverage of Medical Foods for Treatment of Inherited Metabolic Disorders, *Genetics in Medicine*, Volume 15, Number 12, December 2013 at 979: “[A] case of standard powdered infant formula costs the state of Mississippi Women, Infants and Children (WIC) program \$17.66, whereas a case of a specialized medical food formula for infants costs \$202.32.”

¹¹ This reviewer could not find the bill or statute that provided the appropriations for the fund despite considerable effort.

Despite the need for and salutary effects resulting from the specialty formula for children with inherited metabolic disorders, the DPH seeks to repeal Regulation 4103 because it does not have funding to continue providing the specialty formula.

Rather than repeal Regulation 4103, the regulation should remain in the Delaware Code. There are a couple of reasons that can be advanced to maintain the regulation. First, is that assistance under the regulation is dependent upon funds being appropriated by the General Assembly. (6.3). By its own terms, the regulation is self-limiting. If no monies are appropriated, no assistance would be provided. There is no need to repeal the regulation because there are no funds. There is also the possibility that the General Assembly could act and provide appropriations this term or in the future. Further, the DPH could seek funding through the State budget process.

Further, and perhaps more importantly, is action taken by Congress. On December 22, 2023, H.R. 6892—Medical Nutrition Equity Act of 2023 was introduced in the House of Representatives and was referred to several committees. The stated purpose of the bill is “[t]o provide for the coverage of medically necessary food and vitamins and individual amino acids for digestive and inherited metabolic disorders under Federal health programs and private health insurance, to ensure State and Federal protection for existing coverage, and for other purposes.”¹² The bill would amend, inter alia, the Social Security Act and provide coverage under the Medicaid Program.¹³ If the bill becomes law and coverage is mandated under the Medicaid Program, already having an existing regulation in effect about inherited metabolic disorders would greatly benefit children who could again participate in the program.

If the introduced legislation is not enacted into law and if the DPH does repeal Regulation 4103, the paramount concern becomes what happens to those individuals who are currently enrolled in the program and are receiving the specialty formulas. There is no indication from the public notice whether the funds have been totally exhausted or, if they have not yet been exhausted, when they will be. Other questions arise. Have the participants been notified? Has DHSS and DPH taken any steps to segue the individuals currently receiving the specialty formulas into a Medicaid program such as the Children’s Community Alternative Disability Program (CCADP) so that their dietary treatment plan is not disrupted? If not CCADP, is Long-Term Services and Supports (LTSS) a consideration and possibility? To prevent a possible disruption or discontinuation of the specialty formulas, DHSS and DPH should establish policies and procedures to expedite individuals currently in the inherited metabolic disorders program into these other programs.

Another issue is what happens to those individuals who are eligible for the inherited metabolic disorders program but will not be able to participate and receive the specialty formulas because the regulation was repealed and the program terminated. Like individuals currently in the program, DHSS and DPH should determine if these individuals qualify for the specialty formulas under the CCADP or LTSS and streamline their entry into those programs.

Recommendation: The public notice is terse and provides no illumination on the above concerns and how they can be addressed. Councils may wish to urge DPH to maintain Regulation 4103 and not repeal it for the reasons stated above. Councils may wish to urge the DPH to seek funding through

¹² The text of the bill can be found at <https://www.congress.gov/bill/118th-congress/house-bill/6892/text>.

¹³ The bill would require payment for part or all of the cost of “medically necessary food . . . and the medical equipment and supplies necessary to administer such food” 42 U.S.C. §1396d(a)(31).

the State budget process. If that is not possible, Councils should strongly express its concern and recommend that DHSS and DPH take the steps set forth above to prevent or lessen any disruption to the current participants or to those individuals who could participate if the program was not defunded.

➔ **Proposed Department of Health and Social Services Regulation on 16 DE Admin. Code 4470: State of Delaware Medical Marijuana Code, 28 DE Reg. 279 (10/01/24).**

DHSS is proposing to revise the Delaware Medical Marijuana Code regulations to provide clearer guidelines on how individuals can request and use medical marijuana registration identification cards (“MMRIC”). In Delaware, there are 16,800 individuals who use medical marijuana.¹⁴ **We do not provide recommendations on this topic but provide technical analysis, below, as requested by Councils.**

A significant change includes granting those over the age of sixty-five (65) the autonomy to self-certify their qualification for an MMRIC without assistance from a health-care provider. Another significant change is that health-care providers would be allowed to determine whether a patient under sixty-five (65) has a condition that would qualify the individual for an MMRIC. This change does not extend to approving the request for an MMRIC – only to determine whether the individual has a medical condition that falls under the accepted purview of what the Department would approve for an MMRIC. The proposal would allow for those who move to Delaware with an active, valid MMRIC from another state to potentially continue to use that card in Delaware. The amendments also change that those with a qualifying terminal illness must receive a MMRIC with an indefinite expiration date. Additional changes include removing “debilitating” in phrases describing one’s medical condition and replacing ‘physician’ with “health-care provider,” as well as removing unnecessary phrases and definitions. Many of the other changes throughout the proposed rulemaking are not substantive.

There are, however, some changes that could impact individuals with disabilities. Under paragraph 5.5, the Department retains the right to deny applications on the grounds that the Department finds “information provided is false” from the application. The same paragraph states that those who are denied “shall not reapply for six (6) months from the date of denial, unless otherwise authorized by the Department . . .” This language, and the subsequent related paragraphs, do not clarify the circumstances in which the Department may permit another application submission. Moreover, the bill does not clarify whether those who submit applications containing false information due to *honest, unintentional* mistakes should be treated in the same manner as those who *intentionally* provide false and misleading information. Many individuals may not have the ability to provide proper documentation or may misunderstand application instructions and unintentionally offer false or out-of-date information. **The rulemaking currently does not contain language distinguishing those who make a true mistake with those who provide false information intentionally, with the intent to deceive.**

The regulation does not currently grant applicants who made a good-faith error in their submission, a timeframe within which to resubmit their application with the corrected

¹⁴ Marijuana Policy Project, “Medical Cannabis Patient Numbers”, <https://www.mpp.org/issues/medical-marijuana/state-by-state-medical-marijuana-laws/medical-marijuana-patient-numbers/>

information and documentation required. This would prevent denials of individuals who would otherwise be qualified, but for their good-faith error. Further, it is not clear what the Department would consider as grounds to authorize individuals to reapply in fewer than six (6) months; DHSS has not provided examples of such grounds or further elaboration.

Lastly, we turn to the recall plan compassion centers must create when they need to recall their product, under paragraph 16.1. **The rulemaking does not ensure consistency and accessibility in these communications; guidance from DHSS with how the compassion centers must communicate their recall plans is not present.** This rulemaking does not require compassion centers to communicate their recall plan in multiple manners, to meet Delawareans various communication methods and needs, including: physical letters, e-mail, phone call, and other means.

COMMITTEE REPORTS:

INFANT AND EARLY CHILDHOOD COMMITTEE: Jennifer Pulcinella reported meeting with Sam Wooten from the Birth to Three system and discussed infants and toddlers in Delaware. They covered expulsions and suspensions in daycares, the streamlining of the Birth to Three system and how transparency has been welcoming with the transition process.

CHILDREN AND YOUTH COMMITTEE: The Committee discussed the need to establish the Restraints /Seclusions and School Resource Officer Ad Hoc Committee (RS&SRO). They asked Council if it has been established yet.

ADULT AND TRANSITION SERVICES COMMITTEE: Did not meet tonight.

DDOE REPORT:

- Dale Matusевич gave an update on the approved regulations 922, 923, and 925. Their implementation date is July 1, 2025. Dale will provide a copy of the guidance on these new regulations that will be provided to the Local Education Agency (LEAs) to Council. Council inquired how the Exceptional Children Workgroup envisions these changes, working when they directly conflict with the Individuals with Disabilities Education Act (IDEA). Dale responded that the revisions were vetted through their national technical assistance centers, which are funded through the Office of Special Education Programs (OSEP), and did not see any issues with what they were proposing. Right now, according to the guidance provided by OSEP-funded technical assistance centers on a national level, they do not see any conflicts.
- Pam also asked Dale to update Council on the Systemic Process for Enhancing and Assessing Communication Supports (SPEACS) initiative. DOE has been working on this through the Brandywine School District for the past three years. The person at Brandywine School District is no longer there, and they have not found a replacement to continue this collaborative work. DOE did start the program with the Seaford School District this year.

- DOE is working with the University of Kansas and the Schoolwide Integrated Framework for Transformation (SWIFT) center for the second year. They received an Institute of Education Sciences (IES) grant to look at providing a least restrictive environment placement and a least restrictive environment for students with more complex needs. Delaware was one of four states awarded this opportunity with the SWIFT center. DOE is currently working with Cape Henlopen and Red Clay school districts. They also include the Multi-Tiered Systems of Support (MTSS) work along with the SWIFT center work.

CHAIR REPORT:

- Ann announced the visitors and those Council members who were absent. Everyone should have received a copy of the proposed meeting dates for the calendar year 2025, with the Retreat to be determined. Bill Doolittle made the motion to accept the proposed General Membership meeting dates as proposed with the Retreat date to be determined. Al Cavalier seconded the motion, and the motion passed. A Retreat draft survey proposal will be going out to the Leadership Committee for their initial feedback. After feedback is received and changes made to the proposed Retreat format survey, it will be shared with the Full Council.
- Ann approved the formation of the Prison Education Ad Hoc committee and the formation of the Restraints/Seclusions & School Resource Office Ad Hoc committee. Lacie will send out a survey asking for participants' interest in these two committees.
- Per the GACEC Bylaws, a Nominating Committee must be formed to prepare for the election in April 2025. The election will be for the Council Chair and Leadership Committee Member at Large. Lacie will also include this in the survey about the Ad hoc committees to reduce the number of emails sent.
- If you haven't already, please email your committee goals for the year to the staff. Also, remember to send in your committee report from tonight to Lacie and Theresa.

DIRECTOR'S REPORT:

- Pam discussed the successful budget hearing with the Office of Management and Budget, expressing confidence in securing the necessary funds to continue the work we have been doing.
- We had a successful outreach event in October at the YMCA to highlight Disability History and Awareness Month. We will also send the information for the Disability History and Awareness Month Poster Contest that ends this month to Council members so they can share it with their networks.
- The Delaware Disability Hub Advisory Committee was formed, met nine times, and expressed many incredible ideas. They have created marketing materials and made several updates to the website. The contractor has been able to add a tab to the DelDhub website that will include marketing materials and information from the advisory committee. Pam will update Council when the tab goes live.

- Pam will share an outline for developing an IDEA funding 101 with Council to see if anyone would like to tackle a topic and design professional development. This professional development will be used to educate Council members, stakeholders, and legislators.
- During the Director's Report Tika shared a resource in the chat.
www.visioncoalitionde.org/resources/

ADJOURNMENT: Bill Doolittle made a motion to adjourn the meeting. The meeting was seconded by Jennifer Pulcinella. Motion passed. Ann adjourned the meeting at 8:50 pm.