

**Developmental Disabilities Council
Meeting Minutes
Wednesday, July 19, 2017
The Outlook at the Duncan Center, Dover, DE
9:30 a.m. – 12:00 p.m.**

Members Present: Barbara Monaghan (Chairperson), Maitri Campbell, Alex Eldreth, Alvin Emory Jr., Laura Greene, Terri Hancharick, Michael Harris, Brian Hartman, Esq., Katie Howe, Nancy Lemus, Debra McCann, Karen McGloughlin, Daniese McMullin-Powell, Carrie Melchisky, Beth Mineo, Angela Mitchell, Steven Yeatman

Members Absent: Carol Barnett, Angela Ehst, Karen Gallagher, Derrick George, Lillian Gibbons, Rick Kosmalski, HarrietAnn Litwin, Katie Macklin, Joseph Merritt, Jr., Sue Ellen Powell, Shawn Rohe, Jill Scannell

Staff Present: Pat Maichle, Kristin Harvey, Stefanie Lancaster, Emmanuel Jenkins

Guests: Bill Powell, Jahangin Vevai, Nihonfa Vevai, Libby Cusack, Ed Gootzait, Lisa Elias, Lanny Edelsohn, Micki Edelsohn, Catherine Pringle, Victoria Counihan (DAG), Cynthia Campbell, Chie Kelly, Brigitte Hancharick

- I. Call to Order** – Barbara Monaghan called the meeting to order at 9:37 a.m.
- II. Approval of Minutes** – Brian Hartman made a motion to approve the minutes as submitted. Terri Hancharick seconded the motion. The minutes were approved by Council.
- III. Approval of Agenda** – Brian Hartman made a motion to approve the agenda as submitted. Daniese McMullin-Powell seconded the motion. The agenda was approved by Council.
- IV. 5 Minute Public Comment Period** – There were no public comments at this time.
- V. Chair's Report** – Barbara stated that she, along with Pat Maichle, Kristin Harvey, Alvin Emory and Katie Macklin were in Utah last week for the National Association of Councils on Developmental Disabilities (NACDD) Annual Conference. The mountains were beautiful. Barbara met with the new Commissioner of the Administration on Disability (AOD), Melissa Ortiz, and gathered some information regarding some training for First Responders that she feels would be a great training to bring to Delaware.
- VI. Staff Report** – Pat discussed the following:
 - Disabilities Law Program shared information yesterday regarding National Disability Voter Registration Week. The Disabilities Law Program (DLP) is promoting a national effort to make the disability vote more influential. This effort, known as the Rev Up Campaign, has designated July 17-21, 2017 as National Disability Voter

Registration week. Voters are encouraged to use the web-based application to register to vote or update their voter registration information at <https://ivote.de.gov/voterlogin.aspx>.

- The Bureau of Justice Statistics released the Crime Against Persons with Disabilities, 2009-2015 report. This report can be found on their website at www.bjs.gov. The report includes information on crimes against persons with disabilities. The report includes information regarding the type of crime, crime characteristics and comparisons between characteristics of persons with and without disabilities who experienced violent crimes.
- Advocacy from our disability community regarding the current Federal health care bills over last few months has been intense and strong. This has made a difference. House and Senate bills were proposing to make significant cuts to Medicaid with block grants, cuts and funding caps. With the support of national organizations, we have been able to hold off the vote on this. Senator Bob Casey, Senator Coons, and Senator Collins have all been helping with this process. Steve Groff from the Division of Medicaid and Medical Assistance (DMMA) said if these bills pass Delaware will not survive financially.
- Angela Mitchell, who graduated from the 2016 Partners in Policymaking™ class, has been really inspirational and fighting strong with her advocacy for the needs of her son and for all people with disabilities. Angela's advocacy was key in getting a medical marijuana bill introduced this legislative session. House Bill (HB) 210 allows for pediatricians to prescribe medical marijuana for youth using the same medical requirements as adults. Congratulations Angela! Angela has also recently been voted in as a member of the School Board in Christiana School District. Congratulations!
- Pat received a training booklet from the Dale Carnegie Institute. She stated that if anyone is interested in reviewing the booklet to please let her know. Or you can view their list of training opportunities on their website at www.dalecarnegie.com.
- The 2017 Delaware Developmental Disabilities Council Annual Survey results were distributed to all Members present. Please review the results when you have a moment. Based on the survey results, it appears as though Council Members have no major concerns at this time with how the Committees or Council does business.
- There is a "Let's Make It Happen – Disability Rights are Civil Rights" National Self-Advocacy Conference that will be held June 7-9th, 2018 in Birmingham, Alabama. If anyone is interested, please visit www.sabeusa.org for more details.
- Kristin Harvey stated she was honored to be able to attend the NACDD Conference as well as the Technical Assistance Institute training. She was honored to be asked to speak about the Junior Partners in Policymaking™ program Delaware has. The session she spoke in was well attended and several individuals stayed after to ask questions.

VII. Financial Report

Financial Advisory Committee Report – Pat stated that the Financial Advisory Committee (FAC) will meet this afternoon to vote on recommendations for the September Council meeting. Stefanie reported that the 2016 Grant has approximately \$8,000 left which will be obligated by the end of August on upcoming approved projects.

There is currently \$82,000 left in the 2017 Grant. Please continue to think of projects that the Council can work on to obligate these funds by September 2018.

VIII. Current Business

- 1. Legislative Update** – A copy of the finalized legislative tracking document was provided to all members present. This list includes all bills that the Council has been involved with or have been tracking. Any bills that did not pass can be worked on during the second half of the legislative session. Please review the document. Some important bills were:
 - a. Senate Bill (SB)105 - The Moped Helmet Bill
 - b. House Bill (HB) 160- Assisted suicide bill – This topic will be included at the 2018 LIFE conference.
 - c. SB38 - Realty tax exemptions bill – This bill discusses how each county has realty tax for people with disabilities. The geographical areas with the highest tax are in New Castle and Kent Counties.
 - d. HB100 - relating to the amendment of the Delaware code as it relates to the treatment of substance abuse.
 - e. HB21 – Organ transplant bill
 - f. HB40 – Mental health bill
- 2. LIFE Conference** – The LIFE Conference Planning Committee is currently planning the 20th Annual LIFE Conference that will be held on January 24th, 2018 at Dover Downs. The DDC will be partnering with the Center for Disabilities Studies (CDS) on the technology tracks and Department of Education (DOE) on the educational track. The LIFE Conference website will be opening soon for all registrations – sponsor/exhibitor as well as general attendees. Any Council Member that would like to attend the conference please let Stefanie know so she can register you as the DDC covers your registration fee.
- 3. Annual NACDD Conference/TA Institute** – Pat stated that a few staff and members recently attended the NACDD Conference in Salt Lake City, Utah. This was funded by the Administration for Community Living (ACL). While at the conference, the Council was able to meet the new Commissioner, Melissa Ortiz. Commissioner Ortiz met with individual members and chairpersons to discuss any concerns they have. Katie Macklin and Pat made a presentation relating to the connection between Alzheimer's and Down syndrome. Kristin presented on the Junior Partners in Policymaking program™. Both sessions were well attended. While in Utah, Pat was able to make connection with Ohio and their representative in charge of setting up Achieving a Better Life Experience (ABLE) Accounts in Ohio. Ohio has allowed for anyone in country to open up account in their state. Other information that was gathered was copies of the Home and Community Based Services (HCBS) rule presentation. Copies were provided to all Members present to review where our national organization sits on this topic. Pat also was able to get copies of the Developmental Disabilities National report from 2016 that she will soon share with our Congressional representatives.
- 4. Disability History Project – Update** – Emmanuel reported that the DDC staff has been working diligently to get the Disability History project completed. The project is going well. The DDC website has recently had a Disability History page added to

archive information such as the names/organizations of reference, all of the Committee members, reference materials, and will have the transcripts for all of the interviews posted once they are completed. The DDC is currently working with a director and producer for a play that we are aiming to hold next Fall. More information will come regarding this project as it progresses.

5. **Media Update** – Emmanuel Jenkins reported that the DDC's current Facebook likes are at 840. In May, the count was at 831. The goal is still to reach 1,000 by our September meeting. Please continue share our page with your friends and colleagues. The amount of Twitter followers is currently at 242 which is up by 14 followers since May. The Council is currently following 79 organizations. The Supported Decision-Making video the Council did currently has 1,292 views on the DDC's YouTube page. The most recent hashtag to be created is #lifeconference2018.

IX. Committee Reports

1. **Adult Issues** – Terri Hancharick reported that the Committee has received some proposals for the Alzheimer's Request for Proposal and the Down Syndrome Public Awareness Campaign. The next Adult Issues Committee meeting will be held this Friday. Please feel free to attend.
2. **Children and Families**
 - a. **Proposal for Review and Approval – Outside the Box Conference - Statewide Services for the Deaf and Blind** – Alex Eldreth reported the following:
 - * The Committee is currently working on an RFP to contract with someone to develop an educational campaign on healthy lifestyles, exercise and nutrition for people with disabilities and adults. The Executive Committee approved the RFP discussed at the last meeting with one slight change to make the project aimed towards youth. The next Committee meeting will be held this Friday to discuss this.
 - * Outside the Box Conference – This conference focuses on the Deaf, Deaf Blind and Hard-of-Hearing as well as Autism. The conference aims to provide education and networking opportunities to both professionals and families/individuals. Statewide Programs for the Deaf, Hard-of-Hearing & Deaf Blind has asked Autism Delaware to partner with them on this project, so Pat asked anyone associated with the organizations that are partnering with this conference to please recuse themselves. At this time, Alex Eldreth, Beth Mineo and Nancy Lemus all recused themselves and exited the room during the discussion and vote. Kristin Harvey continued the discussion stating that the Council received an unsolicited proposal in the amount of \$6,330 to help fund the conference. The conference will be held on October 6th and 7th here in Delaware. This proposal was approved by Council.
3. **Policy and Law**
 - a. **Self-Advocacy** – Pat reported on Rick's behalf since he was not present at this meeting. Pat reported that the Council has put the Self Advocacy Request for Proposals (RFP) out three times now. This objective is a requirement within our State Plan every year. Only one proposal was received. Council approved the funding for this project last September in the amount of \$5,000. The Policy and Law

committee will meet to discuss this proposal and share more at the September meeting.

4. Membership – Karen McGloughlin stated the following:

- a. The newest member of the DDC is Derrick George. The Council has finally received his official appointment letter.
- b. Karen stated there are several official members that still need to attend Ethics Training hosted by the Council and presented by the Director of the Public Integrity Commission (PIC). This is a requirement for all members. The next Ethics training class is scheduled for July 27th at 9:30 a.m. at the DDC Office in the Margaret O’Neill Building Conference room in Dover. The time of the instructor is very valuable. We need at least 10 members to attend. If you would like to attend, please notify Stefanie so she can add your name to the list.
- c. The Council currently needs one more Member with a disability to maximize membership and keep the federally required percentages in balance.
- d. Thank you to Brian Hartman for your 40 years of service to the disability community. Karen Gallagher was not able to be here today to present Brian with a plaque showing the Council’s appreciation but sent her thoughts. Karen McGloughlin shared Karen Gallagher’s thoughts via a letter. Barbara, Nancy, Kristin, Steve and Alex all shared some kind words as well. Pat also presented some personal gifts she had gotten for Brian.

5. Consumer Caucus – Bill Monaghan reported on behalf of Joseph Merritt who was not present for this meeting. Bill stated the committee meets every three months to discuss any topics that any members may not understand. Information shared at the Council meetings is often discussed in more detail to provide more clarification to those that need it. Bill stated he feels that since Joey took the position as Chair of this committee, he has seen a change in him as a person. He is no longer quiet or frightened. The next meeting will be held on August 26th at 9:30 a.m. at the ChesDel Restaurant. All members are welcome to attend.

6. Partners Oversight – Kristin stated that the Junior Partners in Policymaking™ program was held June 18th through the 23rd at Delaware State University in Dover. The program was led by the contractor, Jamie Wolfe and assisted by sub-contractor Carrie Melkisky. The majority of the 16 member class was boys. However there was a diverse representation of disabilities as well as cultural and geographically diverse populations. The transformation seen in these individuals from the beginning to the end of the program was so humbling to see. Planning is beginning with Karen Bell, the contractor for the Adult Partners in Policymaking program©. More information will be shared as it is developed.

X. New Business

- 1. State Plan Review and Approval** – Copies of the State Plan were provided to all members present. Pat stated that any changes that are requested to be made to the plan are required to be submitted in August. With 2017 being the first year of this State Plan, there were no changes recommended by the Committees. The version of the report that will be submitted as it was approved in July. Alex made a motion to approve the

submittal of the plan. Brian seconded. Without any further discussion, the plan was approved by Council.

2. **Jr. Partners in Policymaking™ Trademark – Review and Approval –** Victoria Counihan, Deputy Attorney General (DAG) to the Council stated that the Office of the Attorney General (DAG) has been working to get the Junior Partners in Policymaking™ program trademarked in Delaware. The Council had decided previously voted to move forward with this process. The DAG is currently working with Colleen Wieck, Director of the Minnesota Developmental Disabilities Council to get her written consent to move forward with trademarking the Junior Partners in Policymaking™ logo and program here in Delaware. The process does take some time to complete. Victoria asked for a motion to authorize Pat Maichle to sign the application and all documentation relating to this process on behalf of the DDC. Karen McGloughlin made the motion to approve. Brian seconded. This was approved by Council.
3. **Annual DDC Survey** – This item was discussed previously in the staff report.
4. **Dr. Lanny Edelsohn, Families Speaking Up (FSU) - Intentional Communities** – Dr. Edelsohn had requested to come to the DDC meeting to present information regarding Intentional Communities. Dr. Edelsohn is a Neurologist and has a 40-year-old son with disabilities. He reviewed the information provided by the Olmstead decision where he highlighted that, “Each disabled person is entitled to treatment in the most integrated setting possible for that person – recognizing on a case-by-case basis, that the setting may be an institution”. Dr. Edelsohn showed a slide that said what the Council’s position was on this topic. Michael Harris pointed out that this was Dr. Edelsohn’s perception, not DDC’s stance. Steve Yeatman stated that the Council’s position is that everyone should be fully included in the most integrated setting possible, not in institutions. Dr. Edelsohn then asked the Council how they would feel if housing was by choice and affordable, independent apartments with full kitchens, common spaces for activities or meetings, fully accessible, available transportation and on-site assistance if needed. Brian stated he felt that that type of description depicted a place similar to the Stockley Center. Dr. Edelsohn countered that he feels many intentional communities are not just for people with disabilities but also include golfing communities, 55+ communities, etc. He showed many slides of the communities that Dr. Edelsohn was referencing. Throughout the discussion, Steve stated that he strongly advocates to choose anywhere in the community to live where his child can be fully included. He stated that anything less is not acceptable. In conclusion, Dr. Edelsohn stated that the DDC must be ready to be open-minded to new, innovative, safe, inviting environments for persons with disabilities. The Chairperson noted a 5 minute finish time to leave time for Q&A. He said that any Member who would like to attend a Families Speaking Up meeting is welcome to do so. All meetings are held on the second Tuesday of every month at Easter Seals in New Castle County.

After 20 minutes speaking, Barbara asked that he wrap up his discussion to keep us on schedule. Dr. Edelsohn found it difficult to concede the floor but eventually did.

5. **Future Speakers** – The September Council meeting will be held at the Outlook at the Duncan Center where we will hold our annual election of officers. The guest speaker for September will be Dr. Brian Freedman from CDS to discuss the work that CDS has been doing regarding Autism. Jane Donovan will come in November to discuss the risk surveys currently being done in schools. In January, a discussion will occur regarding the National Core Indicator Survey.

XI. Other Council Business – Pat Maichle asked that all Council members stay for a group photo at the end of the meeting.

XII. Adjournment – The meeting was adjourned at 11:10 a.m.

“Executive session may be held to discuss legal advice, pursuant to 29 Delaware Code sections 10004.”