Maine Statewide Independent Living Council

Minutes

August 28, 2024

Zoom Meeting

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| **COUNCIL ATTENDANCE** |
| **Member Name** | **Attendance** | **Voting Member?** | **Member Name** | **Attendance** | **Voting Member?** |
| **Darcy Gentle** | **E** | **Yes** | **Diane Frigon** | **P** | **No** |
| **Jessica Cyr** | **P** | **Yes** | **Lee Glynn** | **P** | **Yes** |
| **Samantha Fenderson** | **E** | **No** | **Andrew Smith** | **P** | **Yes** |
| **Tom Newman** | **P** | **Yes** | **Brendan Williams** | **P** | **Yes** |
|  |  |  |  |  |  |

Attendance Key: P = Present, E = Excused, A = Absent without excuse.

**Public Attendees:** Marita Leach, Julie Hovey, Crystal Burke, Mary LeBlanc, Roger Fuller

**Staff Attendees:** Jenn Williams

**Zoom Recorder:** Jenn Williams **Minutes Recorder:** Jenn Williams **Minutes Status:** Vote Needed

**Welcome & Introductions**

**Discussion:** Meeting was called to order at 10:05am and introductions were made.

**Action:** N/A

**Responsible:** N/A

**Acceptance of Minutes**

**May Minutes**

**Discussion:** Diane mentioned a correction to the spelling of a public attendee.

**Action:** Accepted by majority vote contingent upon the above correction.

**Responsible:** Jenn Williams, correct and send to webmaster.

**June Minutes**

**Discussion:** No corrections. Tom abstained because he was not in attendance.

**Action:** Accepted as presented by majority vote.

**Responsible:** Jenn Williams, send to webmaster.

**Financial Expenditure Report**

**Discussion:** Remaining budgetary funds of $20,545 will be given to Alpha One to serve someone on their waitlist. Current waitlist has about 70 people. Discussion around what “advertising” means for the SILC.

**Action:** N/A

**Responsible:** N/A

**Executive Director Updates**

**Discussion:**

**NCIL Conference:** Jenn shared that the conference was very beneficial and encourages appointed members to attend next year. Tom shared that Alpha One is excited to attend next year.

**Committees:** Jenn looking for what committees exist and who is on them. Membership committee has Jessica, Lee, Diane, and Sam. This committee has been in a lull while waiting for member appointments from the Governor’s office. There was previously a SPIL committee but it was disbanded because the Council was small. This was integrated into regular Council meetings.

**Contact Info:** Jenn does not have member contact information.

**Action:** Send mailing address and phone number.

**Responsible:** Appointed Members

**Pre-Meeting:** This would be an opportunity for members or potential members to ask more in depth questions about the agenda, get clarification, etc. Lee shared that this has been successful for the ABIAC.

**Appointments:** Communication with Boards & Commissions has not been successful in the past, but Jenn is actively working on appointments and seems to have a good lead.

**SPIL 2025-2027**

**Discussion:** Jenn asked if members want to continue seeing the SPIL on the screen for each meeting. Members said they liked that everyone was made aware of progress. Idea raised to start a strategic planning committee. This was tabled until the annual training.

**Action:** Add to Annual Training agenda

**Responsible:** Jenn Williams

**Activity Tables**

**Discussion:** Word document previously used was not user friendly and was missing updates from most members. New Excel spreadsheet with drop downs created to make it easier. If members need support adding to the spreadsheet please reach out to Jenn.

**Action:** Add activities to table

**Responsible:** Appointed Members

**Website and Email List**

**Discussion:** Roger (Webmaster) has offered to revamp the website at a lower rate ($750 total cost) if we are open to him creating a template that can be used by other non-profit organization. Roger shared that the WordPress site we are using is very difficult to update. He has been using FirstMagic for fifteen years which is more user friendly. The Maine SILC will also be able to make website updates on their own such as meeting dates, etc. Accessibility was discussed. FirstMagic has already worked with MaineCITE to confirm that their programs meet accessibility guidelines. Tom recommended a Maine CITE review just to have a third party audit. Brendan brought up the idea that we can be a model for municipalities that don’t have accessible websites. He also raised the idea of having social media. Jessica shared concerns that we are not the ones providing services and may not need social media. Jenn shared that she anticipates social media content being sharing what Alpha One is doing, rights information, and meeting notices. Tom shared that the Alpha One Information & Referral department is 24 hours per day and recommends putting a link on the SILC website to this resource. Diane shared that the State has recently released a cyber security directive that may also apply to the SILC. Members voted to approve the website redesign and expenditure contingent upon an independent accessibility review.

**Vote:** Yay

**Action:** Send cyber security directive

**Responsible:** Diane Frigon and Jenn Williams

**Phone Number**

**Discussion:** Jenn shared that the previous phone number for the SILC was used through an app that was not transferrable. She put her personal number on the website but found out that the SILC is subject to Freedom of Information Act requests. In order to protect personal information Jenn recommended getting a phone number through Grasshopper (a phone application), that way it can be transferred if need be, and it is separate from personal usage.

**Action:** Sign up for service

**Responsible:** Jenn Williams

**Maine Brain Injury Conference**

**Discussion:** The Maine Brain Injury Conference is on September 30th and they are looking for exhibitors. Jenn will be volunteering and will not be able to run a table. The cost is $700 and it does include a table at the resource fair in the spring. Jenn also mentioned the idea of sharing the table with Alpha One or having their marketing materials on the table. Tom shared that peer support would be more valuable than sharing other resources and would like to see an expansion of peer supports.

**Vote:** Nay

**Action:** N/A

**Responsible:** N/A

**Annual Training (September meeting)**

**Discussion:** The annual training is on September 25th at the Maine State Library in Augusta.We will have a presentation from Maine Emergency Management and potentially Maine State Housing. Tom offered to do an in-depth presentation on what the CIL is working on. What are services, what is an assessment scope of services new OBH program, etc. Diane recommended Cross Café cater lunch. Diane will reach out to Richard at the Cross Café to see if they can accommodate.

**Action:** Reach out to Cross Cafe

**Responsible:** Diane Frigon

**Action:** Create presentation

**Responsible:** Tom Newman

**Redington Fairview**

**Discussion:** Lee made the Council aware of a teenage girl that is living at Redington Fairview Hospital since 2023. She is a wheelchair user, non-verbal, and has behavioral challenges, which all make it difficult for her family to support her. The family has not found appropriate resources or a place for her to safely go.Brendan pointed out that this could be something that legislators investigate in the next session. Mary did share some resources that helped her when looking for services for her daughter. Marita shared that she sees issues like this often, and are especially difficult if there is a waitlist.

**Action:** N/A

**Responsible:** N/A

**Committee Updates**

**Membership Committee (Jessica):** No updates. Lee forwarded the membership manual from the ABIAC.

**Moving Maine Network (Jessica):** Approved for 501(c)3 status and are doing some internal restructuring. Their annual meeting is coming up and will discuss the Maine Care transportation changes.

**Acquired Brain Injury Advisory Council (Lee):** Listening sessions begin on September 3rd. These help the ABIAC determine their priorities for the year.

**Action:** Send out listening session details.

**Responsible:** Jenn Williams

**MORE Committee (Diane):** No updates. Hopes to reinvigorate the committee at the annual training.

**Announcements**

**Upcoming Meetings:** September 25th (annual training), October 23rd, December 4th

**Public Comment**

**Outreach:** Cystal Burke suggested that for outreach we connect with various support groups. She only found out about Maine SILC from researching, not from a referral or recommendation. Brendan Williams agreed. Tom pointed out that increasing membership of people with disabilities is critical to understanding unmet needs. Mary LeBlanc recommended creating a resource that can be handed out by providers. Tom mentioned that this has been brought up at Alpha One but does not know the SILCs role in something like that. Jessica mentioned that there was a handout created previously for DHHS to distribute, it was also presented to OADS. She explained that SILCs role is more to develop partnerships behind the scenes.

**Systems:** Crystal Burke shared that Colorado has a registry featuring pediatric providers with ratings. It is administered and maintained through Medicaid/Medicare. It is reviewed annually and providers with poor ratings are removed from the database. Thinks this is a replicable program. Julie shared that Alpha One receives calls for services and shares resources as part of their Information & Referral requirement.

**Resources:** Alpha One does have a resource section on their website. Tom recommended that we link these resources on our website.

**Awareness:** Crystal mentioned that she has not seen Alpha One or the SILC at the Maine State School Board events. Encourages our involvement to support children with disabilities. Tom recommended connecting with Maine Parent Federation. Crystal thinks that more representation is best. Tom shared that Alpha One does have resources if a parent or school reaches out for assistance.

**Action:** Send school board meeting information

**Responsibility:** Crystal Burke and Jenn Williams

**Collaboration:** Jessica made us aware of the Veteran’s Symposium. NAMI and is hosting the event at USM’s Portland campus to connect veterans to resources. This has potential for future collaboration.

**Action:** Send symposium information

**Responsibility:** Jessica Cyr

**Assistive Technology:** Julie Hovey shared that Alpha One is partnering with Spurwink to do a home care equipment day. People can bring their gently used equipment and it can be sold at a low cost to people in need. Purchases must be made with cash.

**Long Covid:** Crystal shared that there is a new wave and coronavirus variant that are causing increased cases of long covid. Estimated that a minimum 3% of minors are experiencing long covid nationwide. Maine is suspected to have a higher rate, 6%, because protections were lowered early. The Maine School Administration is planning to more aggressively enforce attendance by sending truancy officers to homes, regardless of disability. Alpha One does have some coronavirus information on their website but Tom would like to expand on it.

**Action:** Send latest coronavirus information

**Responsibility:** Crystal Burke and Jenn Williams

**Adjournment:** Meeting adjourned at 12:28pm.

**People**

**Andrew Smith – Disability Advocate**

**Brendan Williams – Disability Advocate**

**Darcy Gentle – AIVR Program Director**

**Diane Frigon – Regional Director, DBVI**

**Jenn Williams – Executive Director, Maine SILC**

**Jessica Cyr – Disability Advocate**

**Julie Hovey – IL Specialist/Manager, Alpha One**

**Karen Mason – Associate Director, Office on Aging and Disability Services**

**Katie George – IL Specialist, Alpha One**

**Leah Farrell – Disability Advocate**

**Lee Glynn – Acquired Brain Injury Advisory Council**

**Marita Leach – Benefits Counseling Services, Maine Health**

**Mary LeBlanc- Disability Advocate**

**Megan Marquis – Employment Advocate, Disability Rights Maine**

**Rachel Dyer - Developmental Disabilities Council**

**Samantha Fenderson – Assistant Director, DVR**

**Tom Newman - Executive Director, Alpha One**

**Abbreviations**

**ABIAC: Acquired Brain Injury Advisory Council**

**CIL: Center for Independent Living**

**DBVI: Department for the Blind and Visually Impaired**

**DHHS: Department of Health & Human Services**

**DRM: Disability Rights Maine**

**DSE: Designated State Entity**

**DVR: Department of Vocational Rehab**

**IL: Independent Living**

**OADS: Office on Aging and Disability services**

**PPR: Program Progress Report**

**SILC: Statewide Independent Living Council**

**SPIL: State Plan for Independent Living**