**Massachusetts Developmental Disabilities Council Meeting**

**June 12, 2024 (Hybrid)**

**Council Meeting Minutes**

**Present:** Annette Peele, Gyasi Burks-Abbott, Raquel Quezada, Barbara L’Italien, Ann Lynch, Victor Hernandez, Cody Rooney, Alana Russo, Sandra Heller, Elaine Gabovitch, Cindy Thomas, Chelsey Goddard, William Edes, Sarah Kelleher

**Excused:** Paul Lufty

**Absent:** Bridget Levandowski, Andrew Carr, Asha Abdullahi, Dusya Lyubouskaya, Priscilla Bessa, Courtney Waters, Marissa O’Donnell, Sara Scrivener, Mary Mahon McCauley, Carlyon Kain, Diane Lescinskas, Kathleen Biebel, Julia O’Leary, Emily Lauer,

**Guests:**  Sophie Korpics, Cynthia Laine

**Staff:** Craig Hall, Lee Larriu, Christine Joyal, Tamara Huntley, Andre Williams, Patricia Jackson, Jennifer Bertrand, Fatima Baptista, Jackson Crilley, Mary Davis

Raquel Quezada, Chairperson, convened the meeting at 6:02 pm, welcoming everyone.

**1. Acceptance of the Agenda:** Motion to accept passed unanimously**.**

First: Alana Russo Second: Sandra Heller

Voting Poll Results: Passed

**2. Approval of March Meeting Minutes:** Motion to approve passed unanimously**.**

 First: Cody Rooney Second: Gyasi Burks-Abbott

Voting Poll Results: Passed

3. **Updates from the Chairperson, Raquel Quezada, Chairperson**

Raquel stated she wanted to let all members know that one of our Council Members, Sethany Griffin, has resigned from the Council. We thank her for your service to the MDDC and we will be sending her a token of our appreciation.

Gala Roja Por Amora La Inclusion Award – A huge congratulations goes to Gyasi Burks-Abbot for being awarded this award from the CEMPDCD Foundation. This award is given to recipients for their contributions and dedication to make this world better, it is not only an act of kindness, but also a ray of hope for those facing unique challenges in their lives. Thanks to your services, we can continue to provide resources, services and opportunities that empower and enrich the lives of people with disabilities. Congrats Gyasi!!

We also want to give a congratulations to the following members:

Asha Abudualli – Asha and her organization SPACE for an incredible Eid al Fitr celebration in April which received coverage from the Boston Globe. In her work, Asha has been successful in establishing crucial resources for Somali families in Boston. Her dedication and hard work have had a significant positive impact on the lives of many families in our community. Asha, your leadership and commitment are truly inspiring, and we are amazed by the positive change you are bringing about. Congrats Asha.

Cynthia Laine – was nominated by State Representative Michael Kushmerek to be recognized as one of the Commonwealth Heroine of Class 2024 and selected by the Mass Commission on the Status of Women to receive this award. She will be recognized and awarded on June 14th. Congrats Cynthia.

Gyasi Burks-Abbott – Gyasi has contributed an essay to a recently published anthology by Springer Macmillan. The anthology, titled “Placing Disability: Personal Essay of Embodied Geography,” features Gyasi’s essay, “A Sense of Place & Cyberspace: The Hybrid Way I Live, Work, & Play.” Congrats Gyasi.

Raquel shared our upcoming events in collaboration with MDDC as follows:

* June 23 – 28th – Youth Leadership Forum, Emerson College – In Person
* June 29th – Annual West Region Self Advocacy Conference – Sheraton Monarch Place Hotel, Springfield – In Person
* July 22-26th – NACDD Annual Conference, Washington D.C. – In Person
* Sept 11th – MDDC Council Meeting
* September 23-25th – Generational Leaders’ Summit
* October 26th – MASS Advocates Standing Strong Self Advocacy Conference – In Person

**4. Committee Reports:**

**Executive Committee – Raquel Quezada, Chairperson**.

Raquel deferred to Craig Hall. Craig congratulated Raquel for her award at the Gala. Craig shared that MDDC earned the 2024 Excellence in Supplier Diversity Award.

**Membership** – **Cody Rooney, Vice Chairperson-Committee Chairperson**

Cody stated that there really is no update to report tonight. All potential new applicants and reappointments were sent to the Governor’s Appointments office on Dec. 2nd. We are still waiting to hear. We will let you know.

**Public Policy Committee – Gyasi Burks-Abbott, Committee Chairperson**

The MDDC Policy Committee meets monthly (most months) where we typically discuss the following agenda items:

* State Legislative & Budget Updates
(information related to our legislative priorities and endorsed legislation)
* Federal Updates
* Proposed/Final Rules & Regulations
* Recent/Upcoming Legislative Hearings
* Other Bills/Policies of Interest to People with DD
* Partner Updates & Collaborations
* Legislative & Advocacy Opportunities & Events

We also invite an occasional guest presenter to our meetings. In May Ian McIntosh, Director for Disability Outreach, Patients’ Rights Action Fund (PRAF), attend our meeting and presented on the topic of Medical Futility & Disability Bias: Relevance to S.1331/H.2246 An Act Relative to End-of-Life Options. This presentation was intended to educate Council members about physician assisted suicide and how the policy could potentially impact people with developmental disabilities. MA lawmakers are currently considering a policy which is now moved onto the Committee on Senate Ways & Means. The slide decks were sent out to Council members with the May 2024 Policy Committee meeting minutes. The MDDC Policy Committee will meet on the following upcoming dates:

* August 12, 2024
* September 9, 2024
* October 21, 2024 (3rd Monday due to a holiday on Oct. 14th)
* November 18, 2024 (3rd Monday due to Veterans Day on Nov. 11th)

**Diversity, Equity, and Inclusion Committee – Fatima Baptista**

Guest presenters from the Center for Public Representation (CPR)

Summary: The session centered on the significance of thoroughly considering all available options when deliberating on guardianship alternatives for individuals with disabilities. It underscored the need for a gentle and inclusive approach when introducing supported decision-making. Participants shared their experiences and insights on effective community outreach and social impact projects. The conversation also encompassed the crucial roles of continual education and support for decision-making in special education, acknowledging the necessity for ongoing training and logistical support.

Next DEI Meeting: September 3, 2024, 12-1pm

BIPOC Sharing Circle’s: Sawubona Update

The Sharing Circle served as a secure forum for community providers and self-advocates to convene and deliberate on matters concerning the protection and advocacy for the safety and equitable access of individuals with I/DD. It played a vital role in allowing individuals to express their concerns and frustrations. Our primary focus is on fostering new partnerships and expanding the membership base of our Sawubona Group. Our monthly meetings are scheduled for the second Tuesday of every month from 12 pm to 1:30 pm. We are actively engaged in establishing new subcommittees and creating resources tailored to all age groups within the I/DD community. Our objective is to ensure enhanced access to resources that cater to the needs of families, caregivers, and individuals with I/DD.

Sawubona Circle’s: Participating Agencies/ Organizations

* Federation for Children with Special Needs
* Alexis Miranda Foundation
* Black Autism Coalition
* Trash to Treasure Art Foundation
* Massachusetts Advocates for Children
* Department of Public Health
* Inpower Love Coach LLC
* Massachusetts Executive of Health & Human Services
* Parent/ Professional Advocacy League
* Conexiones Latinx of Massachusetts
* Massachusetts Rehabilitation Commission
* Mass Families
* Cambiado el Mundo De Personas con Discapacidad
* HMEA
* Advocates
* Waystone Health and Human Services
* Requipment, Inc
* W.I.S.E
* Somali Parents Advocacy Center Education
* Massachusetts Developmental Disabilities Council
* Self-Advocates Statewide
* Boston University

**CPR Advisory Monthly Committee Collaboration Meetings**

 Diversify Input

- Community organizers, advocates, individuals with lived experience, and attorneys

- Cultural Competency

- Sharing personal experiences

- Building mutually beneficial relationships

**5. Disability Policy Seminar Update – Jennifer Bertrand**

A group of MDDC leaders attended the 2024 Disability Policy Seminar in Washington, DC. Council members learned about key issues and how to advance the grassroots movement for people with intellectual and developmental disabilities (IDD). They also learned how to amplify the concerns of people with DD before Congress. These attendees worked to also establish allies on Capitol Hill and press for progress on critical disability rights issues that make life in the community possible for people. Attending the seminar also allowed Council members to network with experts, professionals, and advocates, and speak directly to delegates (and/or policy staff) about the high-priority issues that affect people with DD, their families, and supporters. On May 10, 2024, Council members conducted seven successful Delegate meetings on Capitol Hill. Attendees included Gyasi Burks-Abbott (LEND), Cynthia Laine (ICI), Sandy Heller (MDDC), Cody Rooney (MDDC), Alana Russo (MDDC), Kaitlin Stober, MDDC Disability Policy Assistant, and Jennifer Bertrand, MDDC Disability Policy Specialist. In advance of the DPS, each Council member developed a powerful personal story related to legislative bills currently being considered by federal lawmakers. These were shared during each of our meetings with MA Delegates on Capitol Hill. To see pictures from the seminar go to the May 2024 MDDC Policy Committee slide deck emailed by Jennifer with the Policy Committee meeting minutes. Feel free to reach out to Jennifer if you have any questions. The links below will take you to a series of short video clips recorded during the 2024 DPS.

* **Gyasi Burks-Abbott:**
<https://www.facebook.com/MassDDCouncil/videos/442443815001712>
Gyasi’s Presentation (video clip):
[(20+) Facebook](https://www.facebook.com/1482066698/videos/pcb.10232559457357213/976357753494634)
* **Sandy Heller:**
<https://www.facebook.com/MassDDCouncil/videos/382074484809082>
* **Cynthis Laine:**
<https://www.facebook.com/MassDDCouncil/videos/1472067906712190>
* **Alana Russo:** <https://www.facebook.com/MassDDCouncil/videos/1828734977589917>
* **Cody Rooney:**
<https://www.facebook.com/MassDDCouncil/videos/1495748604623488>
* **Jennifer Bertrand, MDDC Disability Policy Specialist**
* <https://www.facebook.com/MassDDCouncil/videos/818280853420658>
* **Kaitlin Stober, MDDC Disability Policy Assistant:**
<https://www.facebook.com/MassDDCouncil/videos/2385784678282297>

**6. Gopen Fellow Presentation – Sophie Korpics**

Sophie’s project was titled: Understanding Assistive Technology: Barriers to Access and How to Improve. Sophie Surveyed students with disabilities, teachers and school personnel who work with students with disabilities and parents across MA. Asked participants about use of AT in public schools; awareness; knowledge of how to use and asked students about impact. Her findings were that students are using AT primarily for speech to text and English to Spanish translation. AT offered students a lot of positive results- Most important-increased independence. Teachers & School Personnel- limited exposure to a range of AT options available; some training-not enough; schools place priority on getting AT for students. Falling short on instructing how to use. Parent findings were consistent to teacher & school personnel findings: parents- limited exposure to range of options available; some training- not enough; Schools place priority on getting AT for students. Falling short on teaching parents how to use. Of all the groups surveyed-parents-least informed. Sophie developed recommendations for schools and the committee and spoke about some of her other fellowship activities.

**7. Crocker Fellow Presentation – Cynthia Laine**

Cynthia’s project was titled: Creating a Culture of Inclusion in Church. Cynthia spoke about what it means to be inclusive in church and the barriers parents face when attending church with children with IDD. She spoke about all the negative comments from others, the segregation that parents faced. Cynthia connected with Joni & Friends. Since 1979 Joni and Friends has committed to reaching and serving people with disabilities with practical help and the saving love of Jesus. They envision a world where every person with a disability finds hope, dignity, and their place in the body of Christ.

Cynthia also connected with Dr. Lamar Hardwick. Dr. Hardwick was diagnosed at 36 with ASD in 2014

Dr. Hardwick has not only grown through his experiences as a Black autistic pastor in America but has taken the time to help others learn from these experiences. He created *Disability and the Church*where you will find many principles for creating a welcoming community. He focuses on: People over programs; People with disabilities being *celebrated, not tolerated;* Circles over rows (bringing people together); and Pastor approval versus pastor apathy (the importance of leadership involvement). Will all this work their will be trainings at other churches and more inclusive services.

**Cindy Thomas announced the new fellows for the coming year.** They are as follows:

**Gopen Fellow** – Kelsey Oates. Kelsey will work to develop an app for people with IDD to focus on setting goals and being able to track their progress on their goals.

**Crocker Fellow** – Michelle Brian. Her project is titled: Playdate and Pals and will focus on connecting children with IDD with others in the community.

**8. Policy Update – Jennifer Bertrand**

Legislative leadership continues to bargain over final policy details through the month of July. Some of our priority bills have been reported favorably in committee and others “extended” multiple times for consideration. There is NO guarantee legislation will come up for votes in either branch. See the June 10, 2024, MDDC Policy Committee minutes for a priority bill summary. Only 2 priorities have been sent to “study” meaning that they are no longer being considered this session.

The State Budget: The House and Senate have each created a fiscal year 25 state budget proposal.
A special committee called a conference committee meets to discuss both budgets. The conference committee’s job is to work out the differences between the two proposals. The conference committee is made up of members from both the House and Senate. Lawmakers have not passed an “on time” budget in 14 years so it’s possible the Governor will submit an interim state budget until the legislature has finished their FY 25 state budget deliberations.

MA21 Coalition

The Massachusetts Alliance for 21st Century Policy or “MA21” is a group of disability advocates and statewide advocacy organizations including the MDDC. This coalition advocates for the full implementation of the Real Lives Act and the Department of Developmental Services (DDS) Medicaid 1915(c) Home and Community-Based Service Waivers.

After two years in the making, DDS has released a new draft of the Self-Determination & Self-Direction Regulations. Public comments can be submitted to DDS by June 18, 2024 @ 5PM. DDS is also hosting a virtual Public Forum on Tuesday, June 18, 2024, from 1-3PM to seek input from people with disabilities and the public. For more information go to the links below:

[DDS Notice of Public Hearing and Opportunity for Public Comment | Mass.gov](https://www.mass.gov/info-details/dds-notice-of-public-hearing-and-opportunity-for-public-comment)

[MA21 Basic Fact Sheet - Real Lives Law - Current Version.pdf - Google Drive](https://drive.google.com/file/d/18ofDKxheGmUZkcuL4GoUVuc1vOL-kUEg/view)

[Massachusetts Alliance for 21st Century Disability Policy – Massachusetts needs to make self-directed services work for everyone who chooses them. (ma21alliance.org)](https://ma21alliance.org/)

MA21 Steering Committee reviewed the new proposed DDS regulations and compared those to the Real Lives Law. These leaders are preparing a document with background information and sample talking points that may be useful to draft your public comment. Jennifer will email Council members with more information soon. If you are interested in submitting a public comment and would like assistance call/or email Jennifer Bertrand. The Disability Law Center and the MDDC are collaborating and will submit a joint public comment letter.

**Federal Update:**

**New Proposed FDA Ban of ESDs:** U.S. Food and Drug Administration (FDA) has proposed a new ban of electrical stimulation devices (ESDs) for self-injurious (self-harm) or aggressive behavior. This is the 2nd time the FDA has proposed a ban of these devices. The FDA reviewed evidence and determined ESDs cause an unreasonable and substantial (real) risk of illness or injury. Research shows the use of ESDs often result in:

* Psychological (mental) risks including depression and anxiety,
* Worsening of underlying symptoms & the development of post-traumatic stress disorder
* Physical injuries such as pain, burns, and tissue damage.

MDDC submitted a letter of public comment. We also just learned today that language was introduced in a federal legislative sub-committee to allow the use of these devices on people with disabilities when they are court ordered.

This means the devices could still be used to shock people with disabilities at the Judge Rotenberg Center (JRC) in Canton, MA if the language (the "policy rider") if this language is included in the federal bill. EDSs/Devices used on people with disabilities at the JRC are under a court order. Jennifer will share more information on these developments and what you can do to advocate for people with disabilities.

**“Ensuring Access to Medicaid Services” Final Rule (HCBS Access Rule):**

This Rule aims to improve access to care and quality of care for Medicaid beneficiaries. The rule includes provisions related to home and community-based services (HCBS), the direct care workforce, health and safety protections, access to HCBS, quality measures, and state accountability and transparency.  The rule will go into effect July 9, 2024, with a 6-year transition period for states to comply. The Access Rule is being celebrated as a historic regulation to promote the quality of HCBS, and thus support people with IDD to live and engage in our communities. For more information go to the link below:

[NACDD Commends the Department of Health and Human Services for Improvements to HCBS Services Finalized in the “Ensuring Access to Medicaid Services” (Access Rule) – NACDD](https://nacdd.org/nacdd-commends-the-department-of-health-and-human-services-for-improvements-to-hcbs-services-finalized-in-the-ensuring-access-to-medicaid-services-access-rule/#:~:text=NACDD%20supported%20several%20provisions%20which%20were%20including%20in,they%20receive%20through%20a%20robust%20person-centered%20planning%20process.)

[Improving HCBS Access and Quality: Groundbreaking New Rule From CMS | ACL Administration for Community Living](https://acl.gov/news-and-events/announcements/improving-hcbs-access-and-quality-groundbreaking-new-rule-cms)

**Final Rule Released for Section 504:
Discrimination on the Basis of Disability in HHS Programs or Activities**

On May 1st, 2024, the Office of Civil Rights (OCR) finalized a rule that prohibits discrimination on the basis of disability. The Final Rule is important because it:

* Advances equity,
* Bolsters protections for people with disabilities under Section 504,
* Clarifies and strengthens civil rights protections for people with disabilities,
* Addresses discrimination in medical treatment,
* Adds enforceable standards for accessible medical diagnostic equipment, and
* Ensures accessible web content and mobile apps.

For more information about the Final Rule for Section 504 go to the link below.

[Webinar: Overview of HHS’ Final Rule Implementing Section 504 of the Rehab Act | ACL Administration for Community Living](https://acl.gov/news-and-events/announcements/webinar-overview-hhs-final-rule-implementing-section-504-rehab-act)

**9. Grants Update – Sandra Heller**

Sandra Heller stated that the MDDC small grant recipients were invited to continue their projects for the 2024-25 grant cycle. In May, grant reviewers evaluated the applications. Unanimous recommendation to fund all 3 projects: Conexiones Latinx-MA; MassFamilies; and VongTayChaMeViet /Circle of Vietnamese Parents. Grantees work with people with DD and family members in Latinx, Native American & Vietnamese communities.

Grant awards: $15,000 per organization. Projects begin on/after July 1st and end on June 30, 2025. Committee members emphasized the importance of MDDC investing in small organizations to address unmet needs in diverse underserved communities.

Grant ending on June 30:

Center for Public Representation – Supported Decision-Making (SDM) Project: Addressing Diversity, Equity and Inclusion. Innovative “gap-filling” initiative to make SDM more available to linguistically, ethnically and culturally diverse communities in Massachusetts. Populations trained include family members and youth with developmental disabilities in underserved communities across Massachusetts including Latino, Black, Haitian, Cambodian, LGBTQ+ with DD, dually diagnosed developmental and mental health disabilities. The grant is ending due to uncertainty about future MDDC funding. The MDDC applauds CPR for all their great work and collaboration!

**10. COVID and Public Health Outreach Update – Fatima Baptista**

Fatima has collaborated with non-profit and community organizations throughout the state to engage in community and social inclusion events. At these events, we supply materials such as COVID tests, masks, information, resources, and sensory items for attendees. Meeting people has been a valuable way for MDDC to be present and listen to community members' concerns about health, safety, and inclusion, and to offer support. Fatima is dedicated to the community and committed to promoting unity. The work focuses on the three P’s of public health: preventing disease, promoting health, and prolonging life. We are continually striving to support underserved communities by providing resources, accommodations, education, and fostering community and networking connections.

We recognize the challenges faced by these communities and are devoted to providing compassionate and sympathetic support. The Public Health Community Engagement Trainings have been successful and have attracted more individuals seeking to connect.

Past/ Upcoming Events

|  |  |
| --- | --- |
| Federation for Children with Special Needs: Visions of the Community | 4/1/2024. |
| The Arc: The Transitions Journey | 4/27/2024. |
| Gala Roja: Gala for the Love of Inclusion | 5/11/2024. |
| Touch-a-Truck Family Day | 6/1/2024.  |
| Randolph Health & Wellness Expo | 6/1/2024 & 6/8/24 |
| Massachusetts Cultural Council | Various Dates |
| W.I.S.E. Juneteeth Freedom Day Celebration | 6/19/2024. |
| Community Economic Development Center: Reggae on West Beach | July & Aug 2024 |

AMERICAN RED CROSS BLOOD DRIVE

Sponsored by Massachusetts Developmental Disabilities Council & Quincy Fire Department

Saturday, August 24th, 2024

9am-2pm

Fore River Clubhouse

16 Nevada Road

Quincy, MA  02169

To schedule an appointment, please visit [www.redcrossblood.org](https://urldefense.com/v3/__http%3A/www.redcrossblood.org/__;!!CPANwP4y!UUsC8fERLnNW7YxDCLUTaMiHorY7xlUtM4fWMxybqtD3CuazfsVlXFCwMTKwg000EjJrQcMWM_vdxrFREiIS2N9aOICGKsQ$) and

All Donors will receive a $20 Amazon.com Gift Card\*\* by email. \*

**11. Training Team Update – Lee Larriu and Staff**

The MDDC Training Team ran a total of 6 training series between March through the first week of June, graduating a total of **47 Participants.** The breakdown is as follows: A total of 8 students graduated in our Employment Series. The team ran 3 Self-Esteem series beginning in March graduating a total of 29 students with our newest partners, Boston Collegiate and CASH which stands for Community Academy of Science Health. In the MDDC Supported Decision-Making pilot series we graduated a total of 10 students ages 14-17 through two cohorts that included one freshman class and one Sophomore class.  Students completed final vision boards where they shared personal goals to include being self- sufficient, a college graduate and an owner of their own bakery to name a few. We thanked the Center of Public Representation for the support and guidance they provided the training team over this past year and will miss working with them as their grant with us is ending this month.  Our team was the architect for this series that introduces supported decision making to youth in transition in both English and in Spanish.

The team will be providing a presentation to MRC at their forum on June 26th to parents where we will share information on the opportunities and work of the Mass DD Council, highlight our peer-to-peer model, outline our training series to include: The Self-Esteem Series, The Employment Series, Legislative Advocacy, and our newest training series on Supported Decision Making.

Also in June, Tamara will be attending the Western Mass Self-Advocacy conference to help them celebrate their 20 years of success with 8 self-advocacy groups in 5 western mass counties.

The MDDC Training Team Calendar update is as follows:

The Positive Me: Self-Esteem Series for June is full and already underway

In July we have 1 Series running on the self-esteem series

From July 9-23 on Tuesdays & Thursdays and are currently accepting applications

**In August we will run two Series on Self-Esteem:**

Mondays & Wednesdays from August 5 -21

And Tuesdays & Thursdays from August 6-22 and will be sending out applications soon.

The **Legislative Advocacy Training** will be announced in the next few weeks and will take place sometime during the Week of August 27th, prior to the Massachusetts State Primaries in September.

To learn more about the MDDC’s training, please contact Lee Larriu. Thank you Lee.Larriu@mass.gov 617-770-7676 ext. 118

**9.Other Business – Raquel Quezada, Chairperson**

Raquel mentioned that Adelia will be emailing all members our Annual Conflict of Interest Policy along with the acknowledgement form. Please email the completed form back to Adelia.

**10. Adjournment 7:74pm.**

Motion to adjourn was approved unanimously.

First: Sandra Heller Second: Alana Russo

 Voting Poll Results: Passed

The meeting was adjourned at 7:44pm.

Alana Russo

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Review/ Approved

Alana Russo, Secretary Date: June 25, 2024

Craig Hall /s/

Review/Approved

Craig Hall, Deputy Director Date: June 25, 2024