

# NACDD Board Meeting Minutes

November 30, 2023

Present: Eric Stoker, Julie Horntvedt, Emmanuel Jenkins, Kayla Green, Jon Meyers, Darryle Powell, Emily Hartley, Christine Pisani, Kirsten Murphy, Brett Williams, Patrick Reinhart, Kim Mercer-Schleider.

Guest: Eric Berg, Robin Troutman, Sheryl Matney, Aaron Carruthers, Johnny Calebs, Kate Barrow, Craig Hall, Kristin Harvey, Arlene Poncelet, Amy Deaville, Erin Prangley, Christine Germeyer, Rafa Rolon-Muniz, Beth Swedeem.

Absent: no board members were absent.

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1. Welcome & Roll call.

Kirsten called the meeting to order at 3 pm EST.

2. Minutes.

Julie asked the board to review the October 30, 2023, minutes. Eric Stoker makes a motion to approve, Darrell seconds. Motion carries.

Kirsten requested two changes to the agenda: (1) to add a public comment period for guests; and (2) time to discuss Board priorities under New Business.

## BOARD AND COMMITTEE REPORTS:

3. President's Report from Kirsten Murphy

a) Notable staff accomplishments.

- a. Thanks to Robin for stepping up to serve as Acting Executive Director.
- b. An article by Erin Prangley was recently published in the National Leadership Consortium Bulletin highlighting the impact of DD Councils on improving access to Home and Community Based Services.
- c. Staff are already planning for DD Awareness Month is in March and the Disability Policy Seminar, which will occur April 8-10 in DC this spring.
- d. Staff are working with the Michigan DD Council members to host a workshop series on being a sexual self-advocate.

b) Board Work.

- a. We have chairs for all board committees: Kayla Green will chair the Member Services Committee; Patrick will serve as Treasurer.
- b. Board Activities to Date: Board members received orientation that reviewed board duties and responsibilities, finances, and NACDD's strategic plan. Sheryl Matney helped with the training.
- c. President will continue sending out a board letter to inform the network of board activities.

- d. Membership Satisfaction: Focus groups were conducted and findings shared. A facilitated conversation at the Executive Director’s Retreat also helped address member questions. Staff interviews were recently conducted by consultants Brian Cox and Wanda Willis. A summary of those findings will be shared with the Board soon.
- 4. Acting Executive Director’s Report from Robin Troutman, with presentation on communications by Rafa Rolon-Muniz
  - a) The “ED Living Room” has been set up on Fridays for discussions amongst ED’s.
  - b) In the New Year, staff will add “deeper dive” focused discussions to include more than ED’s.
  - c) National Alliance for Caregiving held a webinar on vaccines.
  - d) Staff are sending a newsletter on the alternate weeks when there is no Wednesday calls.
  - e) OIDD Engagement call will be on 12/6 at 3 p.m. EST with Jack, David, and other ACL staff. All Executive Directors are urged to attend.
  - f) Notice of Awards: ACL is still waiting and hoping before Christmas, but more likely end of year
  - g) Rafa provided an overview of NACDD’s Communications work with data about social media engagement. (slides attached).
- 5. Self-Advocacy Committee from Emmanuel Jenkins (written report attached)
  - a) 16 different states participated at the last meeting. Self-advocates shared what was happening in their state.
  - b) The Committee is working on creating a video about leadership and how self-advocates are in leadership roles in the DD Council network.
  - c) Committee would like to expand its membership. If a self-advocate or a state has or wants help from this committee, they should email Emmanuel or Eric Berg to connect members, or call Emmanuel, or call NACDD Staff to get to Emmanuel/Eric.
- Strategic Communications Work Group from Emmanuel Jenkins
  - a) Group hopes to become an official committee of NACDD rather than a workgroup. They want to be the group that is the primary source of communications needs
  - b) Planning a January webinar with ITACC on communicating SOGI data and a February webinar on DD Awareness Month and a member toolkit, which they will help develop.
  - c) Group hopes to take on more responsibility of DD Awareness month in the future.
- 6. Public Policy Committee from Brett Williams and Erin Prangle (written report attached).
  - a) The committee meets monthly. Issues that they have worked on include advocating for a “clean” continuing resolution for the FFY’24 budget; supporting states seeking to extend their Appendix K flexibilities; supporting Council to comment on Sec. 504 anti-

discrimination updates, testimony in favor of ending 14-c, and policies supporting adult changing tables.

- b) Committee will begin working on FFY'25 appropriation. It is important for Councils to educate their lawmakers on the critical role that Council play in their states.

7. Treasurer Report from Patrick Reinhard:

- a) Patrick will meet with the Finance Committee in January.
- b) With Kirsten and Robin, met with the finance people at Merrill Lynch, we have a little over 200k in our long-term investment account. Funds are well managed and can be liquidated easily if needed.
- c) Patrick is working on a one page dashboard (actuals vs budgeted) to make NACDD finances easy to understand.
- d) Total assets, 1,540,019. We are doing better this year than last.
- e) Kirsten added that final terms for the termination of the former CEO are still in negotiations. NACDD continues to be represented by Counsel.

8. Member Services from Kayla Green

- a) This committee has not met yet. Planning a January meeting to plan for the annual conference and collect ideas on topics.

MEMBER COMMENTS:

- 1. Kristin Harvey thanked the staff and members for the Executive Director Summit, which she said was a great experience.
- 2. Darryle and Julie spoke about our experiences at the Building Better Communities Project in Washington DC.

NEW BUSINESS:

- 1. Search Committee. Committee Chair Beth Swedeen reported that they received 29 surveys from Executive Directors. They developed a job description and recruitment package, which has now been widely distributed. Applications are due by Jan. 3, 2024.

Board members are urged to share the recruitment packet with their personal networks.

A question was raised about whether the recruitment packet indicates that assistance and/or accommodations can be provided for the application process. Beth said that she would make this change.

- 2. Board Priorities for 2024. Kirsten noted that the Board's top priority in the coming year would be "recruiting, identifying, and hiring a top-notch Executive Director for NACDD; and on-boarding the new ED so that our Executive Director has the information, resources, and information to lead NACDD."

Kirsten reviewed the 6 Board-related recommendations that came out of the member focus groups. She asked the Board to pick 2-3 as priority areas for Board work in the next year. The 6 suggestions were:

1. Develop a Board Communications Strategy:
  - Commitment to membership awareness of Board activities.
  - Regular updates to membership.
  - Easier access to meeting schedule and minutes.
2. Review Board orientation and bolster Board member training where needed. Develop and share a Board manual.
3. In partnership with NACDD staff, establish a member grievance process that allows for concerns to be reviewed and remediated as necessary. Should include:
  - Confidential non-biased review by a committee of Board members who will make a recommendation for resolution as needed.
  - Follow up with concerned parties
4. In partnership with NACDD staff, establish a membership code of conduct for use of our listservs and other points of interaction.
5. In partnership with the Bylaws Committee, facilitate membership in considering recommended changes to the by-laws. Membership votes on by-law changes.
6. In partnership with NACDD staff, review where Board roles and authority need to be included in network facing trainings (New ED orientation, Council Chair training, etc.)

The Board agreed that improving communication across NACDD is key to improving member satisfaction and transparency in governance (recommendation 1). They also identified creating a policy/protocol for addressing member grievances as something the Board must address in 2024 (recommendation 3). It was noted that some of the trainings considered under recommendation 6 are sponsored by ITACC and therefore have to be approved by OIDD>

3. Language Access: Kirsten, Eric, Julie, and Emily are finishing up interviews concerning Language Access Plans. We have interviewed 2 Councils so far. A final report will be ready by the next quarterly meeting.
4. Bylaws Committee: Kirsten has spoken with Committee Chair Isadora Legendre, who could not be at today's meeting. Kirsten delivered the committee update.

The Committee will be done with their review in December. The Board discussed next steps. Because the Bylaws Committee was created by the Board, the Board would like to review their findings and recommendations before a draft is circulated more widely. Kirsten will take this request to the Committee Chair.

After Board review, the draft will be circulated for member comment, probably for 45 days. Kirsten also reported that she has asked the Committee to bundle their recommendations specific to each issue they want to address. This structure anticipates voting separately on each related set of changes. Bylaw changes must be voted on by the Assembly and can only pass with a 2/3 majority.

Meeting Adjourned at 4:59 p.m.

Respectfully submitted,

Julie Horntvedt, Secretary

#### Attachments

- Report from the Self-Advocacy Committee
- Report from the Public Policy Committee
- Presentation on NACDD Communications by Rafa Rolon-Muniz,

### 11.30.23 Self Advocacy Committee Board Report

**Attendance of most recent Committee Meeting (10.17.23):** Max Lowe Nevada, Sheryl Beard North Dakota, Arlene Poncelet (SD) Brett Williams (Michigan) Chris Hendricks North Carolina, Santa Perez Nevada, Emmanuel Jenkins Delaware, Riana Hardin California, Allison Wymer Indiana, Max Barrows Vermont GMSA, Gary Arnold IL, Christine Germeyer Virginia, Dana Thompson PA DD, Jennifer Bertrand Massachusetts, Hannah Baker Oregon DD Council

**Action Item:** Action Item: Developing Peer to Peer webinar on Leadership. Dynamic conversation of being a leader, how they became an executive director, etc.

Stretch Goal: peer to peer staff meeting on strategies to support I/DD in Staff / ED / Whatever. What strategies can everyone be doing to help people get in place?

### **Committee Report:**

#### **Established overview of what each Council is working on or supporting in regards to Self Advocacy**

[Max Lowe Nevada: We are working on healthcare policies, 3 different healthcare policies, one for general, mental, sexual health, Silver State Self Advocacy Conference

Allison Wymer, Grant with Self Advocates of Indiana, sending people to conferences, training people in charting a life course, doing a lot of trainings and curriculums. Also doing Council and Community interactive events, trying to engage community members through that. Ongoing plan to invest more in community engagement to bolster participation, discussion groups on other topics.

My name is Morgan Davis. I am a training coordinator for the Oklahoma Developmental Disabilities Council. The ODDC is working on updating Self Advocacy curriculum and making it more accessible to people with disabilities. Some self advocates are also preparing to present at the Oklahoma Transition Institute. We will be doing a training overview to include curriculum on healthcare , bullying Disability history, and most importantly why peer test peer advocacy is important

Jennifer Bertrand: SIS recommendations, concerns about recommendations leading to medicalization and resource allocation, just did Spooner? Leadership summit, applications for a new generation of advocates, 20 participants, overnight 2-day summit, discussed where disability advocacy needs to go, reflect and learn from the past.

Riana Hardin Cali: Regional offices of state council (LA region) offices just got done doing a leadership development (similar to policy and partners making, little different) for self advocates interested in developing their leadership skills. Monthly chat that's hosted. Statewide self-advocacy network currently putting together a webinar for the end of this month for employment resources, employment stories and journeys, as well as providing support in the self determination program.

Gary Arnold Illinois: Home of 6-7 state operated centers and many sheltered workshops, next week at the capital there's going to be a rally around NDEAM, raising awareness around a piece of legislation (Dignity in Pay, phase out subminimum wage over the course of 5 years)

Sheryl: Every two years, legislative sessions. Legislative committee talking about the bills. Writing to the senator. It's like we go forwards and backwards. Do the legislators understand what we need? Do lots of good things, lots of small grants, foster a self advocate group called (All ??? active 10 years) All part of DD Council Projects. Leadership in the DD Council, starting to look at the transportation. (ND not good transportation.)

Max Lowe: Working on Criminal Justice for I/DD in general, too dangerous to live in certain states if you have a disability because of threats and murder. Working to get targeting I/DD under hatecrime legislation [enforcement emphasis]]

### **Planning Developing Peer to Peer Leadership Webinar**

Committee Support for working on Webinar for Leadership Training – Member support Max Lowe, Riana Hardin, Dana Thompson, Allison Wymer, Sheryl Beard

### **Hotspots Identified:**

Issue with how Job Descriptions are written: Things like requirements (College degrees, etc) manage to exclude people with disabilities. Produces hesitancy with even applying.

Concern that people have to be “perfect” to get into the government appointed position.

Need to be real on what it takes to be a director, or staff - education, management skills

NACDD Public Policy Committee Report to  
NACDD Board of Directors from  
Brett Williams, Chairman, NACDD Public Policy Committee and  
Erin Prangle, NACDD Policy Director

November 2023

The Public Policy Committee (PPC) held meetings in September, October, and November. The PPC members received briefings from staff on NACDD public policy priorities and provided feedback on issues including appropriations strategies, FEMA (Federal Emergency Management Agency) policy panel at NACDD Convention, proposed federal regulations (504 anti-discrimination), membership participation in 14(c) DOL stakeholder meetings, K-waiver deadlines and advocating for HCBS (Home and Community Based Services) state plans, NACDD Direct Care Worker report and NACDD Medicaid Waivers article and more.

NACDD Convention:

Sherman Gilliums, Director, Office of Disability Integration & Coordination, Federal Emergency Management Agency, presented a plenary discussion alongside NACDD members Sue Kabot (FL), Scott Daigle, (TX), Darryle Powell (AL), Lauren Gerken (TX). They discussed potential points of inequity that can extend the disaster lifecycle for people with disabilities and shared examples of best practices from DD Councils on how we are working to shorten the emergency cycle for people with I/DD.

Appropriations: Staff successfully advocated for a “clean” continuing resolution (CR), continued to communicate with Hill champions for the need for increases in FY2024 appropriations for DD Councils, and began work on FY2025 appropriations.

- **Good Report Language for FY2024.** Staff obtained level-funding for councils in the Senate and House Appropriations reports despite considerable pressure for cuts. This is a good sign, but not a guarantee of level funding in the final bill which must be worked out next year. We continue our position that we need additional funding, but that is unlikely for 2024.
- **Hill Visits on CR and FY2024 Appropriations.** NACDD staff participated in several Hill meetings with the Clean Budget Coalition and sent several coalitions letters to the Hill calling for a “clean” CR with no further cuts or extreme policy riders. The current “clean” CR through early February for our appropriations bill (Labor, Education and Health and Human Services).
- **FY2025 Work Begins.** Staff began work on the FY2025 Appropriations bill and will be reaching out to councils for updates to their information and support starting in December. Hill meetings will be held in February with select congressional offices.



Federal and State Regulatory Work: NACDD membership provided robust comments and testimony for proposed regulations and policy changes at Centers for Medicare and Medicaid Services (CMS), Department of Labor (DOL), and state Medicaid agencies.

- **HCBS State Waivers.** Committee members and NACDD staff provided training and technical assistance to NACDD members who advocated for maintaining HCBS waivers after the end of COVID K waivers on November 11. DD Councils played a role in systems change by successfully advocating for these waiver services in dozens of states!
- **504 Anti-Discrimination Regulations.** NACDD worked with Autism Society to advocate for HHS (Health and Human Services) 504 anti-discrimination regulation updates. We created an advocacy toolkit to help councils and advocates submit their own comments, held a training webinar with self-advocates, shared information at regular “All NACDD” calls, held “Office Hours” for advocates submitting comments, signed on to coalition comments, and submitted our own comments.
- **NACDD and Council Testimony on Ending 14(c).** DOL invited NACDD to a listening session for organizations that support ending the practice of subminimum wage were to speak with DOL leadership on Friday, October 20th. Erin Prangle (NACDD), David Pinno (WI), and Donna Spears (NC) gave testimony. NACDD provided information and talking points to advocates and councils who wished to participate in additional sessions. For example, Jon Taylor (AR) testified, sent comments to ODEP (Office of Disability Employment Policy), and drafted an op-ed around 14 (c).
- **CMS Site Visits.** CMS continued site visits to include DD Councils to oversee HCBS waiver services in the states including WA. Brandi Monts (WA) participated in the agency’s listening session.
- **Adult Changing Tables.** Kate Barrow, State Policy Co-Chair, is taking the lead on a new workgroup on adult-sized changing tables. Several councils are part of the group including MI, HI, UT, NH, TN, IN. Members are encouraged to contact Kate to join the group.

#### NACDD Reports/Updates/Presentations

- **NACDD Report on Councils' Activities to Address the Direct Care Workforce Crisis.** In September, staff released a report showing how councils are actively engaged in finding solutions to the direct care workforce (DCW) crisis. The survey received 39 responses out of 56 DD Councils, with a 68% response rate. The survey was shared with ACL (Administration for Community Living), coalition partners and the NACDD network.
- **NACDD and Councils featured in National Leadership Consortium Bulletin: Realizing HCBS in Everyday Leadership.** In October, NACDD published an article highlighting state council leadership in improving access to HCBS services including examples from MN, MD, WV, PA, NE, NC, FL, GA, WI. See Prangle, E. “The Role of State Councils on Developmental Disabilities in Improving Access to HCBS,” National Leadership

Consortium Bulletin (October 2023) at

[https://www.natleadership.org/bulletin/NLCDD\\_Bulletin\\_Edition\\_8\\_Oct\\_2023.pdf](https://www.natleadership.org/bulletin/NLCDD_Bulletin_Edition_8_Oct_2023.pdf)

- **NACDD Staff at Council Meetings.** Erin Prangley continues to provide federal policy updates to councils. During this quarter, she presented at AL, KS, NV, VA.
- **NACDD Staff at OH “Fly-In” Day.** In September, Erin Prangley gave a presentation on “How to Advocate” and federal policy update to a delegation from OH which included council members and others. NACDD interns assisted the OH delegation with their federal advocacy day on the Hill.
- **NACDD was represented by Robin Troutman at the 60<sup>th</sup> Anniversary of the Rehabilitation Act with President Biden.** Robin also released a statement on the anniversary.
- **NACDD Staff and Members at AUCD (Association of University Centers on Disabilities) Conference.** Robin Troutman presented the Aging and Disability grant at the conference. Wesley Witherspoon and Maria Marquez (California State Council on Developmental Disabilities) also presented about their life experiences that have led them to leadership positions and the importance of people with disabilities being in community and state leadership.

Upcoming Policy Events. In the next few months, the NACDD Policy Committee will be working on a few events.

- Developmental Disabilities Awareness Month (March 2024).
- Disability Policy Seminar (April 8-10, 2024) See <https://disabilitypolicyseminar.org/>  
NACDD agreed to lead the following sessions:
  - How Congress and the Budget Work (Break-out)
  - Civic Engagement & Voting
  - Preparing for Hill visits
  - Disability Funding

**The next Public Policy Meeting is December 7, 2pm, via Zoom at**  
**<https://us02web.zoom.us/j/82156490017?pwd=amdsUTliajUrVllwbit1WHR4VmxpUT09>.**

All NACDD representatives (council members, self-advocates, and staff) are welcome to attend.

For additional policy updates remember to sign up for the Policy Listserv at  
<https://bit.ly/3Ux1PEN>.

# Communications Update: Nov 2023



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## Followers by Platform

Platform	2020	2021	2022	2023
Facebook	3,348	4,925	6,178	7,463
Twitter	5,639	6,482	7,395	7,508
YouTube	13	26	69	102
LinkedIn	141	206	472	802
Instagram	-	-	80	311

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## Twitter Metrics

Month	Tweets		Engagement		Impressions		New Followers	
	2022	2023	2022	2023	2022	2023	2022	2023
January	73	25	163	42	11.4k	2.5k	32	+13
February	53	35	390	85	14.9k	4.9k	43	+7
March	128	173	1,550	443	50k	22k	131	+70
April	52	46	310	175	7.7k	8.9k	63	+21
May	53	41	528	89	27k	23.3k	84	-7
June	67	39	217	120	13.7k	7.7k	55	+3
July	65	26	273	85	5k	4.2k	57	+2
August	52	27	201	49	16.4k	9.1k	61	-3
September	68	26	152	53	9.3k	4.1k	18	-6
October	61	39	219	101	9.9k	4.8k	5	+10
November	63	44	92	202	4.1k	11.3k	-33	+8
December	35	--	56	--	2.7k	--	-2	--

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## Facebook Metrics

Month	Posts	Engagement	Reach	Impressions
	2023			
January	24	149	3158	3385
February	37	391	9058	9403
March	173	2329	46295	48517
April	48	3062	84959	90779
May	43	746	17269	19382
June	39	19667	505768	526979
July	33	1316	23806	31481
August	27	354	9772	12956
September	28	1247	24821	32307
October	42	1007	23253	26975
November	49	731	17691	19167
December	--	--	--	--

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## 2024 Communications Updates & Goals

- Updated NACDD Strategic Communications Plan
  - NACDD is developing an updated communications plan focusing on identifying and analyzing current and prospective audiences in the diverse social media landscape. This plan will also address social media challenges and observations on which NACDD needs to change.
- NACDD Newsletter
  - NACDD has begun deploying a bi-weekly newsletter focusing on current success stories, policy updates, save the dates and resources. This newsletter will go out on weeks that NACDD does not host its all-call and hopes to use it as a way to connect with the NACDD Community.

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## Newsletter Metrics for November

- |  |   |
|--|---|
| <ul style="list-style-type: none"> <li>• November 9           <ul style="list-style-type: none"> <li>• Opened: 405               <ul style="list-style-type: none"> <li>• Total Opens: 694</li> </ul> </li> <li>• Clicked: 25               <ul style="list-style-type: none"> <li>• Total Clicks: 81</li> </ul> </li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li>• November 28           <ul style="list-style-type: none"> <li>• Opened: 382               <ul style="list-style-type: none"> <li>• Total Opens: 469</li> </ul> </li> <li>• Clicked: 21               <ul style="list-style-type: none"> <li>• Total Clicks: 76</li> </ul> </li> </ul> </li> </ul> |
|--|---|
- Definition:
    - Total Clicks: Total times a link has been clicked
    - Total Opens: Total times an email was opened

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## Next Projects

- DDAM Themes
  - Belonging is Community
  - A World of Opportunities
- Develop Updated Strategic Communications Plan and Content Calendar
- Continue expanding use of newsletter