

Board of Directors Meeting Minutes

Date: June 30, 2019 Time: 2:15 PM EST

Location: Virtual Meeting (audio recording)

- I. Call to Order
- II. Attendance (T.K., E.W., B.M., D.D., M.S.)
- III. Adopt Minutes April 17, 2019 (B.M. moves, D.D. seconds, (4-0-1) T.K. abstained
- IV. Announcements A.L.'s birthday, E.W. gets MBI
- V. President's Report (E.W.)
 - A. Echo Dot Donation (10 Dots from ImproveAbility an AT eval company Raffle of people who don't have Dots U.K. compatibility question)
 - B. Legacy Planning (More robust plan needed to keep org going E.W. is researching)
 - C. 2019 Board Retreat in NYC (Discussion and it was determined that this plan is not doable/realistic because of timeline, logistics, and finances)
- VI. Vice President/Treasurer's Report (T.K.S.)
 - A. Current Financial Position Update Financial statements for 1st quarter and as of 6/30/19 (day the second quarter ends), \$1085.84 in PP, \$28,147.75 - \$29,233.59 combined
 - B. Accountant Nicholas Reid Update On budget We aren't getting maximum functionality out of the budgeting software, especially the mailing lists on previous donors
 - C. 2018 Tax Filing Status 5/15 Deadline Not addressed
 - D. 2019 Budget We're on budget
 - E. Incorporation Research Update Not addressed
- VII. Secretary's Report (K.S.) Written Report Provided

K.S. will post the announcement for Board vacancies on July 1 to the website, Living with M.D. and through our social media channels (Facebook and Twitter) with a 90-day deadline.

- VIII. Chapter Updates (M.S.) Little updates, planning on checking in on all the chapters, and catching up with communication reach outs. E.W. recommends that we consider putting together a welcome package for chapter organizers.
 - A. Chattanooga, TN In contact with Jean-Marie and will find out their next meeting date
 - B. Atlanta, GA Not discussed
 - C. Houston, TX Coordinator reached out to her for advice on planning meetings and pulling people together in a large city. Maria is suggesting Doodle app
 - D. Austin, TX E.W. reports that Austin chapter has low participation.

IX. Current Projects

- A. Social Media Updates (B.M.) Things are good, increased followers and likes on all IG, FB, and TW we have hit over 2000 likes on FB. IndependTips are working, enjoyed, and getting lots of feedback.
- B. Website Updates (E.W.) An eventual redesign is in the future w/ new host. Wix states that our cost is going up this year from \$120 to \$156. D.D. said that this is a lot. B.M. wants to look at alternatives. T.K. asked when we need to renew. E.W. tells him 8/1/19. T.K. states this should be our last year with Wix and we should pay the increase for this year only. D.D. said he will take the lead on the website w/ B.M.'s help.
- C. ALEF Committee (K.S.) Written Report Provided E.W. summarized and clarified Knack launch for the end of August w/ D.D.. D.D. says Knack will have grant portal and donations directly into PayPal. It would keep track of our donors, members, and member directory is the only thing that is left to figure out.
 - As of 6/30/19, ALEF Grants have been spent out in the amount of \$8,472. Assistive Tech remains our most popular grant.
- D. Fundraising Committee (T.K.S.)
 - 5th Birthday Fundraiser Review E.W. states that we haven't made money from our BD fundraiser, but we are making money off of people hosting BD fundraisers. If we can get 16 people to host BD fundraisers, we'd have our budget. D.D. said this isn't sustainable for the long term.
 - 2. Committee Membership Outreach T.K. says he's having a hard time getting interest from LWMD in helping with the committee.
 - 3. IndependTips Calendar Fundraiser (E.W.)
- E. Toolkit Committee (E.W.) No updates not active
- F. Virtual University (E.W.) On hold due to TX grant
- G. Smith's Showcase (B.M.) Hannah Soyer will be our next S.S. interviewee. E.W. reminded B.M. of Steve Way Q & A. That will be next and then Hannah.

X. Old Business

- A. NMD United Unites Texas VILS Grant (E.W.) Going well. Huge report due in June. TX SILC is very hands-off with not a lot of feedback. It's good and bad. 121 who are participating. 7th workgroup w/ Alana on SSI/SSDI benefits. Budget is on target. Captioning request caused some panic, was resolved.
- B. Stop EVV Update (K.S.) *Written Report Provided* E.W. encouraged everyone to read the report.

Rep. DeGette has drafted our bill to prohibit GPS and biometrics in EVV. We are still asking folks to contact members of the House Energy and Commerce Committee to cosponsor. We do not yet have a bill number because we are in queue to introduce the bill to the Committee.

Stop EVV began working with Justice In Aging (California branch) to research the legal landscape in Ohio. Their law intern, [REDACTED], began last month with a goal to produce a legal memo outlining potential legal avenues to pursue.

NCIL has produced a short (10 Question) survey to better understand how EVV has already impacted individuals. It will be released in July. The survey data will be paired with the JIA legal memo as we hit hard at the end of this year with identifying attorneys to fight EVV in court.

CMS held its second Quarterly Collaborative Webinar event this past week. The topic of this session was Self-Directed Services. CMS gave a wonderful presentation that outlined nearly all concerns NCIL and Stop EVV brought to them during our meeting with CMS staff earlier this year. (They did not discuss workforce shortage impact.) The webinar had a 9 member panel to discuss topics in depth. The panel was made up of subject matter experts on disability and self direction, including staff from ANCOR, Applied Self Direction, Justice In Aging, and others. CMS staff told states that "by now everyone should be familiar with Nothing About Us Without Us" and directed stated to ensure that consumers on a self directed program are at the table for design, implementation and training of EVV systems "as an equal". We consider this to be a big win!

Stop EVV NY Coalition held an organizational meeting via NMDU Zoom in mid-May to prep for NY stakeholder engagement meetings. We have had representatives at all 5 NY meetings. We developed a one-pager handout of concerns and demands that can be modified for any state. Stop EVV is expanding to offer training webinars to any state Stop EVV coalition to assist in their advocacy work. Stop EVV has begun a social media photo campaign that will run this summer. We are collecting photos

of individuals holding varying signs about the impact of EVV. To participate, please send an email to HelpStopEVV@gmail.com.

- C. Transition to Adulthood (E.W.) No updates not active.
- D. Top Contributor Award (J.T.) No updates
- E. NMD U Connect (D.D.) Addressed above.
- F. Quarterly e-News (A.L.) Haven't heard much.
- G. Social Media Expansion (E.W.) Talking to Tiltify a fundraiser who raises through Twitch.
- H. State Chapters Proposal (E.W.) Thinking of us doing NMD United Unites Texas state-by-state and branching out.
- SXSW Proposal Update (M.S) No news on that other than receiving an email about the app for SXSW music. No word on anything else and very TBA. E.W. states this would be a good opportunity for us to get together for the Board.
- J. Socialization Events (E.W.) formerly: Gimps on Thrones T.K. thought it was good and look forward to our get togethers and to have an excuse to buy a, "high quality" crown. He also thinks it's a good opportunity to give social outlets is important. E.W. thought it was cool to get to know people we don't usually hang with.
 - 1. Steve Way Q&A Review May 9th Event B.M. thought it was well attended and went really well.
 - 2. Future Chat Topics Discussion E.W. recommends a random bullshit gathering now and then.
- K. Employee E-Mail Policy (K.S.) *Written Report Provided* We'll review it and address it at the next board meeting.
- L. By-Law Revision Proposal re: E.D. Voting Rights Research (E.W.) E.W. is trying to think of ways we can compensate board members who are going above and beyond volunteerism for the org. Wanting to look at revising the bylaws to promise to never to use individual donations for our compensation, but money that comes in from other sources can pay us for our labor. Is this feasible? Asked for a discussion. B.M. understands and said that it makes sense, but doesn't know how that would look on paper or what the logistics would be because she's never been on a board that gets paid. D.D. asks if we'd be employees and E.W. said this is more like a contract for work performed/stipend. E.W. has heard of NFP's splitting into a for-profit/not-for-profit hybrid. T.K.S. wants to table it and end the meeting.
- M. Equipment Depreciation Policy (T.K.S.) No updates

XI. New Business

- A. Brand Identity Guidelines (J.T.) No updates
- B. Facebook Grant (T.K.S.) Sent email to see what's going on
- C. NMD United Course Work Development (E.W.) D.D. and TK.S. like the idea and E.W. thinks it has a lot of potential.

- D. By-Law Revision Proposal re: Paid Directors (E.W.) Discussed above.
- E. Marketing Strategy Discussion (E.W.) 3 sample marketing ads for FB to see which marketing tag lines gets the most attention. B.M. and M.S. thinks it's needed. E.W. was going to work with J.T. on that. E.W. asks how much we should spend on marketing?
- F. Technology Committee (E.W) Discussed and D.D. has volunteered to sit on the committee as a board member. B.M. has offered to help. D.D. worries that too many cooks can't be in the kitchen. E.W. said it could be small. D.D. doesn't know who could be on it and what would go. E.W. gives some ideas for the committee who could tackle things like our website, researching captioning services, pricing hosting and application. Motion to establish the tech committee: M.S., Seconds: B.M. unanimous

XII. Adjournment - T.K. moves to end the meeting, D.D. seconds, unanimous

Minutes Submitted by: Emily Wolinsky, *President*

Approved by Board: November 13, 2019