

**Quarterly Meeting
January 27, 2020
Teleconference**

ATTENDANCE

Members

Neil Romano, Chairman
Billy Altom
James Brett
Rabia Belt
Benro Ogunyipe
Clyde Terry
Andres Gallegos
Wendy Harbour

Staff

Lisa Grubb, Executive Director
Joan Durocher
Keith Woods
Netterie Lewis
Nick Sabula
Amy Nicholas
Ana Torres-Davis
Amged Soliman
Stacey Brown

NCD Contractor

Anthony Simpson

Guests

Mary Lamielle, Executive Director, National Center for Environmental Health Strategies, Inc., Roger Severino, Director of the Office of Civil Rights, U.S. Department of Health & Human Services

Welcome and Introductions

Chairman Neil Romano called the meeting to order at 10:00 AM (ET) and welcomed Council members, staff and the public.

Acceptance of the Agenda

MOTION: Mr. Clyde Terry moved to accept the agenda.

SECONDED: Ms. Rabia Belt

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye

James Brett: Aye

Andres Gallegos: Aye

Benro Ogunyipe: Aye

Clyde Terry: Aye

Rabia Belt: Aye

Wendy Harbour: Aye

Call for Vote of August Council Meeting

MOTION: Mr. Billy Altom moved to accept the August Council meeting minutes.

SECONDED: Ms. Rabia Belt

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Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye

James Brett: Aye

Andres Gallegos: Aye

Benro Ogunyipe: Aye

Clyde Terry: Aye

Rabia Belt: Aye

Wendy Harbour: Aye

Chairman's Report

Mr. Romano thanked fellow council member Benro Ogunyipe for serving as vice chair, Rabia Belt for chairing the governance committee and Billy Altom for serving as finance chair and now will be serving as the chair for the governance committee.

Mr. Romano stated that he has asked council members to rotate chairing various positions to have a better understanding of the overall functions of the Council. They are as follows:

Jim Brett – Vice Chair

Billy Altom –Governance Representative

Wendy Harbour – Financial Representative

Mr. Romano added that he's decided to create an ad hoc committee which will be co-chaired by Rabia Belt and Andres Gallegos will ensure that the Council continue to have successes we have had with a better representation of people with minorities of our community.

Mr. Romano reported the following:

- Bioethics report is a success with positive feedback from HHS, Capitol Hill and people outside of government;
- ADA 30th Anniversary celebration scheduled for July 26th at the Kennedy Center;
- Visit to Spain to organization called Once the premier disability organization in Europe;
- The Council has engaged the Henry Shrinne Foundation about educating American doctors and dentists about their responsibilities under the ADA;
- The medical community has agreed to work with NCD through an MOU;
- NCD will review materials from the medical community and goal is for NCD to communicate to the medical professionals in the US and Canada;
- Progress within the dental community regarding care for people with intellectual disabilities;
- Finalized tour on 14c

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Executive Director's Report

Ms. Grubb reported the following:

- Recognized staff for their hard work;
- Ms. Durocher and the policy team for the work on the bioethics report;
- Progress report with focus on employment;
- Finalization of the Dearborn Medical Equipment Project;
- Audit completion with no deficiencies;
- Chair to appoint subgroups for ADA event (programming and outreach)

Finance Report

Mr. Keith Woods reported that the Council's current budget stands at \$3,350,000 which includes \$100,000 increase currently though December 31. Mr. Woods stated the following:

- Update of funds raised for ADA event;
- \$218,000 budgeted for research projects;
- \$100,000 for cybersecurity

MOTION: Wendy Harbour moved to accept the Finance Committee Report.

SECONDED: Rabia Belt

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye

James Brett: Aye

Andres Gallego: Aye

Benro Ogunyipe: Aye

Clyde Terry: Aye

Rabia Belt: Aye

Wendy Harbour: Aye

MOTION: Jim Brett called for a second vote to accept the status of funds ending December 31, 2019.

SECONDED: Rabia Belt

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye

James Brett: Aye

Andres Gallegos: Aye

Benro Ogunyipe: Aye

Clyde Terry: Aye

Rabia Belt: Aye

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Wendy Harbour: Aye

Policy Report

Ms. Durocher and Ms. Grubb presented proposed projects to the Council for a vote.

- Medical discrimination against children with disabilities;
- Employment;
- Technology;
- state accessible medical equipment project;
- Acquiring complex rehabilitation technology equipment;
- Designation of persons with disabilities as medically under-served health disparity population;
- section 504 compliance;
- selective placement program coordinators in the federal government
- access to opioids for people with disabilities;
- strategies to support employment of college graduates with disabilities;
- update to housing report;
- bioethics report
- treatment of severe mental illness in children
- treatment of immigrant children with disabilities with chronic health needs
- that there has been one approved vote electronically since the last Council meeting on the bioethics report with four approval votes and no votes from five Council members and one abstained.

Governance Report

Mr. Altom asked that the Council approve the minutes that was included in the packets.

MOTION: Billy Altom asked for a motion to accept the minutes from the executive committee meetings.

SECONDED: Rabia Belt

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye

James Brett: Aye

Andres Gallego: Aye

Benro Ogunyipe: Aye

Clyde Terry: Aye

Rabia Belt: Aye

Wendy Harbour: Aye

Legislative Report

Ms. Anne Sommers reported the following:

- Expected new hire mid-February;

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- Jim Brett's placement of 2 op-eds since NCD's last meeting;
- International disability rights and accessible voting recommendations;
- Three briefings on bioethics;
- Series of outreach activities since August Council meeting;
- Congressional briefing on assistive suicide;
- Convened an interagency meeting on ABLE;
- Stakeholders meeting at the request of two hill offices regarding single use plastic bans

Mary Lamielle, Executive Director, National Center for Environmental Health Strategies, Inc.

Ms. Lamielle spoke on various issues that affect those with environmental sensitivities they were as follows:

- Spoke on the natural of one's disability;
- Importance of healthy indoor environmental quality;
- Review of federal recognition of chemical intolerances and recommendations for actions;
- Electrical hypersensitivity reacting to electromagnetic fields from devices and frequencies (i.e. electrical appliances, cordless phones, cell phones, Smart Phones, meters);
- Chemical and fragrances intolerances;

Ms. Lamielle supports someone with expertise on environmental illness and intolerance to the Council and for it to be addressed in its progress report in consultation with members of the community and propose, support legislative initiative in consultation with members of our community.

Roger Severino, Director of the Office for Civil Rights (OCR), U.S. Department of Health and Human Services

Mr. Severino stated this the department is alignment with the initiatives of the Council. He stated that his office has gotten involved with Oregon who has agreed to change their policies instruments such as IQ test which were found discriminatory against people with disabilities telling them they are not worthy to be parents because they are disabled.

Mr. Severino stated that the Council's reports is the data and arguments which has empowered the OCR to do its work to help people with disabilities. He stated that OCR will be conducting outreach and will work with the Council to get the word out about the Council's reports and what OCR can do.

MOTION: Billy Altom asked for a motion to adjourn the meeting.

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SECONDED: Benro Ogunyipe

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye

James Brett: Aye

Andres Gallegos: Aye

Benro Ogunyipe: Aye

Clyde Terry: Aye

Rabia Belt: Aye

Wendy Harbour: Aye

ADJOURNMENT

The meeting adjourned at 12:00 p.m.

Date Approved by the Council: May 18, 2020



Signature

Neil Romano, Chairman

Printed Name