

**National Council on Disability
Council Meeting
March 11, 2021
1:00 PM- 4:00 PM (ET)
Virtual / Zoom meeting**

ATTENDANCE

Members

Andres Gallegos, Chairman
James Brett
David D’Arcangelo
Munr Kazmir, M.D.
Rick Rader, MD, FAAIDD, DL (hon)
Daniel Schreck
Andres Gallegos
Mary Vought

Staff

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

NCD Contractors

Anthony Simpson
Kadedra Walters

Guests

Javier Robles, disability advocate; Sylvia Yee, Disability Rights Education Defense Fund (DREDF)

A. Welcome and Call to Order

Chairman Andres Gallegos called the meeting to order at 1:00 PM (ET) and welcomed Council members, staff, and the public.

B. Roll Call

Chairman Gallegos conducted a roll call of Council members, staff and contractors and asked that everyone give a brief bio.

C. Acceptance of the Agenda

MOTION: Mr. Jim Brett moved to accept the agenda of the March quarterly meeting.

SECONDED: Dr. Munz Kazmir

Roll Call Vote:

Andres Gallegos, Chairman

James Brett: Aye

David D’Arcangelo: Aye

Dr. Munz Kazmir: Aye

Dr, Rick Rader: Aye

Neil Romano: Aye

Daniel Schreck: Aye

Mary Vought: Aye

D. Acceptance of November 2020 Council Meeting Minutes

MOTION: Dr. Rader moved to accept the draft minutes of the November quarterly minutes.

SECONDED: Dr. Munz Kazmir

Roll Call Vote:

Andres Gallegos, Chairman

James Brett: Aye

David D’Arcangelo: Aye

Dr. Munz Kazmir: Aye

Dr, Rick Rader: Aye

Neil Romano: Aye

Daniel Schreck: Aye

Mary Vought: Aye

E. Chairman’s Report

Chairman Gallegos stated that he is very pleased to serve the agency’s Chair and looks forward to working closely to the NCD staff teams. He thanked Neil Romano for his leadership and his guidance to the Council over the past several years during his tenure as chairman. Under Mr. Romano’s leadership the Council developed and unveiled a series of policy recommendations under its bioethics series covering organ transplant discrimination, the dangers of assisted suicide laws, genetic testing, qualified adjusted life years, devaluation of persons with disabilities, medical futility and disability bias as well as calling for greater employment of persons with disabilities in the labor force and in critical examination of the Ability One program and Section 14C of the Fair Labor Standards Act which provides for payment of subminimum wages to certain persons with disabilities.

Chairman Gallegos commended Lis Grubb for serving as executive director during Mr. Romano's tenure as chairman as well as serving as accounting, finance and operations lead.

Chairman Gallegos stated that there has been no official travel do the pandemic, thus having our council meetings to be held via telephonically.

Chairman Gallegos listed the focus areas that are underway. They are as follows:

- Chairman's published vision and priority statement for the Council;
- focus on health care as in relates to an array of issues, especially to that of COVID;
- addressing the implicit and explicit bias against persons with disabilities in health care;
- advocating for dedicated funding for home and community-based services;
- urging the adoption of the Access Board's voluntary standards for accessible medical diagnostic equipment;
- strengthening the federal nondiscrimination mandates in our legal and civil rights among other important health care related issues;
- continue to advance employment initiatives
- address disparities of persons with disabilities who reside in our territories;
- working closely with our federal partners and legislators on commitments expressed in the President's disability plan;
- the council will continue to be a trusted and valued resource on all topics in relation to people with disabilities;
- the Council will respond to the immediate needs of its federal partners
- develop a strategic plan

Chairman Gallegos briefly shared information regarding the FY '22 budget and said that the President's budget process has been delayed this year. The Council's pass-back is OMB's formal response to the agency's request of an additional \$800,000 up from last year's budget. The congressional appropriations process is underway and hearings are to commence in May.

Chairman Gallegos stated that the Council will have its bi-annual audit beginning in May.

Chairman Gallegos stated that there were some remaining items opened since the November 2020 Council meeting. They were as follows:

- inventory of the federal disability employment programs;
- mandating changes in medical education to ensure future clinicians have qualified skills, experience, and motivation to adequately treat patients with intellectual and developmental disabilities;
- accessible access to medical equipment pertaining to drugs;
- recognizing the role of direct support professionals in achieving meaningful employment for people with intellectual disabilities;

- conduct a thorough national survey of crisis standards of care and triage in public and private health care facilities;
- improving health and well-being for persons with disabilities through accessible fitness and recreational facilities.

Chairman Gallegos stated that these projects will be voted on at the July Council meeting.

F. Executive Director's Report

Ms. McIntosh stated that by this meeting being the first virtual one, she referred council members and staff to their meeting materials for updates which included the latest policy, administrative and media written reports.

Ms. McIntosh stated that public comments were received in advance via email submission therefore a set aside time has not been included as part of the meeting.

Ms. McIntosh's report included the following highlights. They were as follows:

- Chairman Gallegos, the staff and she will continue to brainstorm to solicit and incorporate the incorporate the invaluable insights of the community in the work of the Council;
- The Council has conducted several phone and virtual meetings with the new disability advisor to the Domestic Policy Council;
- NCD's has communicated its areas of focus and priority as well as the interest and willingness to lay a convener role as we do to bring diverse perspectives together to advance our policy discussions;
- NCD may serve a role in the near future in the interest of the administration in pursuing legislation that would address many of the long-standing concerns of diverse constituencies;
- NCD has offered to assist in bringing diverse constituencies together and the Council and staff will be apprised if taken up on an offer;
- With respect to the AbilityOne Report, the legislative affairs and outreach team has conducted briefings at the request of the Senate and House Appropriations Committees;
- Correspondence to the National Conference on State Legislatures;
- Chairman's correspondence to HHS, Office of Civil Rights, National Governor's and to President Biden and leadership in Congress
- Congress passed the American Rescue Plan including several requests made by the community and the Council;
- The LAO team looks forward to bringing a detailed analysis of the Medicaid and community-based services bill and its important pieces to the disability community;
- The AFO team are working behind the scenes to make sure that office operations are running smoothly as well as audit preparation and digitizing the NCD documents in compliance with federal mandates.

G. Governance Report

Dr. Rader reported on three items. They were as follows:

- Accessible diagnostic medical equipment report was voted and approved;
- Five-year strategic planning process;
- Review of the bylaws

MOTION: Dr. Kazmir moved to accept the Governance Report.

SECONDED: Ms. Mary Vought

Roll Call Vote:

Andres Gallegos, Chairman

James Brett: Aye

David D’Arcangelo: Aye

Dr. Munz Kazmir: Aye

Dr, Rick Rader: Aye

Neil Romano: Aye

Daniel Schreck: Aye

Mary Vought: Aye

H. Finance Report

Mr. Schreck stated that he is working with the AFO team to update the format of the status of funds report. We have developed a more efficient and transparent report to have a better tool to make strategic decisions to serve those we are commissioned to serve.

Mr. Schreck stated the finance committee continues to operate at level funding for FY’20 of \$3.35 million up by \$100,000.

MOTION: Dr. Kazmir moved to accept the Finance Committee Report.

SECONDED: Ms. Mary Vought

Roll Call Vote:

Andres Gallegos, Chairman

James Brett: Aye

David D’Arcangelo: Aye

Dr. Munz Kazmir: Aye

Dr, Rick Rader: Aye

Neil Romano: Aye

Daniel Schreck: Aye

Mary Vought: Aye

Mr. Schreck stated there are unobligated for FY ’21 to be \$434,475.00 which will be submitted to the Council for approval. He specified the areas of interests as follows:

\$25,000 for printing with GPO, IT and advisory services;

\$120,000 for infrastructure, the website, PIV cards;

\$155,144 for research contracts;

\$75,000 backfill of LAO team position;
\$25,000 for computers and refreshing of infrastructure;
\$33,000 for anti-deficiency bucket;\$30,000 crisis standards of care;
\$30,000 for quality and accessible drug project;
\$20,000 for medical curriculum;\$5,000 for external reviews of all projects;
\$20,000 for the Puerto Rico project

MOTION: Mr. Schreck moved to accept the proposed new obligations as presented and opened the floor to discussion on each item.

SECONDED: Dr. Rick Rader

Roll Call Vote:

Andres Gallegos, Chairman

James Brett: Aye

David D’Arcangelo: Aye

Dr. Munz Kazmir: Aye

Dr, Rick Rader: Aye

Neil Romano: Aye

Daniel Schreck: Aye

Mary Vought: Abstained to have more time to go through the numbers.

Mr. Schreck stated that the Council is request an increase of \$800,00 for FY '22. Ms. Lisa Grubb spoke on the reason for the increase.

Ms. Grubb reported that the Council has received its FY '22 budget and awaiting its pass-back. She stated that the FY'22 the Council is working hard to make certain that its deliverables are paid in that year because there cannot be a carryover of funds.

Mr. Nicholas Sabula stated that he agency needs to update its website and that he is reviewing vendors in this endeavor. He added that the Council has looked at different platforms and have worked with GSA which run a platform called *Federalist*. The group behind *Federalist* have assured that the Council is using the most accessible streamlined, and secure manner to deliver correct information to the public.

Chairman Gallegos introduced Javier Robles, disability advocate from New Jersey. Mr. Robles stated that he has been an advocate since his injury in 1983. He spoke about his advocacy work in relationship to CVID and people with disabilities in the state of New Jersey.

Mr. Robles started a Facebook to help people with disabilities during this pandemic. We have asked the state ombudsman, state leaders and other individuals to come together on this issue.

Mr. Robles stated that the group has proposed the following regarding COVID:

- People with disabilities are able to use their benefit cards for online food ordering;

- Proposed that the Department of Health form a committee with the Department of Health to address the disability issues seen during the start of the pandemic which includes ventilator shortages, hospitals denying of services to individuals with disabilities;
- Proposed a commission on people with disabilities at the state level to work on these issues;
- That the office of the Ombudsman for people with developmental and intellectual disabilities be changed to an office that will serve everyone;
- Worked on issues that effect those that are deaf by requesting a bill for clear mask usage;
- Requested more funding for the Office of Emergency Management in New Jersey

I. Policy Project Updates, remainder FY 21

Ms. Durocher gave an update on the ongoing projects that will be completed during the remainder of the fiscal year. They were as follows:

- Accessible Medical Diagnostic Report (AMDE), developed through a cooperative agreement with the University of Illinois, Chicago and describes the long standing health disparities experienced by people with disabilities compared with nondisabled peers and argues that the federal standards on accessible medical equipment contributes to these disparities.
- IDD Medicaid Mental Reimbursement Project-a project through a cooperative agreement with the Banak Street Graduate School, New York. It will examine the existing Medicaid reimbursement rate and how it deters oral health care that is more cost effective than increasing the Medicaid reimbursement rate and could potentially be adopted by the federal government.
- Puerto Rico Report which will examine disparate treatment of US citizens with disabilities in Puerto Rico. The report will look at SSI, SSDI, SNAP, Medicaid and a transportation. It will compare and contrast eligibility requirements coverage, benefits and monetary and human resource funding for programs and beneficiaries residing on the mainland and those in Puerto Rico.
- Progress Report and the focus will be on the impact of COVID-19and its effects on people with disabilities. Ms. Sylvia Yee, DREDF have been actively involved in the pandemic work in a variety of area, including vaccines.

Ms. Yee along with the Bazelon Center for Mental Health Law are working on this together. She indicated that the first task was to commence stakeholder meetings in November and it will include medical providers, bioethicists, employment lawyers, teachers, communication experts, union leaders, direct care employees and other community-based service providers, mental health experts and people with disabilities.

Ms. Yee stated that the report will deal with various topics such as health care discrimination, congregate living facilities where 40% of deaths have occurred in nursing facilities. She added that they will be looking at the direct care workforce, education, employment, mental health and suicide policy and effective communication. The

framing draft of the report will be done by the end of April with the final draft being ready by the end of June or July.

J. Follow-up Projects on Former Policy Reports

Ms. Durocher stated the projects as being the following. They are:

- Medically underserved population designation and disability cultural competency curriculum;
- The use of quality adjusted life years as used in barriers to health care access;
- Rationing and denying health care to people with disabilities;
- Medicaid portability;
- Fostering growth for people with disabilities;
- Pursuing better data in federal guidance regarding sexual assault of colored students with disabilities

K. Schedule of 2021 Council meetings, Unfinished Business

Ms. McIntosh submitted the remaining quarterly meeting schedule for the year. May 13, July 22nd (via zoom) October 7th (hopefully in person).

L. Adjournment

MOTION: Dr. Kazmir moved to adjourn the meeting.

SECONDED: Dr.Rader

Roll Call Vote:

Andres Gallegos, Chairman

James Brett: Aye

David D’Arcangelo: Aye

Dr. Munz Kazmir: Aye

Dr, Rick Rader: Aye

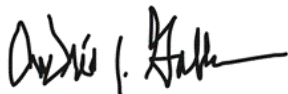
Neil Romano: Aye

Daniel Schreck: Aye

Mary Vought: Aye

The meeting adjourned at 3:48 p.m.

Date Approved by the Council:



Signature

Andrés J. Gallegos, Chairman

Printed Name

