

**National Council on Disability
Council Meeting
October 7, 2021
1:00 PM- 4:00 PM (ET)**

ATTENDANCE

Members

Andrés Gallegos, Chairman
James Brett, Vice-Chairman
David D’Arcangelo
Munr Kazmir, M.D
Daniel Schreck
Mary Vought

Staff

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

NCD Contractors

Anthony Simpson
Kadedra Walters
Cindy Smith

Guests

Dr. Heather Koball, Co-Director, National Center for Children in Poverty, Bank Street Graduate School of Education, New York City; Suma Setty, Senior Research Associate and Project Director, National Center for Children in Poverty; Misty Deon, CEO, Roads to Freedom Center; Chelsea Fosse, dentist and health policy analyst; Misty Dion, CEO of Roads to Freedom Center for Independent Living of North Central Pennsylvania; Ebony Payne; female quadriplegic; Marcie Roth, Executive Director, World Institute on Disability; German Parodi and Shaylin Sluzalis, Partnership for Inclusive Disaster Strategies; Mary Lamielle, Executive Director, National Center for Environmental Health Strategies; Christopher Cross, Aaliyah Frazier, Dilber Haytat, Jay Tulin, Melissa Cariben, Mwaura Mungai.

A. Welcome and Call to Order

Chairman Andres Gallegos called the meeting to order at 12:00 PM (ET) and welcomed Council members, staff, and the public.

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B. Roll Call

Chairman Gallegos conducted a roll call of Council members, staff, and contractors.

C. Acceptance of the Agenda

MOTION: The motion was not audible. However, Chairman Gallegos stated that the agenda was approved.

Roll Call Vote:

Andrés Gallegos, Chairman

James Brett: Aye

David D’Arcangelo: Aye

Dr. Munr Kazmir: Aye

Daniel Schreck: Aye

Mary Vought: Aye

Motion Passed Unanimously

D. Acceptance of the October 7, 2021 Council Meeting Minutes

MOTION: Dr. Kazmir moved to accept the draft minutes of the October 7, 2021 quarterly minutes.

SECONDED: Mr. Brett

Roll Call Vote:

Andrés Gallegos, Chairman

James Brett: Aye

David D’Arcangelo: Aye

Dr. Munr Kazmir: Aye

Daniel Schreck: Aye

Mary Vought: Aye

Motion Passed Unanimously

E. Policy Project Updates, FY 22

Medicaid Dental Reimbursement Project

Dr. Heather Koball, Co-Director, National Center for Children and Suma Setty, senior research associate and project director submitted a draft report and gave a brief overview of the findings and recommendations. The information provided were as follows:

- Motivation to the study;
- Providing background information about why the study was done;
- Go through research questions and methods; and
- Discuss key findings and provide policy background context that will provide the context for the recommendations.

Dr. Chelsea Fosse stated that the project focuses on adults with I/DD which are from the age of 18. I/DD is defined as intellectual and developmental disabilities that

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manifest before the age of 18 and uniquely affect the trajectory of individuals development.

Adults with I/DD have poorer oral health than the general population, including increased prevalence of periodontal disease and more problems than the general population.

Dr. Fosse stated that adults with I/DD adults with I/DD varies across states and there are a lot of flexibility in how Medicaid programs are implemented. Also, it is important to know that Medicaid can reimburse providers either as a fee for service structure or through managed care organizations. 70% of Medicaid beneficiaries treatments though MCO.

Ms. Durocher continued with NCD updates. They are as follows:

- Release of COVID-19 Progress Report late October;
- Puerto Rico report that needs full Council vote;
- Medicaid reimbursement;
- QALY's report is underway;
- New-Home and community-based service study;
- 2022 Progress Report;
- Finalization of scope of work for a project to assess a longstanding exemption under federal employment tax laws for people with disabilities in congregate settings;
- Environmental scan to get a sense of the employment programs that the federal government has for people with disabilities across the board; and
- Chairman' working with two Illinois students looking at voting rights and recent laws I that area.

F. Chairman's Report

Chairman Gallegos thanked the staff and Council for their hard work and commitment to its mission and for the various subcommittee work that has been conducted throughout the year in furtherance of its projects and reports.

Chairman Gallegos discussed the projects that are underway at the Council. They are as follows:

- Continue to conduct outreach and engage various federal agencies in furtherance of the roll out of the Council's accessible medical diagnostic equipment report;
- Briefed the Office of Minority Health on the findings of our report for the adoption of enforceable medical diagnostic equipment;
- Met with the Office of the National Coordinator of Health Information Technology and the Agency for Healthcare Research and Quality;
- Met with Assistant Attorney General Kristen Clarke;
- Met with Chief of the Disability Rights of DOJ Rebecca Bond and members of her team to discuss the adoption of the enforceable accessible medical diagnostic equipment standards as part of the regulations under the ADA;

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- Met with the Joint Commission and Accreditation Council for Graduate Medical Education;
- NCD staff lead on its health equities subcommittee and arranged a meeting with the Joint Commission and coordinating further outreach;
- Amy and I cohosted a meeting on disaster preparedness with FEMA; and
- Spoke at an event on Ability1 hosted by St. Cloud University, Minnesota.

G. Executive Director's Report

Ms. McIntosh state that the Council will be receiving public comment live through its Zoom platform with the advance public comments received in advance of the meeting.

She reported the following:

- Update on operational procedures with respect to Executive Order 14043-to be vaccinated against COVID-19;
- Netterie Lewis, COVID Safety Coordinator has attended various OPM and GAO meetings regrading safety protocols about the pandemic and reentry plans;
- Government shutdown has averted through December 3, with the agency hopefully having a \$400,000 increase;
- Overhaul of NCD.gov website;
- The Council is working on pursuance of appropriations committee report language to facilitate progress in its report recommendations haven spoken with appropriations committee staff and members; and
- Items that are included in the committee report language in the House include the following:
 1. Encouragement to recommend that hospitals create a disability ombudsperson position who would be authorized to facilitate communication between healthcare providers and patients with disabilities or their proxies and advocate on the patient's behalf.
 2. Study for appropriate alternatives to the QALY in determining indexes for prices for medications, treatments, and other services, citing NCD's QALY report.
 3. Request for HHS to report on how the efforts to implement the prenatally and postnatally and diagnose awareness pact have been going in the course of their congressional budget justification.
 4. To encourage the CDC to ensure that disability data is included as core demographic component across surveys and surveillance systems.

Ms. McIntosh stated that she is committed to staying focus as the executive director as being an optimal position management for the agency and charting a course to address the agency's staffing needs with hopes that NCD will grow year after year to meet the work with a greater semblance of sustainable workloads for the staff.

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H. Governance Report

Ms. Durocher reported in Dr. Rick Rader's stead and stated that the Council voted for the approval of the Progress Report.

I. Finance Representative Report

Dr. Schreck stated that there needs to be three votes made today. They are as follows:

- Spend plan through August 31st;
- Approval of status of funds; and
- FY'22 Budget

MOTION: Dr. Kazmir moved to approve the spend plan as of August 31, 2021.

SECONDED: Mr. Brett

Roll Call Vote:

Andrés Gallegos, Chairman

James Brett: Aye

David D'Arcangelo: Aye

Dr. Munr Kazmir: Aye

Daniel Schreck: Aye

Mary Vought: Aye

Motion Passed Unanimously

MOTION: Dr. Kazmir moved for the approval of the status of funds.

SECONDED: Mr. Brett

Roll Call Vote:

Andrés Gallegos, Chairman

James Brett: Aye

David D'Arcangelo: Aye

Dr. Munr Kazmir: Aye

Daniel Schreck: Aye

Mary Vought: Aye

Motion Passed Unanimously

MOTION: Dr. Kazmir moved to approve the proposed FY'22 budget.

SECONDED: Mr. Brett

Roll Call Vote:

Andrés Gallegos, Chairman

James Brett: Aye

David D'Arcangelo: Aye

Dr. Munr Kazmir: Aye

Daniel Schreck: Aye

Mary Vought: Aye

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Motion Passed Unanimously

Mr. Schreck asked that the AFO team share findings of the biannual fiscal year 2021 audit.

Mr. Woods stated the following:

- Interviews of upper management conducted by auditing firm;
- Review of new lease agreement as well as sample of the contracts;
- Reviewed 60 payable samples from FY'20 and 61 payable examples from FY '21;
- Checked coding procedures;
- Reviewed actions (payrolls and time sheets); and
- Reviewed the Council's fixed asset schedule.

Ms. Sommers stated in late September the Council submitted its FY'23 budget to OMB for review and discussion. It was written to comply with guidance that asks for a written reduction of 7% below the 2023 of our 2022 submission which would be in the amount of \$3,560.738 the larger figure of \$3.8 million would include additional funds to support additional full-time staff, in-person council meetings and more policy work.

There was a vote called for the following:

- 2022 Progress Report;
- Medicaid reimbursement follow-report; and
- Misclassification tax project report.

MOTION: Dr. Kazmir moved for the approval of \$185,000 for the 2022 Progress Report.

SECONDED: Mr. Schreck

Roll Call Vote:

Andrés Gallegos, Chairman

James Brett: Aye

David D'Arcangelo: Aye

Dr. Munr Kazmir: Aye

Daniel Schreck: Aye

Mary Vought: Aye

Motion Passed Unanimously

MOTION: Dr. Kazmir moved for the approval of Medicaid reimbursement report.

SECONDED: Mr. Brett

Roll Call Vote:

Andrés Gallegos, Chairman

James Brett: Aye

David D'Arcangelo: Aye

Dr. Munr Kazmir: Aye

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Daniel Schreck: Aye

Mary Vought: Aye

Motion Passed Unanimously

MOTION: Dr. Kazmir moved for the approval of the allocation \$100,000 employee misclassification tax policy project.

SECONDED: Mr. Schreck

Roll Call Vote:

Andrés Gallegos, Chairman

James Brett: Aye

David D’Arcangelo: Aye

Dr. Munr Kazmir: Aye

Daniel Schreck: Aye

Mary Vought: Aye

Motion Passed Unanimously

J. State Advocacy Highlights

Misty Dion, CEO, Roads to Freedom Center for Independent Living of North Central Pennsylvania

Ms. Dion spoke on the devastation that has been experienced do to COVID-19 in long term care facilities and the disproportionate deaths in settings due to lack of emergency response provided to those residents.

Ms. Ebony Payne, African American quadriplegic lives in a facility shared her experiences. She stated that her facility houses over 200 residents experienced an outbreak of residents with flu-like symptoms she shared her personal experience with suffering and being hospitalized for 2 weeks receiving antibiotics and breathing treatments.

Ms. Dion shared a video which depicted the 700,000 flags of lives lost to COVID-19 located on the grounds of the US Monument in Washington DC.

Ms. Dion stated that her organization has begun calling on safety measures, including reducing density for emergency relocation into congregate emergency housing like hotels. Advocate met with dozens of officials, issued public calls to action, organized protests, video town halls, formed new coalitions with nursing facility residents and drafted proposals to start emergency relocation programs.

Marcie Roth, Executive Director, World Institute on Disability spoke about FEMA category B emergency measures.

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She stated currently FEMA identifies certain private nonprofit essential social services that include day, residential services, and sheltered workshops for individuals with disabilities. She stated that she is confident that independent living centers should be added and the importance of making sure that they and other disability-led non-profit organizations are able to serve these communities before, during and after disasters.

German Parodi, Puerto Rican quadriplegic stated FEMA needs to engage the disability community leaders at every level because it's the disabled individuals who are the subject experts of their lives. Thus, without their input in the planning, lives will be affected and many more will die in future disasters.

K. Update on Theme Projects

Health Equity/Medically Underserved Population Designation & Disability Cultural Competency Curriculum

Mr. Brett stated that people with disabilities in the United States continue to have battles with physicians and other health providers to receive basic medical services and often been unable to receive proper examinations, life sustaining treatment and provided the medical equipment necessary for adequate treatment.

Mr. Brett stated that healthcare system still does not require adequate disability competency and curricula for the medical professionals and training. Mr. Brett stated that the Council continues to do the following:

- Collect sufficient disability status data for healthcare needs;
- Continue to address the lack of healthcare equity in this country for people with disabilities; and
- Continues to meet with the director of disability policy at the Domestic Policy Council of the White House to discuss the Council's health equity framework which the four primary policy issues of concern being, potential designation of people with disabilities as a special medically underserved population, disability competency training of medical professionals; accessible medical equipment; and disability status data collection in healthcare.

Mr. Brett stated that Council has drafted an issue briefing outlining its health equity framework and continues to reach out to responsive federal agencies and congressional offices concerning the next steps.

Mr. Brett stated the Council has reached out to and met representatives of the Joint Commission on hospital accreditation to provide recommended revisions to their accreditation standards, recommendations that align with the Council's framework in the areas of disability, competency training, accessible equipment, and improved data collection. The Joint Commission published an editorial in its journal declaring the need for improved standards within healthcare in relation to the Council's policy areas and we continue to correspond with them concerning what revisions, if any, they may have made to their standards.

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Use of Quality-Adjusted Life Years (QALYs) as a Barrier to Health Care Access

Ms. Vought stated the project will examine the states' uses of QALY as well as internet national drug prices set on reliance=of QALY to determine Medicaid coverage. The Council entered a cooperative agreement with Turtle Consulting which they will produce a report in 6 months. In September the group began researching state Medicaid programs and submitted a preliminary report framing paper with the first progress teleconference scheduled for October 13 at 12:30 pm (ET).

Rationing and Dying Healthcare for People with Disabilities

Mr. Schreck stated this fully funded project will develop a project will do the following:

- show the widespread deaths of people with I/DD living in congregate settings during the pandemic;
- examine the state of the nation's home-and community-based services, HCBS;
- place prior to and during the pandemic that contributed to the inability of residents with I/DD to transition to lesser density community settings; and
- seek out root causes and remedies of any of the disproportionate amount of deaths in these facilities and how regional, state, and federal policies and agencies have failed or exacerbated the deaths those they were commissioner to serve.

Mr. Shreck stated that the Council has entered into a cooperative agreement August 17th with Dr. Kara Ayers, Director of Dignity in Healthcare for People with Disabilities at the University of Cincinnati Center for Excellence in Developmental Disabilities. Dr. Ayers created a plan to convene six meetings that will commence in the Fall. She's also developed an extensive preliminary list of convening of its and attended several meetings to inform her work including FEMA, HHS, and the Administration on Aging. The first progress call is scheduled for October 20th at 10:30 am (et).

Medical Affordability

Chairman Gallegos stated the Council has identified this issue and several other of disaster public housing preparedness of inequitable accommodations for people with disabilities. Recommendations have been drafted concerning the consideration and needs of people disabilities in the drafting of the Department of Health and Human Services 2022-2026 health security strategy, in relation to public health emergencies as well as have met with HHS representatives to share those recommendations.

Chairman Gallegos stated that the Council has scheduled a roundtable to discuss the FEMA public assistance category B fundings. CIL's are looking for funding to relocate people out of nursing homes to non-congregate settings and the Council continues to work on this issue. There was a roundtable discussion September 24th and present were the Department of Justice, HHS, DHS, and FEMA. A follow-up discussion was scheduled October 12th at 11:00 am(et).

8 (a) Program Work

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Ms. Nicholas stated that the SBA has gotten funds flowing for this project and are open for dialogue. She suggested that a meeting be scheduled with officials at the SBA.

Pursuing Better Data and Federal Guidance Regarding Sexual Assault of Students with Disabilities

Dr. Kazmir stated that the Council has found through research that 30% of female college students with a disability have reported experiencing sexual assault on campus. The Council have raised such concerns to federal agencies conducting research on campuses.

Dr. Kazmir stated that the chairman and Ms. Durocher met with the OMB to share concerns on the issues of sexual assault and Title IX and requested a copy of the Council's report on sexual assault.

L. Legislative and Public Affairs Report

Chairman Gallegos stated the Council continues to get requests for their participation in various conferences and speak on various matters and enjoy having Council members participate in these conferences and speaking engagements.

Chairman Gallegos stated council member Neil Romano was a key speaker at the National Syndrome Society Summit. Council member David D'Arcangelo spoke on computer electronic accommodations programs at a virtual Disability and Reasonable Accommodations Summit.

Ms. Eacobacci stated the Council has been invited to speak the National Down Syndrome Society CEO virtual event. The event was attended by CEOs from Fortune 500 companies that talked about the benefits of including people with disabilities, especially people with significant disabilities into their workforce as part of diversity. She added that Mr. Romano's presentation discussed the history of how disability policies have changed since the 1930's from the subminimum wage segregated model to the present competitive integrated employment model.

Ms. Eacobacci shared recent activities. They were as follows:

- September 28th- Senate Judiciary Subcommittee on the Constitution held a hearing on conservatorship and guardianship;
- Meetings were held with congressional staff in consistent with the Council's 2012 and 2018 reports regarding the use of Section 14c. The current draft of the reconciliation package that was published several weeks ago includes funding for transformation grants to current 14c certificate holders and states to assist with the successful transformation away from the outdated subminimum and segregated employment model from the 1930s to its current competitive integrated employment model which is consistent with current disability employment policies;
- Received congressional referrals to other congressional offices, one being from the Education and Labor office;

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- The Council provides policy ideas to offices as well as talking to offices about becoming a part of these efforts;
- Some meetings include House speaker staff and Senate Majority Leader staff;
- Met with House majority and minority leadership staff;
- The Council continue to have ongoing communications with the bipartisan caucus around national coverage determination for complex rehabilitation technology;
- The council has been meeting with cochairs of the doctors caucus; and
- Met with members of the newly developed bipartisan social determinants of health caucus.

Mr. Sabula highlighted updates were as follows:

- The Council has been having regular meetings with the White House Office of Engagement regarding collaboration on future disability-related events;
- Chairman Gallegos attended White House Rose Garden event to commemorate the ADA Anniversary;
- Attending a series of meetings with the Access Board and State Department looking at the International Day of Persons with Disabilities December 3rd;
- September 22nd held an interview with the state cloud reimbursement program in relation to the UN Convention on the Rights of Persons with Disabilities;
- Event held for the accessible medical diagnostic report; Council member Brett and staff Amged Soliman moderated a 2-hour on August 3rd on the Council's strategic plan;
- Chairman Gallegos was a keynote speaker at the National Organization on Nurses and Disabilities;
- Twitter professional s are interested in the Council's participation in the new Twitter space, a new audio-only platform;
- Upcoming event Melwood and Ocoli to commence in November;
- The Council has referenced in coverage regarding the guardianship and conservatorship of Brittany Spears; and
- NCD's new website development.

M. Public Comment

The following individuals submitted public comments to the Council.

1. Brock Hunsaker, spoke on social security concerns.
2. Mary Lamielle, spoke on environmental intolerance and sensitivities and the NCD website.
3. Eric Clements, regarding social security insurance.
4. Christopher Cross regarding guardianship.
5. Aaliyah Frazier regarding a disability case issue.

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6. Dilber Hayat regarding Afghanistan.
7. Judy Wilkey regarding SSDI and the cost of living.
8. Jay Tulin regarding the US Access Board pedestrian rights of way accessibility guidelines, healthcare equity, and voting.
9. Melissa Cariben spoke to the Council about individuals that are struggling with myalic encephalitis chronic fatigue syndrome (ME/CFS) she stated that there are over a million people in the United States affected by this condition and coming out of long COVID there will be an equally large population. It is estimated that 25-25% of people that had COVID will develop long-term symptoms and have long COVID will be disabled and unable to work.
10. Ms. Cariben is advocating that the Council needs to do more to educate the medical community so when people applying for social security and disability assistance that they have the backup from the medical community for these diseases that they need because they are debilitating to their body and there are studies to show that, however doctors are not aware.

Chairman Gallegos submitted a proposed calendar of future Council meetings as follows:

January 27, 2022 virtual

May 12, 2022 virtual

July 25-26, 2022 in person meeting (tentatively)

N. Unfinished Business

Ms. Grubb conducted a Council member training on processing of their time and the SGE report.

MOTION: Chairman Gallegos moved to adjourn the meeting.

SECONDED: Mr. Jim Brett

Roll Call Vote:

Andrés Gallegos, Chairman

James Brett: Aye

David D’Arcangelo: Aye

Dr. Munr Kazmir: Aye

Daniel Schreck: Aye

Mary Vought: Aye

Motion Passed Unanimously

The meeting adjourned at 3:36 p.m.

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Date Approved by the Council: January 27, 2022

Signature

Andrés J. Gallegos, Chairman

Printed Name