

**National Council on Disability
Council Meeting
July 22, 2021
1:00 PM- 4:00 PM (ET)**

ATTENDANCE

Members

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

Staff

Stacey Brown
Joan Durocher
Nick Sabula
Keith Woods
Amy Nicholas
Ana Torres-Davies
Amged Soliman
Kimie Eacobacci
Netterie Lewis

NCD Contractors

Anthony Simpson
Kadedra Walters
Cindy Smith

Guests

Michael Morris and Nannette Goodman, National Disability Institute

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: Chairman Gallegos moved to accept the agenda.

SECONDED: James Brett

Roll Call Vote:

Andrés 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

Motion Passed Unanimously

D. Acceptance of May 13, 2021 Council Meeting Minutes

MOTION: Dr. Kazmir moved to accept the draft minutes of the May 13, 2021 quarterly minutes.

SECONDED: Mr. D’Arcangelo

Roll Call Vote:

Andrés 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

Motion Passed Unanimously

E. Chairman’s Report

Chairman Gallegos reported the following:

- May 19th met with the Office of Management and Budget (OMB) regarding the Council’s view on the use of quality-adjusted life years in form prescription pricing;
- May 20th the Council released a report on accessible medical equipment in which a webcast was conducted along with the Departments of Justice and Health and Human Services Office of Civil Rights with 308 in attendance;
- May 25th provided testimony before the U.S. Commission on Civil Rights on FEMA’s response to Hurricanes Maria and Harvey. As a follow up to the testimony, the commissioners have posed a handful of additional questions for which the Council will be responding. Chairman Gallegos thanked Amy Nicholas for her assistance in preparing the testimony and researching the answers to the follow up questions pose;
- June 4th the chairman delivered a keynote address at the American Academy of Developmental Medicine and Dentistry’s annual conference. Chairman Gallegos thanked and recognized the outstanding achievements of Council member Neil Romano, Amged Soliman and other Council members for their work;
- Chairman Gallegos met with the Institute of Exceptional Care’, CEO Mai Pham and shared the work of the Council on health equity;
- June 8th wrote to the Secretary of the Department of Health and Human Services to discuss health disparity and ableism with the healthcare profession. The Council

wanted to discuss strengthening its federal nondiscrimination mandates moving forward with section 307 of the Affordable Care Act which required the Secretary of Human Services to develop a model curriculum;

- June 21st the Council wrote to the Joint Commission, it's President and CEO Mark Chassin regarding a meeting to discuss the role of the Commission to discuss the absence of disability cultural competence training in medical education, including post-graduate clinical training and residency and fellowship programs, the Council received a response and a meeting is scheduled for August 4th;
- June 22nd audit kick off Almond and Company, CCP will be conducting the audit and anticipated completion November 15th;
- July 14th a letter was sent to Thomas Nasca, CEO, Council on Graduate Medical Education and requested their assistance in incorporating into residency and fellowship disability culture competent curricula;
- June 24th sent a letter to the U.S. Attorney General, and assistant Attorney General requesting a meeting with the Council and US Access Board to discuss to discuss the adoption of the Access Board standards for medical diagnostic equipment and to discuss strengthening Title II and III of the ADA regulations with respect to accessible healthcare;
- July 12th NCD staff and the chair met with FEMA administrator and the director of the Office of Disability Integration and Coordination and discussed a closer working relationship between the two agencies;
- Chairman Gallegos and Ms. Nicholas spoke with the Saving Institutional Lives via Emergency Relocation Conference. The conference was hosted by Marcie Roth and the Partnership for Inclusive Disaster Strategies hosted the meeting. The focus was on the lives lost during the pandemic, work that still continues and answers that are needed from the government in order to protect the most vulnerable to COVID-19 which would be to protect and save the lives;
- Presented at the Shirley Ryan AbilityLab and highlighted the role of the Council as a federal voice for people with disabilities and inclusive healthcare;
- In commemoration of the 31st anniversary of the ADA interviewed Lex Frieden, an NCD former chairman and attended an event at the White House commemorating the anniversary;
- Met with Emily Voorde, Associate Director of the White House Office of Public Engagement and discussed the Council's interest in having a White House convening to take a critical look at the disproportionate effect the pandemic has had on people with disabilities, primarily those with emotional and intellectual disabilities living in congregate settings.

F. Puerto Rico Report

Ms. Amy Nicholas reported the major findings as being:

- Puerto Rico is the poorest of territories; with many residents that live well below the poverty line. The annual per capita income being \$18,000;
- Between hurricanes and earthquakes, Puerto Ricans have been migrating to the mainland in great numbers, 2011-2012 approximately 55,000 , 2018 60% live on the mainland of the United States with only 36% residing on the island;

- Puerto Rican population of people with disabilities is 21% compared to the average in the states of 15%;
- Shipping costs to other islands are less than that to Puerto Rico which in turn, affects and impacts people with disabilities who need medical equipment with residents paying 11-50% higher prices for their DME than those that reside in the states;
- During the disaster relief from hurricane Maria \$600 million in food aid was provided as well as construction, the additional cost of construction because of the Jones Act led to a 10-20% reduction in aid to the island;
- 39% of all Puerto Rican residents receive Medicaid, whereas only 10% do on the island, with Puerto Rico receiving less funding than any other state for their Medicaid program;
- Approximately 29% of people on the island are covered by Medicare compared to 15% in the states;
- Social security is the biggest disparity of Puerto Rico but are eligible for Aged, Blind or Disabled program. The SSI monthly benefit is \$75 a month as compared to \$700 for residents in the states;
- Supplemental Nutrition Assistance Program (SNAP) is not available but are to other territories (i.e., Guam and the U.S. Virgin Islands);
- There are also disparities in education, employment, housing, transportation, and emergency preparedness.

Recommendations are as follows:

- Private and Public universities and the federal government start including data on Puerto Ricans with disabilities living on the island, and other territories, to improve accountability so we can ensure appropriate resources are provided to ensure equity in programs;
- The Council recommends that Congress repeal the portion of the Jones Act provisions as has been done in other territories;
- The Council recommended the amendment of Title 16 of the Social Security Act so that benefits are awarded to Puerto Rican residents;
- The Council recommended the same regarding Food Stamp Act to include Puerto Rico in the SNAP Program;
- The Council has asked federal agencies reevaluate their funding formulas for the federal benefits and programs to ensure equitable distribution of funding for programs in education, employment, housing, transportation and that the Puerto Rican government can attain these funds to make things more accessible for those with disabilities;
- The Council has asked that HUD ensure that all construction projects destined for the island territories to have efficient and effective use of funds.

G. Executive Report

Ms. Joan Durocher submitted the executive report in Anne McIntosh's stead. Ms. Durocher coordinated a vote on the upcoming policy work for FY '22. Council members who submitted their proposal spoke briefly on them and each Council member voted on their top three.

Project One: Puerto Rico Chairman Andres Gallegos

Chairman Gallegos stated that the Council had the opportunity to file an amicus briefs. There are two Supreme Court cases coming up on the October 21st report that will be of importance to people with disabilities. They are the following:

- United States v. Vaello-Madero and it questions whether Congress violated the equal protection of competent of due process clause by establishing supplemental disability income to needy, aged, and blind disabled in the 50 states, the District of Columbia and Northern Mariana Islands but not extended to Puerto Rico.
- Cummings v. Premier Rehabilitation, 5th Circuit Court of Appeals. This issue is whether the damages Under Title VI of the Civil Rights Act of 1964 and the statutes from it is for victims of discrimination such as Rehabilitation Act of 1973 and Section 5057 of the Affordable Care Act include compensation for emotional distress.

Chairman Gallego that the Council has identified a couple of third year law students that are very interested in helping with our research projects and will assist with helping us filing amicus briefs and assisting in that research.

Project Two: Medicare Coverage, determination of Complex Rehabilitation Technology Chairman Andres Gallegos

Chairman Gallegos stated in the connection with the Puerto Rico Report and that would be the ability for people with disabilities and paralysis to get approval for complex rehabilitation technology. Complex rehabilitation technology is a wheelchair or a mobility device that has tilt and recline function, an elevated seat, standing capability and balance as well as other features to allow wheelchairs to drive up and down steep inclines and over a wide variety of terrain. The new technology will allow climbing up and down stairs.

Chairman Gallegos stated that the Veterans Administration uses an approach where they look at the quality of life of an individual and whether or not the technology that's being requested is going to improve their lives and ability to integrate into their community and live the independent lives that they desire.

Chairman Gallegos stated that the projects will do the following:

- will critically analyze the method by which Medicare is reviewing the request for complex rehabilitation technology;
- take in account the emotional and mental health of people requesting the equipment;
- look at the improvements that the equipment will have on their physical health;
- look at the financial well-being impact on an individual once they receive the equipment;
- determine whether or not the government is doing what is responsible and holistically.

Project Three: Federal Disability Job Programs Inventory and Assessment Neil Romano

Mr. Romano stated the Government Accountability Office (GAO) has said that 20-30% of funds spent on employment of people with disabilities are either not known where they are going or completely wasted. There is no assessment of these programs. We

need to know what needs more funding, and what needs to be rolled into another program.

Project Four: Tax Policy Project Kimi Eacobacci

Ms. Eacobacci recommends the Council examine the legal implications of a longstanding categorical exclusion that has been recognized by the Internal Revenue Service (IRS) regarding people with disabilities working in congregate settings. During the pandemic people were being furloughed, many working from congregate settings who were being paid well above minimum wages and were applying for unemployment benefits. Findings have shown in Louisiana they people were being denied and that they were not employees under the state's unemployment tax definition.

Ms. Eacobacci stated that the Council has found in 1965 the IRS created a revenue ruling that stated that people with disabilities working in congregate settings are in fact not employees. The pay they receive is not wages for FICA and unemployment tax purposes, therefore they were being segregated on their benefits.

Ms. Eacobacci stated that sheltered workshops were getting private rulings from the IRS to find that people with disabilities working in their settings were not clients and according to the Social Security Administration (SSA) and the Department of Justice (DOJ) actually enforced several of these cases and found that many people in these congregate settings around the country were not employees as well.

Ms. Eacobacci stated that the Council has also found that other federal agencies have also incorporated a categorical exclusion that the IRS recognizes as well as the National Labor Relations Board has adopted as well.

Ms. Eacobacci stated that the Council would like to have a conversation with the IRS and SSA to make sure that people with disabilities working in congregate settings are collecting the credits that they are working towards.

Project Five: Environmental Justice Amy Nicholas

Ms. Nicholas stated that this year's progress report is environmental justice. She stated that the poorest people will continue to experience the worst effects of climate change through displacement, lack of food resources, and impacts of their health. As reported in the Puerto Rico Report, Institutionalization, and other reports the incidence of dealing with disasters before, during and after a disaster the difficulties in getting accessible shelter and being reintegrated back into society when the community has been destroyed.

Ms. Nicholas stated that the report will also address the following:

- aimed to look at the intersecting factors of discrimination that relate to disability as well as gender and race;
- look at the impact to a person with a disability's access to healthcare and the ability to survive extreme weather events;
- will integrate the administration's reinvigoration of Executive Order 13175 which states that all departments and agencies should engage in regular, meaningful, and robust consultation with tribal agencies;
- climate change and effects on people with disabilities;
- Medicaid probability in regard to disasters and the ability to be able to care for oneself.

Project Six: Convention on the Rights of People with Disabilities & International Development Joan Durocher

Ms. Durocher stated she has met with the State Department and the United States Agency for International Development to discuss the status of the CRPD and what the Council can do to move forward its international efforts impacting people with disabilities. She added that it was suggested that the Council look at environmental scan or mapping project t at what federal agencies are doing across the government in their international development efforts. The Unites States spends millions of dollars on overseas development efforts and within those assistance programs there should be assisting people with disabilities.

Project Seven: Medicaid Reimbursement Neil Romano and Dr. Rick Rader

Dr. Rader stated that 80% of adults have some form of gum disease which they have for life. Poor oral health contributes to the 20-year longevity disparity that are seen in people with intellectual developmental disabilities. He added that oral healthcare is the number one unmet health need not only for those with intellectual developmental disabilities but the full spectrum of disabilities.

The Council has done great work in the past with the National Council on Dental Accreditation and the American Dental Association in which the Council influenced them change their code of ethics. This has manifested a mandate that all dental students graduating from U.S. dental schools will be able to demonstrate hands on competency training in the evaluation , management, and treatment of oral healthcare for people with disabilities.

Dr. Rader stated that the Council needs to create and provide an economic sensibility for dentists to practice on individuals with intellectual and developmental disabilities as well as a variety of sensory, cognitive, physical, neuro-motor disabilities, etc.

Ms. Durocher asked Council members to submit their projects by priority. They were as follows:

Chairman Gallegos	Number 1 - project 2 Number 2 - project 3 Number 3 - project 9
Jim Brett	Number 1 - project 9 Number 2 - project 3 Number 3 - project 4
Dr. Rick Rader	Number 1 - project 8 Number 2 – project 4 Number 3 – project 6
Daniel Schreck	Number 1 – project 1 Number 2 – project 2 Number 3 – project 4

Neil Romano	Number 1 – project 8 Number 2 – project 6 Number 3 – project 4
David D’Arcangelo	Number 1 – project 4 Number 2 – project 6 Number 3 – project 9
Dr. Munz Kazmir	Number 1 – project Medicare reimbursement Number 2 – Jobs Number 3 – project 5
Mary Vought	Number 1 – project 9 Number 2 - project 6 Number 3 – jobs project

H. Governance Committee

Dr. Rader stated there was nothing new to report at this time, however, remain vigilant to ongoing suggestions and potential future actions.

I. Finance Report

Mr. Schreck stated that there are two orders of business and they were as follows:

- Approval of the status of funds for June 30, 2021;
- Full fiscal year budget

Mr. Schreck commended Mr. Woods for his work on the financial reporting and audit in Lisa Grubb’s stead. The Council is operating under a \$3.35 million which has increased \$100,000 and a pass back of an extra \$400,000.

- \$100,000 increase in travel and transportation;
- \$83,000 increase in salary and benefits;
- \$227,000 a 25% increase in contracts and policy work;
- 27% increase in research contracts;
- 67% increase in contracts services;
- 24% increase in IT services

MOTION: Chairman Gallegos moved to approve the status of funds as of June 30, 2021.

SECONDED: Dr. Munz Kazmir

Roll Call Vote:

Andrés Gallegos, Chairman: Aye

James Brett: Aye

David D’Arcangelo: Aye

Dr. Munz Kazmir: Aye

Dr. Rick Rader: Aye

Neil Romano: Aye

Daniel Schreck: Aye

Mary Vought: Aye

Motion Passed Unanimously

MOTION: Chairman Gallegos moved for approval of the Council budget for the full FY '21.

SECONDED: Dr. Rick Rader

Roll Call Vote:

Andrés Gallegos, Chairman: Aye

James Brett: Aye

David D’Arcangelo: Aye

Dr. Munz Kazmir: Aye

Dr. Rick Rader: Aye

Neil Romano: Aye

Daniel Schreck: Aye

Mary Vought: Aye

Motion Passed Unanimously

J. National Disability Institute- Michael Morris and Nannette Goodman

Chairman Gallegos introduced the present and former heads of the National Disability Institute who addressed the Council about the cost of being disabled in the United States

Mr. Morris is the founder and senior strategic adviser and Ms. Goodman, research adviser who has written journals, books, and prepared reports for the Council. They shared very significant implications for both existing policy as well as the activities and operations of multiple public benefits and programs by an array of federal agencies and departments.

K. Strategic Plan Presentation

Mr. Jim Brett and Mr. Soliman reported the following:

- Council submitted to OMB June 4th which outlines the Council goals and related objectives for 2022-2026;
- The Council is currently putting together a rough draft of a full initiative which is due to OMB mid-September;
- The Council will seek input in the form of public comment, from the community, and Congress;
- The Council has scheduled a virtual event for August 3rd 1:00-3:00 pm.

L. Subcommittee Updates

Medically Underserved Population Designation & Disability Cultural Competency Curriculum

Dr. Rader stated the Council continues to build upon its previous efforts and successes to address the lack of health equity in the U.S. for people with disabilities. They council also has done the following:

- The Council organized a meeting of experts to discuss the potential drafting of new broad based health equity legislation;
- Executive action aimed at addressing health equity across all disabilities;
- Met with the Domestic Policy Council at the White House to begin developing a plan for potential interagency working group to address issues of health equity;
- The council has drafted an executive order and presented to the White House for consideration;
- The Council is exploring recommendations for congressional action, including not limited to the goal of designating people with a disability as a specifically medically underserved population;
- Lack of disability competency training of medical students and professionals to be address, Council to meet with the hospital accreditation;
- The council is having ongoing conversations with the Society of Teachers of Family Medicine, the Association of Family Medicine Residency Directors, the American Association of Medical Colleges, the Liaison Committee on Medical Education, and the Accreditation Council for Graduate Medical Education.

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

Ms. Vought stated that Ms. Torres-Davis has done tremendous work and drafted a statement of work for a report that would examine the extent of which states are using QALYs based effectiveness reports or international drug prices. The report will gather evidence that shows whether reliance of this information is denied access or coverage to drugs that are necessary for those with chronic illnesses.

Ms. Vought stated the Council publicly posted a notice of funding opportunity incorporating statement of work on grants.gov and the Council website in hopes of seeking a contractor to help develop this report over the next six months. We received a proposal from Turdohl Consulting LLC which will be evaluated by an external review panel and hopefully work on the report will commence I August.

Ms. Vought stated the Council was successful in getting QALY language included in the recent House appropriations report. It encourages CMS to study alternatives to the use of QALY in determining prices and coverage for medications and treatments, requests an alternative to QALY and any best practices that can be used for the pricing of medications and treatments involving coverage.

Rationing and Denying Health Care for People with Disabilities

Mr. Schreck stated that this policy builds on the Council's soon-to-be released progress report of 2021, specifically as it regards to the widespread deaths of people with intellectual and developmental disabilities living in congregate settings during the pandemic.

Mr. Schreck added the following:

- Ms. Torres Davis developed a statement of work to examine the state of the nation's home and community-based services;
- Report will layout a solid foundation for the need for permanent sufficient HCBS funding to ensure that states have the capacity to provide more non-congregate housing options and services for to people with disabilities who can and want to live in a community;
- Proposal of a comprehensive plan to increase community living options with necessary services and supports;
- The Council has been at the forefront of advising on institutionalization of people with disabilities after disasters ;
- Highlights obligations under the Supreme Court's Olmstead decision and the ADA's most integrated setting mandate;
- Dr. Cars Airs, Associate Director, University Center for Excellence in Developmental Disabilities will work on this project.

Emergency Management in disaster relief

Chairman Gallegos stated the following:

- The Council has provided recommendations in the form of draft legislative language to the Senate;
- The Council met with the FEMA administrator and discussed the need of additional guidance;
- The Council is drafting recommendations concerning the consideration and needs of people with disabilities;
Councill Chair testified at the U.S. Commission on Civil Rights concerning necessary emergency planning and disaster relief for people with disabilities and that it is unacceptable to institutionalize people with disabilities during disasters;
- The Council continues to review current law and policies and comprised specific recommendations to address vital matters;
- Continue to address FEMA and other federal agencies.

Fostering Job Growth for People with Disabilities through Small Business Administration 8 (a) Business Developmental Program

Mr. D'Arcangelo stated that he met with Council staff and comprised an introductory approach and gathered some data from the subcommittee in submitting a letter to the SBA and wanting to meet with them to discuss programmatic definition of disabilities.

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

Dr. Kazmir stated based on the Council's 2018 report, sexual assault on college students with disabilities which founded that 30% of female students with disabilities reported experiencing sexual assault on campus. Since the last Council meeting, the Council submitted two recommendations from this report congressional offices as suggested language for the upcoming appropriation bill.

UN Convention on Civil Rights for Persons with Disabilities

Ms. Durocher stated since the last Council meeting, she's met with the State Department and the United States Agency for International Development to talk about the current status of the CRPD and its current status. We are pursuing an alternative project and looking at disability inclusion in international affairs.

M. Public Comments

Chairman Gallegos stated that the Council has received public comment and asked Nick Sabula to give an update.

Mr. Sabula reported the following comments received from the public. They were from the following:

- Alyssa Marlow-focused on disabled veteran employee, FERS and HUD grants
- Amy Cooper-need of funding and research
- Melissa Karabin-focused on long effects of COVID
- Laura Kiesel-focused on affordable housing
- Phillip Kahn-Pauli-submitted comment on behalf of RespectAbility
- John Derby
- Lisa Cooley-transportation companies
- Eric Clements-focused on housing and non-emergency medical transportation
- Leslie Schultz-submitted on negligence of the disabled
- Paulissa Kipp-trauma -informed care and disability awareness in emergency departments
- Mary Lamielle-environmental intolerance and sensitivities
- Brock Hunsacker-SSI online applications, expanded online status checks for SSA
- Heather Hussey-inclusive education
- Steve Warner-resiliency

N. Unfinished Business & Next Council Meeting

Mr. D'Arcangelo stated that Becca Myers is a Paralympic athlete that is competing the Paralympics.

Chairman Gallegos stated that the Fall Council meeting is scheduled for October 7, 2021 12:00 noon – 4:00 pm (ET)

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. Munz Kazmir: Aye

Dr. Rick Rader: Aye

Neil Romano: Aye

Daniel Schreck: Aye

Mary Vought: Aye

Motion Passed Unanimously

The meeting adjourned at 4:00 p.m.

Date Approved by the Council: October 7, 2021



Signature

Andrés J. Gallegos

Printed Name