

**National Council on Disability
Council Meeting
May 13, 2021
2:00 PM- 5:00 PM (ET)**

ATTENDANCE

Members

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

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

Ann Jackson, PTT, DPT, MPF; Angela Szczepanik-Sanchez, M.Ed., M.S. Ed.; Robert O’Shea, PT, Ph.D., DPT-Jaguar Jumps (post High School Advancement of Individuals with Intellectual and Developmental Disabilities; Betzaida Ramos Charriez, Carol Salas Pagan, Puerto Rico UNICEF Director; Carmen Ramos

A. Welcome and Call to Order

Chairman Andres Gallegos called the meeting to order at 2:00 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: There was amotion to accept the agenda (Council member to be identified).

SECONDED: (Council member to be identified)

Roll Call Vote:

Andres Gallegos, Chairman

James Brett: Aye

Jim Baldwin: 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 March 2021 Council Meeting Minutes

MOTION: (Council member to be identified) moved to accept the draft minutes of the March 11, 2021 quarterly minutes.

SECONDED: Dr. Rick Rader

Roll Call Vote:

Andres Gallegos, Chairman

James Brett: Aye

Jim Baldwin: 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 reported the following:

- A series of letters were written and submitted to congressional leaders and federal agency leaders on subminimum wage, competitive employment, organ transplant, anti-discrimination, and the use of QALY adjusted life years in drug pricing;
- Sub-minimum wage letters were sent introducing transformation to the competitive integrated competitive integrated employment act which further advances the

Council's pre-existing and current advice policy makers onto phase out section C of the Fair Labor Standards Act;

- A series of letters were written to Special Vocations and Rehabilitative Services urging clarification of guidance regarding competitive integrative employment;
- Meet with CDL director and staff to discuss the quality concerns and recommendations;
- Met with congressional staff of various committees to voice the Council's concerns.

Chairman Gallegos stated that he is pleased with the progress of the work that the Council is doing and its subcommittee work. He added that he and Ms. Sommers-McIntosh will continue to meet with the advocacy organizations as part of our community engagement strategy with the most recent meetings being held with the National Organization of Nurses with Disabilities and the discussions were on no barriers and needs for self-disclosure of nurses with disabilities.

Chairman Gallegos stated that the Council engaged in other meetings and discussions which included the following:

- Met with the America Academy of Physical Medicine and Rehabilitation regarding the support for the advocacy efforts to address the COVID-19 crisis; and a call for a 9/11 equivalent commission to develop a comprehensive plan to address the crisis;
- Meet with the director of Office of Disability Integration and Coordinate Union to discuss cooperation and coordination and the need for guidance to states and local tribes and territories at the Stafford Act category B funds can be used to reimburse centers for independent living to relocate to hotels and apartments and other locations, persons with disabilities out of nursing homes during COVID-19 crisis.

F. Executive Director

Ms. Sommers-McIntosh reported the following:

- The Council has received 4 public comments via email prior to the meeting and from whom they were received;
- Had a meeting with policy makers around the quality-of-life report (2019);
- The policy and legislative staff have been very active in developing suggestions for consideration of congressional offices for the inclusion as language in appropriations committee report;
- The Council will be releasing its accessible medical and diagnostic report online and an arranged panel presentation involving several government officials and advocates;
- NCD reports continue to be highlighted regularly in the media, Dan Schreck authored an op-Ed regarding assisted suicide proposal in Connecticut that was placed in a Connecticut newspaper;
- Office audit preparations are continuing with the audit beginning in June,
- AFO team is preparing for compliance to NARA with December 22 being the deadline.

G. Finance Report

Dr. Rick Rader stated that he and Ms. Durocher have been reviewing the bylaws to determine any updates that they deem necessary.

Mr. Dan Schreck reviewed and discussed that status of funds for FY'21. He added that the Council is continuing to operate and with level funding at \$3.35 million up by \$100,000.

Mr. Schreck stated the pass back was increased by \$400,000 thanks to the leadership of Neil Romano and Lisa Grubb.

MOTION: Chairman Gallegos moved to accept the Finance Committee Report.

SECONDED: Dr. Rick Rader

Roll Call Vote:

Andres Gallegos, Chairman

James Brett: Aye

Jim Baldwin: Aye

David D'Arcangelo: Aye

Dr. Munz Kazmir: Aye

Dr, Rick Rader: Aye

Neil Romano: Aye

Daniel Schreck: Aye

Mary Vought: Aye

H. Summaries of shift in Policies Projects

Ms. Sommers-McIntosh discussed the shift in policy projects which are as follows:

- Crisis Standards Care project
- Accessible Drug Project
- Budget Allocation on the medical curriculum in the medically underserved population
- Accessible drug projection of the envisioned crisis standards of care project has been accomplished by an academic publication that just came out and mirrors the scope of the envisioned project.

MOTION: Dr. Munz Kazmir moved to approve the shift in policy projects.

SECONDED: Mr. Neil Romano

Roll Call Vote:

Andres Gallegos, Chairman

James Brett: Aye

Jim Baldwin: Aye

David D'Arcangelo: Aye

Dr. Munz Kazmir: Aye

Dr., Rick Rader: Aye

Neil Romano: Aye

Daniel Schreck: Aye

Mary Vought: Aye

I. Public Policy Updates

Ms. Joan Durocher gave the following update. They are as follows:

- Medical Diagnostic Equipment Report with panelists to respond to the Council's recommendations;
- COVID-19 Project Report;
- Committee on Progress Report;
- Oral Healthcare Report;
- Collection of raw data from CMS Report;
- Report on the disparate treatment of Puerto Rican residents

J. Disparate Treatment of Puerto Rican Residents with Disabilities Report

Ms. Carol Salas who is part of the research team for the NCD report on Puerto Rico stated the following:

- Medicaid the main healthcare program that provides services to 39% of adults of Puerto Rico who are of low income;
- According to the census there is a rate of 21.7% of people with disabilities on the island which has a higher rate of heart disease, high blood pressure, asthma on the island;
- The Council produced a report in 2013 of the potential impact if the Medicare program which includes converting the medical program on the mainland to a state program;
- The citizens of Puerto Rico do not have the necessary services such as special care, long-term care, prescription medication, medical equipment, assistant technology, and barriers to access;
- Puerto Rican citizens with disabilities are at a higher risk of developing age related health conditions and should be entitled to comprehensive healthcare;
- Disability stakeholders living in Puerto Rico were interviewed and some have described how benefits allowed them to live independently on the mainland;
- Research showed that lack of services and support coverage is likely due to the cap and lack of funding of Medicaid.

Ms. Carmen Ramos stated that there is a significant disparity in the income benefits assistance programs for seniors, the blind, and people with disabilities to help them with the basic needs.

Ms. Ramos stated that the United States initiated a program in 1974 for the Northern Mariana Islands with entitlement programs with no statutory cap. The feds pay, establishes eligibility standards, determines amounts and pays the total sum of benefits and administration expenses but not for Puerto Rico.

Ms. Ramos stated that 436,000 are eligible for SSI in Puerto Rico. With 11% of the people are seniors and people with disabilities that receive the benefits. There is a disparity in benefits available to Puerto Rican residents who are dependent on imports for more than 80% of the food that is consumed on the island.

Ms. Ramos stated that the recommendation of the current program in most territories for the SSI program as well as the Nap for the SNAP program to ensure that American citizens with disabilities have access to complete safety net programs that work to make quality of life better for people with disabilities.

Ms. Ramos stated responses from federal legislators is that Puerto Rican residents do not pay federal income taxes and thus should not be eligible for the federal programs and its benefits.

Ms. Ramos stated that after the 2017 disaster Puerto Rico had received disaster aid more than \$19 trillion and such allocation of funds have been criticized on a national level.

K. State Advocacy Highlight: Jaguar Jumps

The creators of Jaguar Jumps- Ann Jackson, Angela Sanchez and Roberta O'Shea is a novel post-high school program for individuals with intellectual and developmental disabilities it gives students a chance to jump into adulthood by attending college courses that may lead to employment or attending a degree program at a college or university.

The creators explained the historical grounding of educational opportunities and inequities for citizens with intellectual disabilities and described the existing national and local educational infrastructures that exist currently and identified inequity and they hoped the Council could help with.

They are a myriad of ways to qualify for services under the ADA. Thus, they have proposed a uniform safety net to fill in the gaps to increase the student's capacity. Students with intellectual disabilities that are not maximizing their capacity. There are programs and workshops for individuals with disabilities who meet that capacity and university programs for students who can attend a university and perhaps pay the differential to live in the dorm for students with disabilities to get the services of a personal attendant while they are in school.

Jaguar jumps provides an opportunity for students to create a peer-based community around shared goals and experiences and bring them together which in turn allows the caregivers to see the students in a different light. Jagua Jumps wants to increase public awareness of the existing federal and state transitional programs address the needs of students in underserved and under resource areas. Evaluate the equity of funding and transition programs of students with equitable expectations.

L. Update on Theme Projects

Mr. Jim Brett stated the Council is doing great work medically underserved population and that we fight for our loved ones to get basic medical care. He added that many professionals do not know how to diagnose, treat, or deal with people with disabilities.

Dr. Rader and Jed Solomon are currently drafting letters on behalf the NCD's initiative to the Joint Commission on Hospital Accreditation and the U.S. Surgeon General in hopes that they will play a role in requiring disability competency training of medical professionals.

Mr. Brett stated that the Council will look at several health equity issues including the designation of people disabilities as an exceptional medically underserved population.

Ms. Mary Vought stated work that the Council did its 2019 report on QALY with be expanded. The report highlighted how the use of QALY devaluing the lives of people with disabilities. Therefore, the initial plan was to develop a report on the civil rights implications of the US reliance on foreign drug prices. Congress has made this a priority and the Council has acted as it relates to HR- Elijah Cummings Lower Drug Cost Act which proposes using foreign drug prices to set drug prices in the United States.

Ms. Vought stated the Council Chair sent a letter to the Congressional Budget Office recording the use of QALY and requested a meeting. In April, the Council sent a report and statement to the Senate Health Subcommittee regarding the hearing held April 23rd on why the US pay the highest prices for prescription drugs.

Rationing and Denying Healthcare to People with Disabilities

Mr. Daniel Schreck stated the Council wanted to do a nationwide survey at different hospitals and provide a model of the crisis standard of care. Group settings, hospitals are going to be addressed in the Progress Report on COVID-19 and the Council wants the report to develop more on institutionalization in congregate settings and examine alternative protocols to fill out the policy prescriptions going forward.

Medicaid Portability

Mr. Schreck stated that Medicaid portability arises in natural disasters where the individuals with disabilities must relocate for their safety from one state to another and unable to access medical care or any benefits under Medicaid. He added that there is a Council subcommittee has met and discussed looking at laws that exist or lack the administrative mechanisms that has led to the current Medicaid not being portable.

Fostering Job Growth

Mr. Schreck stated that the Small Business Administration (SBA) has a disadvantaged business development program (8A) which helps minority groups, women owned businesses and other disadvantaged groups but not people with disabilities. The Council has done letters to see if we can get people with disabilities added as entrepreneurs and get them funding through the SBA so they may be able to start businesses.

UN Convention on the Rights of People with Disabilities

Dr. Muz Kazmir stated he and Mr. David D’Arcangelo are leading efforts to address this issue. Ms. Joan Durocher is providing the Council with an update what the Council has done historically and what needs addressed going forward.

M. Schedule of 2021 NCD Council Meetings

Chairman Gallegos stated that the next Council meeting is schedule for July 22nd from 1:00-4:00 pm (et) followed by the fall meeting October 7th and 8th anticipating a in person meeting. If it becomes a remote meeting than it will be October 7th 2:00-5:00 pm (et).

Chairman Gallegos stated that the July Council meeting will have a full agenda with voting for FY22 solicitation of ideas and recommendations regarding the acknowledgement of the 31st anniversary of the ADA.

N. Adjournment

MOTION: Dr. Kazmir moved to adjourn the meeting.

SECONDED: Mr. Jim Baldwin

Roll Call Vote:

Andres Gallegos, Chairman

James Brett: Aye

David D’Arcangelo: Aye

Dr. Munz Kazmir: Aye

Dr, Rick Rader: Aye

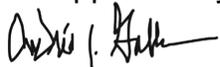
Neil Romano: Aye

Daniel Schreck: Aye

Mary Vought: Aye

The meeting adjourned at 5:00 p.m.

Date Approved by the Council: July 22, 2021



Signature

Andrés J. Gallegos

Printed Name