**ATTENDANCE**

**Members Staff**

Neil Romano, Chairman Lisa Grubb, Executive Director

Billy Altom Phoebe Ball

James Brett Keith Woods

Rabia Belt Netterie Lewis

Benro Ogunyipe Nick Sabula

Clyde Terry Amy Nicholas

Andres Gallegos Ana Torres-Davis

Daniel Gade, telephone

**Absent** **Absent**

Wendy Harbour Joan Durocher

Daniel Gade Amged Soliman

Rabia Belt Stacey Brown

**NCD Contractor**

Anthony Simpson

**Guests**

Irma Mamje, MAVI; Myrianne Z. Roa-Menendez, Puerto Rico Developmental Disabilities Council; Dr. Adela Vazquez-Costa, Parent of a person with a disability; Maria del Carmen Rodriguez, person with a developmental disability; Marcie Roth, CEO, Partnership for Inclusive Disaster Strategies; C. Janet Collazo, Executive Director, Protection and Advocacy Systems of Puerto Rico; Dr. Carol Salas Pagan, Executive Director, PR-UCEDD, University Center for Education on Development Deficiencies-University of Puerto Rico; Mildred De la Torre, Movement for Achieving Independent Living (MAVI) Maria Miranda, Executive Director, Puerto Rico Assistive Technology Program – University of Puerto Rico; Fernando A. Gil Ensenat, Esq., Secretary of Housing of Puerto Rico; Eileen Poueymirou Yunque, Puerto Rico Planning Board; Shannon Davies, FEMA; Jesus Silva Riguero, Unversity Sagrado;

Dorielle Santiago; Ruth M Lozado; Mother; Richard Ortiz Lozado; MAVI; David Hutt, NDRN; B. Ramos, MAVI; Terry Rogers, Chesco Services; Jennie Dela Mota, OHI-ANCOR; Carlos Olivera, lolmobility.com; Armando Ariles, COR3; Barbara Merrill, ANCOR; Charles Hooker, Keystone Human Services; Robert Budd, F.R.E.E. ANCOR; Francine V. Barnett, HHS Recovery; Leticia Manning, HHS Recovery; Judith Torres-Kilgore, HHS/Recovery Support; Ingrid Zambrana, HHS; Alicia McClurian, FEMA; Sara Camilo, PAS-FEMA; Diana Collazo, PR DD Council; Anne Marie Mayberry, ANCOR; Alga Alvez, PRFZEC; Esther Caro, AMPT; Denice Rivera Lugo; Diana Sambolin, Rebeckah Tosado; Batzaida Ramos Charriez; Carol Salas Pagan; Anna Miron Mejias; Esther Caro; Mellybar Correa, MAVI; Yolanda Gonzalez; Carlos Olivera; Erlis Bagan; Barbara Merrill, CEO for ANCOR; `Carmen Warren; Dr. Jeanette Vazquez, clinical psychologist;

1. **Welcome and Introductions**

Chairman Neil Romano called the meeting to order at 9:00 AM (ET) and welcomed Council members, staff and the public.

1. **Acceptance of the Agenda**

**MOTION:** Mr. Billy Altom moved to accept the agenda of the May quarterly meeting.

**SECONDED:** Mr. James Brett

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye

James Brett: Aye

Andres Gallegos: Aye

Daniel Gade: Aye, telephone

Benro Ogunyipe: Aye

Clyde Terry: Aye

1. **Attendance and Roll Call**

Neil Romano, Chairman

Billy Altom: Aye

Rabia Belt: Aye

James Brett: Aye

Andres Gallegos: Aye

Daniel Gade, Aye, telephone

Benro Ogunyipe; Aye

Clyde Terry: Aye

1. **Approval of the Minutes**

**MOTION:** Mr. Billy Altom moved to approve the January Council meeting minutes.

**SECONDED:** Mr. Billy Altom

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye

James Brett: Aye

Andres Gallegos: Aye

Daniel Gade: Aye, telephone

Benro Ogunyipe: Aye

Clyde Terry: Aye

1. **Welcome from Puerto Rico**

Ms. Myrainne Z. Roa-Mendez welcomed council members and staff to Puerto Rico Spiegel welcomed the Council and staff to Puerto Rico. She stated that the Council will have the opportunity to hear from the disability Puerto Rican community and its stories since the hurricane.

1. **Perspectives of the Puerto Rico Community with Disability**

Ms. Adela Vazquez-Costa is a victim of hurricanes Irma and Maria and stated she was sent home in an ambulance with no electricity, water and unable to feed herself. She stated during her hospitalization she became aware that hospital staff were not familiar with disabilities and that she also learned that there were no metrics to guide the provision of physical therapy to individuals with cerebral palsy.

She added during an interview with social workers she was informed that the priority was institutionalized persons were referred by the court.

She stated that here must be a law as strong and forceful as IDEA for the people with disabilities and the needs of adults living under the Commonwealth regime cannot be a mater of mendacity. There needs to be community-based services for all, not for court cases, nor for those who have a GED or for guardianship of a government agency.

Parents should be involved and more participation in the identification of needs of the population.

Maria del Carmen Rodriguez stated she was born with spinal muscular atrophy and that her educational process involved many schools due to the lack of access to obtain services related to therapy.

She stated that transportation was difficult on the island but a little more accessible on the mainland but on the south side and the center of the island, transportation is very difficult.

Ms. Rodriguez stated that 5% of Puerto Rican residence must be accessible, but when looking for a home that is part of a new project is complex.

1. **Executive Reports from NCD members and staff**

**Chairman’s Report, Neil Romano**

Mr. Romano stated the areas of concentration from the Council. They were as follows:

* 14(c);
* AbilityOne;
* Meeting with CEO and Source of America;
* Address of the American Academy of Development

**Executive Director’s Report, Lisa Grubb**

Ms. Grubb thanked Puerto Rico for inviting the Council for hosting their meeting and staff for their endless hard work and dedication.

She stated that there were three approved votes since council meeting. They were as follows:

* Reallocation of funds;
* NCD Institutionalization After Disasters Report;
* Letter to FCC Commission

MOTION: Mr. Altom moved to accept the three report collectively.

**SECONDED:** Mr. Andres Gallegos

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye

James Brett: Aye

Andres Gallego: Aye

Daniel Gade: Aye, telephone

Benro Ogunyipe : Aye

Clyde Terry: Aye

**Financial Representative’s Report, Billy Altom**

Mr. Altom reported that the Council is seven months into the fiscal year and have expended 51% of its budget.

**MOTION:** Mr. Altom moved to accept the finance report.

**SECONDED:** Andres Gallegos

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye

James Brett: Aye

Andres Gallegos: Aye

Daniel Gad: Aye: telephone

Benro Ogunyipe: Aye

Clyde Terry: Aye

**Policy Report, Ana Torres-Davis**

Ms. Torres-Davis stated the projects that are underway. They were as follows:

* Release of Institutionalization Report;
* Ability 1 Report;
* Accessible medical equipment solicitation;
* 2020 ADA Anniversary Progress Report

Ms. Torres-Davis stated last October the American Dental Association followed NCD’s recommendation and updated the code of ethics to specify that dentists could not discriminate against patients with disabilities.

Ms. Torres-Davis stated the Council received its second drafts of t=its five reports on bioethics and disability and those reports address medical futility decisions, genetic discrimination, quality adjected life years, assisted suicide and organ transplant discrimination.

Ms. Torres-Davis stated that this year’s progress report will focus on federal agencies: DOJ, FCC and HUD and how they are tasked with enforcing disability civil rights laws. The Council will be evaluating and monitoring enforcement activities and recommendations for improvement in that report.

Mr. Davis Hutt, NDRN submitted a synopsis of the progress report to the Council. He stated the following:

* NDRN is working with the National Association of the Deaf and the Center for Public Representation;
* 11 elements will be used to look at DOL, FCC and HUD;
* The three federal agencies have developed comprehensive regulations to implement and enforce disability rights law, namely the ADA, The Rehab Act, the Fair Housing Act; Help America Vote and other laws

Mr. Hutt spoke on the ole and responsibilities of each federal agency.

**Legislative Affairs Report, Phoebe Ball**

Ms. Ball reported that NCD’s appropriation received a pass back from OMB with in $200,000 increase to use for cybersecurity.

Ms. Ball reported the following tasks that are underway. They are as follows:

* NCD was tasked by Congress to provide information and coordinate in the Achieving a Better Life Experience Act;
* NCD conducted its second interagency coordination meeting on ABLE Accounts;
* Met with the National Association of State Treasurers;
* Council member Terry attended a congressional briefing on the Rights of parents with Disabilities which offered findings and recommendations from the Council’s report, *“Rocking the Cradle”;*
* NCD will host two congressional briefings on the NEW Deal to Real Deal Report regarding provider transformations away from 14c certificates toward pursuing competitive, integrated employment for people with disabilities;
* A presentation to the National Resource Center on Supported Decision-Making is schedule for June 10which is on the turning rights into reality guardianship alternatives;
* ABLE Age Adjustment Act has not received a markup, but has strong support in both House and Senate;
* The Heads-Up Act would make people with developmental disabilities part of an underserved medical population which connects the dental brief work;
* The REAADI Act and Disaster Relief Act were introduced last session;
* Money follows the person reauthorization has been extended through September 30;
* Child Abuse Prevention and Treatment Act is proceeding to the House and Senate;
* Older Americans Act Reauthorization is proceeding to both houses of Congress

1. **Highlights from NCD’s Report on Institutionalization During and After Disasters**

Ms. Amy Nicholas stated that the report will provide recommendations to help diminish the usage of institutionalization of persons with disabilities during and after disasters.

Date from this report came from daily local and national disaster and disability stakeholder teleconferences held at the height of the disaster response and recovery, as well as focus groups and interviews with key informants about the institutionalization of people with disabilities during and after disasters.

Ms. Nicholas stated the report included recommendations for shelter policies and procedures at federal, state and local levels to improve the outcomes of persons with disabilities.

Marcie Roth, CEO the Partnership fir Inclusive Disasters Strategies and she stated that she welcomes the opportunity to share what has been continually found in addressing the needs of disaster impacted people with disabilities.

She spoke on the Disaster Relief Medicaid Act (DRM).

Ms. Roth stated that the DRM would ensure that individuals eligible for Medicaid who are forced to relocate due to a disaster are able to continue to access their Medicaid supportive services. The bill will provide states with resources to support the Medicaid needs of individuals forced to relocate following a disaster.

Ms. Roth stated he legislation would designate an individual who resides in an area covered under a presidential disaster declaration as a relief-eligible survivor and allow them to continue to access their Medicaid supportive services. The bill would provide states with resources to support the Medicaid needs of individuals forced to relocate following a disaster.

The Disaster Relief Medicaid Act helps states to meet with the needs of relief-eligible survivors through a limited time 100% federal match for displaced individuals, technical assistance and support to develop innovative state strategies to respond to an influx of out of state individuals.

The bill includes a grant to provide home and community-based services. The legislation also guarantees that 100% federal matching payment for medical assistance is provided to states in disaster areas.

Ms. Diana Sambolin stated that VA healthcare needs to develop a directory update system for physical or location addresses and encourage veterans to confirm their locations at least at every medical appointment.

She stated that the VA healthcare provide alternatives for medication, but that information was unknown to the veterans and must be improved.

Puerto Rico does not have a long- term facilities outside of VA hospital facilities. During an emergency, VA needs to send some of our members to private nursing homes for better medical care for its special needs’ patients.

Ms. Rebeckah Tosado stated that they have held listening sessions across the country with FEMA to hear directly from communities about the impact if the major hurricanes and other disasters on individuals with disabilities.

Recommendations were made to state agencies to the central recovery and reconstruction office and as such were to improve the delivery of disaster assistance to survivors who have disabilities.

Ms. Carol Salas Pagan included data of the island for people to have and to share. She shared statistical date after the impact from Hurricane Maria and the lessons learned after its impact.

In terms of demographics and economics, there are 21% that identify as having a disability with 20% of the people over the age of 65 with 40-45% of the them in need of some assistance. She added that 40% are living under the poverty level before the hurricane.

Ms. Salas Pagan stated currently the federal government provides Puerto Rico with 55% of funds for the cost sharing to its Medicaid program but will reach its cap by 2020. Participants who wish to receive services through VITAL must be preselected by the Medicaid office. The qualifications are considered elderly, low income, unemployed and be citizens or have permanent citizenship.

Myrainne Roa Mendez spoke on the effects that the island suffered at the hurricane. She stated the following:

* 100% without power;
* 70% was left without water;
* 100% of the municipalities without water;
* 92.7% of communication towers fell due to the winds;
* 98% uprooted trees;
* Hospitals lost power;
* Emergency personnel rescued approximately 2,000 people in boats;
* 80% of crops were destroyed, a loss of $740 million;
* Only one accessible shelter which located in the metropolitan area;
* 472,00 homes sustained damaged with 25,000-30,000 in total destroyed;
* Dialysis centers were destroyed;
* Lack of operating pharmacies;
* Loss of assistive technology equipment;
* Emergency oxygen was needed;
* Loss of wheelchairs, hearing aid and other critical equipment for living day-to-day

Ms. Roa Mendez stated that family members were the only source of personal assistance to people with disabilities. Those who were taken care of their bedridden family members had to leave their homes to access services, food, water, and gas for them.

Ms. Roa Mendez stated that 68% of those who died between September and December 2017 was due to the catastrophe caused by the hurricane and the number of suicide related deaths doubled from 2,046 to 4,548.

People with disabilities required medical equipment for 24/7 were required to purchase generators to sustain their lives and of course there was a shortage of such equipment.

Ms. C. Janet Collazo reported that between the Puerto Rican bureaucracy, FEMA state and federal agencies no one was able to communicate during the hurricane.

She stated there came about the creation of the Puerto Rico Community Relief Network (PRDCRN). This relief effort was responsible for the following:

* Visited the entire island;
* shelters;
* elderly in their homes;
* hospitals;
* provided water;
* medical equipment;
* created a call center to receive supplies to distribute to people in need and those with disabilities;
* food;
* clothing;
* medication;
* assistive technology;
* hygiene;
* first ad;
* portable stoves;
* solar generators

She added that they created a long-term strategic network to continue to advocate for the rights of people with disabilities in emergency preparedness situations. The goal is disseminating our evidence-based approaches, conduct research and evaluation and to be actively involved about emergency preparedness.

1. **Rebuilding after a Disaster**

Fernando A. Gil Ensenat, Esq., Secretary of Housing of Puerto Rico reported that the CDBG-DR is a disaster recovery grant that provide 24/7 accessible technology for people.it also provides the following:

* opportunity for participation of all citizens including people with disabilities;
* those with limited English proficiency;
* information is provided in alternative formats;

The program has been allocated $32.5 million and it also covers housing for the special needs’ population, homeless, senior citizens, domestic violence victims, and persons with disabilities living with HIV/AIDS.

Eileen Poueymirou Yunque, Puerto Rico Planning Board stated that they oversee coordinating, allocating in an economic manner according to the present and future social needs and human environmental, physical and economic resources to best promote health, safety, assistance, prosperity, culture, economic stability and the general welfare for the present and future inhabitants of Puerto Rico.

She stated their duties are as follows:

* prepare integral development plan for Puerto Rico;
* guide land use plans;
* adopt and approve zoning regulations;
* flood regulations;
* coastal zone regulations;
* zoning maps;
* prepare and adopt four-year capital investment plan
* economic accounts for Puerto Rico
* recommendations for the Governor by annual economic report

Ms. Poueymirou Yunque stated under the CDBG-DR-agency planning initiatives there is a planning integration project which has assigned $50 million to the Puerto Rico planning board to develop a uniform partial registry address mapping and GIS data. A project will be completing the partial level data sets for all unregistered properties in Puerto Rico, a project that will map and help identify areas with high incidence of special populations, locations of special them and which will include the elderly and disabled.

**H. Andres Gallegos, Public Comment**

Campanella spoke on individuals that were diagnosed with a rare disease and not having the opportunity to have an accurate diagnosis due to scientific limitations, technological access and resources.

Ms. Anna Miron Mejias reported that she has a four-year old with autism and ADHD and that the Puerto Rico does not have the AVA program through Medicare that the United States has. She suggested a respite program to help mothers.

Ms. Esther Caro stated that the independent living housing facilities for the last 10 ten years provided housing for adults with developmental disabilities through AMP., but the programs have become a burden due to lack of available funding.

She requested that the Council investigate possibilities of recommending to the proper authorities of reactivating the availability for 11 funds so that the many organizations willing to provide housing services in Puerto Rico can access these funds and make adequate housing opportunities available for the may adults in need of such services.

Ms. Mellybar Correa, MAVI stated that Puerto Rico is facing many struggles daily and they are still training and educating people with disabilities. There needs to be more collaborations with urgency. Emergency plans are being worked on, but they are not taking people with disabilities into consideration.

Ms. Yolanda Gonzalez, special education teacher and trainer at the University of Puerto Rico. She stated her interest are in research and autism. She stated that he son has autism and that the family is responsible for his education and haven’t received and assistance from the government for his health or education.

She stated that their needs to be opportunities for no-site training and mentoring programs for companies and people.

Mr. Carlos Olivera, accessibility mobility specialist stated that there is no enforcement or accountability in commercial and institutional settings. There is a caveat in the Puerto Rican tax code where any solution for accessibility and mobility is tax exempt.

Mr. Erlis Bagan, Ombudsman for people with disabilities represents all people with disabilities. Everyone needs to come together to rebuild the country and guarantee the rights of people with disabilities.

Ms. Barbara Merrill, CEO, ANCOR represents 1600 providers across the United States and provides services for people with intellectual and developmental disabilities and autism.

Ms. Merrill stated that members collectively support over 1 million people and have transitioned thousands of people from private and public state institutions into successful community lives.

Ms. Ramon Fevo, parent with a 35-year son who has multiple disabilities. She stated that she has a day service program which has been very hard to continue due to lack of funds.

Ms. Carmen Warren stated that there is a lawsuit against the Department of Education and the Puerto Rican government.

Ms. Carmen stated that there needs to be mental health care assistance. Parents with children with disabilities would like to be included in the participation and decision-making process.

Mr. Armando Garcia, COR stated that they are responsible for helping municipal employees who work in shelters after hurricanes and emergencies and to accommodate and include all specifics needed to assist people with disabilities.

Dr. Jeannette Vazquez stated that a task force should be formed to work with evidence base to provide services to the people in Puerto Rico and that we find a plan to work on the mental aspect.

**ADJOURNMENT**

MOTION: Mr. Terry moved to accept adjourn the Council meeting.

**SECONDED:** Mr. James Brett

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye

James Brett: Aye

Andres Gallego: Aye

Daniel Gade: Aye, telephone

Benro Ogunyipe : Aye

Clyde Terry: Aye

The meeting adjourned at 4:23 p.m.

Date Approved by the Council: July 15, 2019