ATTENDANCE

Members Staff

Neil Romano, Chairman Lisa Grubb, Executive Director

Billy Altom Stacey Brown
James Brett Keith Woods
Rabia Belt Netterie Lewis
Mary Vought Nick Sabula
Daniel Schreck Amy Nicholas
Andres Gallegos Ana Torres-Davis

Rick Rader Amged Soliman
Joan Durocher

NCD Contractors

Anthony Simpson Kadedra Walter

Guests

Catherine Lhamon, U.S. Commission Civil Rights; Tonya Milling, Executive Director, The ARC of Virginia; Helen Armstrong, Parent Perspective on CIE; Jackie Armstrong, Consumer Perspective on CIE; Phyllis Ferguson, Consumer Perspective on CIE; Mary Lamielle, Executive Director, National Center for Environmental Health Strategies; Mary Rosenberg, Texas Council for Developmental Disabilities; Cara Ayers, Matt Bellier, Executive Director, Patient's Rights Action Fund; Stephanie, Director of the National Center for Prenatal Resources, University of Kentucky; John Pare, National Federation of the Blind; Aaron National Association of Developmental Disabilities

A. Welcome and Call to Order

Chairman Neil Romano called the meeting to order at 10:05 AM and welcomed Council members, staff, and the public.

B. Roll Call

Chairman Romano conducted a roll call of Council members and staff. Current Council members welcomed and introduced themselves to the new members and gave a brief bio.

C. Acceptance of the Agenda

MOTION: Mr. Billy Altom Terry moved to accept the agenda of the November quarterly meeting.

SECONDED: Rabia Belt

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye
James Brett: Aye
Rabia Belt: Aye
Mary Vought: Aye
Daniel Schreck: Aye
Andres Gallegos: Aye
Rick Rader: Aye

D. Acceptance of July 2020 Council Meeting Minutes

MOTION: Mr. James Brett moved to accept the draft minutes of the July quarterly

meeting.

SECONDED: Rabia Belt

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye
James Brett: Aye
Rabia Belt: Aye
Mary Vought: Aye
Daniel Schreck: Aye
Andres Gallegos: Aye

Rick Rader: Ave

E. Chairman's Report and Future Work of the Council

Chairman Romano reported that there has been a large amount of work that has been done since the last Council meeting.

Chairman Romano shared the following in his report:

- Council member Belt and I attended 20 radio interviews regarding COVID and people with disabilities and bioethics issues.
- In October 2020 the Council sent a statement of support to the president's executive order on protecting vulnerable newborns and infants.
- The Council recommended the phase out and replacement of federal employment program for people with disabilities (AbilityOne)
- The Councill released a statement on the harm of using international pricing index for the US prescription drug industry.
- Participated in an ADA anniversary celebration with the Department of Transportation.

- The Councill sent correspondences to the Congress on various issues including a COVID-19 legislative package.
- Letter sent to Secretary Azar on the need for accessible medical equipment rules.
- Meetings with a group called PAY, a sexual assault assistance group and wants to work with the Councill regarding sexual assault and people with disabilities.
- Conducted a series of AbilityOne press briefings.
- Conducted remote new members swearing ins

Chairman Romano stated that the Council would like to continue its work on COVID and the impact that it has had on persons with disabilities. There will be a continued project statements and correspondence in unrelated areas in response to emerging needs.

Mr. Gallegos presented a proposal on the improving health and wellness for persons with disabilities. His proposal focuses on 3.8 million persons with mobility disabilities to use mobility devices and to address their inability to participate and have an equal opportunity to benefit from the services of federally funded recreational facilities and fitness centers.

Ms. Vought presented her proposal on the expansion of the bioethics report that was put out last year.

Dr. Rader presented his proposal on both employment and healthcare disparities among people with disabilities and in direct support professionals. He also proposed mandate that all medical students and medical reports receive competency- based training gin treating patients with disabilities.

Mr. Schreck presented his proposal on a report that will work in tandem with the 2021 report on COVID. He recommends that he Council conduct a thorough national survey of crisis standards of care at public and private healthcare facilities, examine how protocols were applied throughout the crisis and ongoing, and make recommendations based on the Council's findings.

Chairman Romano presented a project follow up proposal to AbilityOne report. He proposed an inventory be taken of the federal disability employment helping people with disabilities gain competitive integrated employment. He suggested using the Government Accountability Office (GAO) reports as a guide.

F. Governance Committee Report

Mr. Altom stated the Council's response to COVID, the administration, Office of Personnel Management (OPM) and the Office of Management and Budget (OMB) been providing timely on ongoing guidance. Other points of interest were as follows:

- Update on award allocations for the performance year 2020, OPM and OMB are
 encouraging agencies to reward employees for excellence and to recognize
 individuals for accomplishing mission critical work; therefore, in response to the
 workforce fund plan, the effort is to increase the amount agencies reward their top
 employees.
- The executive committee voted to reallocate \$23,500 from its deficiency reserve to performance awards for FY 2020

MOTION: Mr. James Brett moved to memorialize the vote and accept the governance report.

SECONDED: Rabia Belt

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye
James Brett: Aye
Rabia Belt: Aye
Mary Vought: Aye
Daniel Schreck: Aye
Andres Gallegos: Aye
Rick Rader: Aye

G. Finance Report

Mr. Gallegos reported the Council's budget as follows:

- FY 20 closeout report
 - reallocation of funds supported an increase from \$242,000 to \$428,600 in fiscal year 2020 toward policy and research projects
 - Cybersecurity requirements presented an increase from \$187,000 to \$297,000
- FY21
- The progress report on COVID is fully budgeted
- NCD is under a continuing resolution from October 11-December 11 with a proportion of the agency's budget.

MOTION: Mr. Jim Baldwin moved to accept the finance report.

SECONDED: Rabia Belt

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye
James Brett: Aye
Rabia Belt: Aye
Mary Vought: Aye
Daniel Schreck: Aye
Andres Gallegos: Aye

Rick Rader: Aye

H. Executive Director's Report

Ms. Grubb provided the executive director report. She commended staff for their hard work. She reported the following activities had occurred since the last council meeting. They are as follows:

Ms. Grubb reminded everyone that the office has been operating in a maximum telework posture since mid-March and shared how quickly we transitioned as an office and how proud she was of the staff and the work that continues to be produced in this remote environment. She thanked the council members for their commendations of staff and reiterated those comments, with special recognition to our staff assistant Stacey Brown who has continued to report to the office each day, ensuring all onsite duties such as checking the mail, mailing correspondence, assisting with the technical needs necessary to ensure everyone can telework and all other on-site duties are completed. He has been working diligently to prepare the office to a return to work environment by ensuring we have all the required PPE. He has also been attending trainings and participating in meetings to ensure he is fully trained to implement safety procedures so when we return to the office our staff will be in the safest office environment.

Ms. Grubb highlighted activity since our last council meeting and extended an invitation to follow up for any additional information, and noted the update is not inclusive of all the work that occurred during the quarter.

In regard to our Human Capital --

- NCD invests in our staff and they have used this time to obtain remote training, and we strongly encourage that to continue.
- We continue to work with EEOC to ensure full compliance in the agency's polices and employment practices. We closed out FY20 with the submission of the MD-715 report which calls for periodic agency self-assessments and the identification and elimination of barriers that prevent equal employment opportunities in the workplace. Additionally, the MD-715 requires federal agencies to work toward meeting essential elements of a model EEO program.
- In the coming weeks, we will submit the Telework Data Call Report Under the Telework Enhancement Act of 2010 and we have continually been recognized as a model agency for our telework program.

Operationally --

• We continue to move toward implementation of the electronic Archives and Records. OMB M-19-21 dictates that all permanent Federal Records are created, retained, and managed in electronic formats, with appropriate metadata by January 01, 2020. We have been working closely with NARA to ensure compliance by the deadline date. Our records will be divided into 3 categories – permanent, permanent metadata and

temporary. In order to meet NARA Electronic Records mandate, NCD is also building a NARA Library in SharePoint to house all temporary and permanent records. We will be rolling out new procedures to implement this requirement.

- To assist with our transition to an electronic record platform, we began implementation of SharePoint and we are working with our contractor to implement NARA's milestones on the road to digitization for NCD. We are diligently working with our contractor to ensure accessibility of our intranet platform, as this platform will serve as an archive and present time dashboard for employee and agency activity.
- We are continuing to explore various meeting platforms and have been testing such platforms as zoom and Webex. Once we can ensure complete accessibility, we will transition to various platforms for our meetings.
- Due to the redistribution of funds as a result of COVID, we have moved the needle on our cybersecurity mandates –
- We are completing our Risk Management Framework
- We uploaded our Authority to Operate on Open Fisma +
- We successfully implemented MTIPS
- We have all the equipment in place to turn on VOIP when employees return to the office
- We are utilizing Open Fisma + to identify our plan of actions

Under Chairman Romano's leadership and with the assistance of our hard-working professional staff and the support of our esteemed council members, we have had a very busy quarter --

- Our AbilityOne report was released mid-October, Polices from the Past in a Modern Era: The Unintended Consequences of the AbilityOne Program & Section 14(c). We are happy to share that we received national press coverage of the report following the release by Disability Scoop, GovExec, and Federal News Network, and Nonprofit Quarterly. We continued our release efforts by hosting a targeted press briefing followed by hosting an educational four-part policy briefing series for congressional staff on the report, breaking out the material into the four subject areas covered in the report. The briefings were attended by congressional staff and members of the disability community, with a total of over 500 attendees. These briefings were audio recorded, and each briefing's audio as well as associated policy script posted is or will be on the NCD website for ongoing consumption by anyone who visits our website.
- In observance of the National Disability Employment Awareness Month (NDEAM) and throughout the month of October, Chairman Romano and Council Member Rabia Belt participated in radio interviews and podcasts, focusing talking points on employment and subminimum wage phase out. Interviews also included discussion on Covid and the impact on persons with disabilities.
- Our bioethics report series continues to generate great interest, particularly in regard to our QALYs report. We are continuing to look at these issues nationally and on a state level.

- In late July, the House Appropriations Committee Report language included strong encouragements of HHS OCR consistent with NCD's recommendations in its Dangers of Assisted Suicide Laws report issued last fall as a part of NCD's bioethics series.
- Also, in July, NCD's report on involuntary institutionalization during disasters was entered into the record in a House Committee on Transportation and Infrastructure hearing entitled, "Experiences of Vulnerable Populations During Disaster" without objection.
- Our 2021 Progress Report is underway, and we are examining the broadscale impact of COVID-19 on the lives of people with disabilities in healthcare, direct care services, employment, education, group homes, communications, and mental health.
- We participated on a panel discussing disability rights and access to justice at the Equal Justice Works conference, with a particular focus on access to justice issues through the lens of the 30th anniversary of the ADA.
- We continue to meet with the ACL Center for Policy and Evaluation to discuss NCD's recent letter to CMS regarding coverage of seat elevation/ standing systems.
- We issued a statement of support for the President's September 25, Executive Order on protecting vulnerable newborns and infants, and recommending that HHS' Office for Civil Rights issue a proposed rule to implement the EO.
- The final draft of the Accessible Medical Diagnostic Equipment is undergoing its final revisions and we hope it will be ready for a vote very soon.
- We kicked off the IDD Medicaid-Dental Reimbursement Project which is seeking to increase of the oral healthcare Medicaid reimbursement rate for people with I/DD. The Virtual Stakeholder meeting for this project occurred recently as part of data gathering process.
- We also kicked off our report on Puerto Rico, which is looking at the disparate treatment people with disabilities receive in terms of federal programs solely because they are residents of Puerto Rico.
- We are developing an MOU with the Administration on Community Living to update NCD's tribal lands toolkit.
- We are in the final phases of sending a letter to the Department of Defense (DOD) asking it to reverse its decision on cutting its CAP accommodation program to other federal agencies along with supporting the development of a centralized accommodation fund for the entire federal government.

Budgetary,

- We revamped the organizations budget to adjust as needed for Covid. Additional details will be provided during the financial report.
- We continue to operate under a continuing resolution with a limited budget until December 11th.
- We submitted our budget request and were granted permission to write to an above budget request.

In closing Ms. Grubb shared that it is NCD's practice to schedule council meetings one year in advance to allow for adequate planning. If you have not already responded to the request for date availability please check your NCD email and respond as soon as possible so we can lock in the quarterly meeting dates for the next year.

I. Presentation by Chair Catherine Lhamon, Commission on Civil Rights
Ms. Lhamon stated that the sub-minimum wage is very important to the Commission on
Civil Rights and the work that the Council has done.

Ms. Lhamon stated the commission's majority's findings and recommendations are consistent with the art of the Council's that states the program is discriminatory and with such recommendations made, that it be phased out.

She stated that 14c does not serve its stated purpose to prevent curtailment of opportunities for employment and the most recent census shows that 35.9 % of people with disabilities were employed.

Ms. Lhamon stated that the commission received testimony from the Center for Mental Health Law that people with disabilities still participate in the labor force at less than half the rate of people without disabilities; and only 20 percent of people receiving public mental health services have any form of employment.

Ms. Lhamon stated the commission has investigated and concluded that federal agencies do not have sufficient enforcement authority to address the range of legal risks inherent in the program and have not sufficiently used the authorities that they do have.

In conclusion, the commission investigation shows that competitive integrate active employment is possible in at least two states that have succeeded in which funding supports have been in place to ensure 14 C workers will not lose their jobs and have time to learn new skills.

J. Successful Transitions from 14 c Subminimum Wage Employment Ms., Tonya Milling, ARC Virginia stated the ARC wants to help people live in their homes and work a job of their choice where they are valued; paid fairly and spend time doing what they enjoy.

Ms., Milling stated that ARC is trying to be creative to help people explore ideas regarding jobs outside of workshops.

Ms. Milling stated that ARC has assured that every person was able to meet with a benefits counselor and have an assessment completed to help ensure they were able to maintain their benefits.

Ms. Helen Armstrong, parent shared the experiences that her daughter had as being a disabled adult who has been fully integrated a neuro typical workforce. She attributed her family having moved to Sacramento, California do to the Lantraman Act, a law that gives disabled persons the right to access services that really enable them to be who they want to be and live independent lives.

Ms. Jackie Armstrong, consumer stated that she now at 35 years old lives independently and she was diagnosed with autism and prior to the pandemic she had a very active lifestyle with numerous friends with a very active lifestyle.

K. Progress Report 2021, COVID-19, Chairman Neil Romano

Chairman Romano stated that the Council has decided to focus its 2020 progress report on COVID-19's broad scale impart on the lives of people with disabilities.

The report will specifically examine the following:

- access to life saving health care.
- how the virus impacts direct care workers and the people with disabilities who rely
 on direct care worker to maintain their health and independence.
- the impact on employment of people with disabilities, particularly those who have had underlying medical conditions that made them more susceptible to the virus.
- the impact of the virus on those living in group homes.
- how virtual communication has impacted the disability community particularly those with sensory disabilities.
- how the virus impacted the ability of people with mental health disabilities to receive the care they need.

In addition, chairman Romano stated that this report could be used a s a tool for future natural disasters and the research and the development of it will continue through the spring with the anticipated release in the summer of 2021.

L. Accessible Medical Diagnostic Equipment, Billy Altom

Mr. Altom reported that people with mobility disabilities continue to have unequal access to healthcare due to physical barriers, such as inaccessible examination tables, radiology machines, weight scales and other routine examination equipment.

Mr. Altom stated the inability to access medical equipment has contributed to the well documented poor health outcomes of people with disabilities.

The report details, includes with recommends the following:

History and prevalence of poor health outcomes of people with disabilities.

- developing standards for medical equipment and the legal framework for the provisions of such equipment.
- challenges to legal adoption of accessible medical equipment standards.
- availability of accessible equipment.
- all health care facilities nationwide and standards for such equipment are integrated into existing civil rights laws.

M. Disparate Treatment of Puerto Rico Residents in Federal Programs, Andres Gallegos

Mr. Gallegos stated that the report will examine what it means to be a United States citizen with a disability residing in Puerto Rico. It also will examine the disparate treatment of 687,000 citizens residing in Puerto Rico under various federal programs in contrast to those counterparts residing in the mainland.

Mr. Gallegos stated that the report will specifically discuss the following:

- Puerto Ricans with disabilities employment and poverty rates.
- Educational obtainment.
- Access to healthcare.
- Housing.
- Transportation.
- Access and participation within their community.
- Access to medical supplies; durable medical equipment and repairs.
- The impact of the Jones Act and its requirement of prohibiting foreign flagged ships to carry cargo between the United States and Puerto Rico.
- Final report will include recommendations from research and interviews

N. IDD Medicaid Reimbursement, Examining Medicaid Reimbursement for Oral Healthcare of People with IDD, Rabia Belt

Ms. Belt reported that this project builds off the Council's recent work regarding proper oral healthcare for people with IDD. It also will examine the potential increase of oral healthcare and Medicaid reimbursement rates for people with IDD. She added that the Council and its contractors will analyze the available data, report the findings, and make necessary recommendations such date will be gathered and reviewed with a few months with a completion due summer 2021.

O. Public Comment on 14c and People with disabilities during COVID, Rabia Belt

Mr. Baldwin stated that no one should be left behind, cause no harm along the way, work to make disability employment a priority in the states nationwide. He added that consumer input is very important.

Ms. Mary Lamielle, Executive Director of the National Center for Environmental Health Strategies stated that people with environmental intolerance suffered greatly to access healthcare, amongst having access of accessible buildings and medical facilities. There is also an absence of medical personnel and support staff or the willingness to accommodate such individuals in a manner that meets their needs.

Ms. Lamielle added now the impact of COVID has amplified such individual's health. Complex health problems and serious underlying conditions independent of or related to their environmental illness which may need medical attention in a world that has become more challenging during this pandemic.

Ms. Lamielle stated that the skills that she has developed through the years have helped her agency survive the pandemic for she has being wearing masks.

Ms. Mary Rosenberg, Texas Council for Developmental Disabilities stated she has been monitoring how people with disabilities and their families have been impacted by the COVID-19 pandemic. Two surveys have been conducted. The first survey covers access to healthcare, basic needs, and day programs. The second survey participants were asked if their access to therapy had improved.

Dr. Cara Ayers stated her center's mission is to reduce life limiting healthcare experienced by people with disabilities related to COVID. She stated that people living in healthcare facilities face a much greater risk of contracting and dying from COVID-19, with a shortage of PPE contributing to that risk.

Dr. Ayers stated that employees work to address the inequities and we commend the Office of Civil Rights for its work to doing the same. There is significant danger that people face with disabilities experiencing hospital visitors being banned which gives the support they need.

Matt Bellier, Executive Director, Patient's Rights Action Fund stated his organization is a secular nonpartisan leader working nationally to protects patients, people with disabilities and others from the impact of legalized assisted suicide.

Stephanie, Director of the National Center for Prenatal and Post Resources, University of Kentucky. The center provides support to parents learning that they have a genetic condition. Medical and advocacy partners have reported that genetic screening and counseling decrease during quarantine.

She stated that safety measures need to stay in place so people with disabilities can continue to participate in society until the pandemic subsides.

Mr. John Pare, National Federation of the Blind commended the Council on its most recent report on minimum wages and the Council meeting.

Mr. Pare stated the federation recently passed a resolution on unemployment and hopes that the Council and his organization can work together to raise expectations in all areas of unemployment.

Aaron, a representative with the National Association for Developmental Disabilities spoke on the Council's work to investigate the impact of COVID-19 on people with IDD. Several of the COVID-19 specific issues that has been addressed in data collections included the lack of technology, internet access, and training as an obstacle to services that will be provided remotely. Other issues that have been addressed are as follows:

- Food and security in several states due to the pandemic.
- Shortage of PPE for direct support for individuals and families.
- Discriminatory hospital visitation policies and access to urgent medical care.
- Lack of educational services for students with individualized education plans

Mr. Anthony Simpson presented public comments from an email. It stated the following:

- Isolation has been a significant issue for much of the population during the pandemic.
- Decrease in access to health providers across the board. Home health, primary care, mental health, and transportation.
- Inaccessible testing sites.
- Working with community partners to find permanent housing.
- Higher rates of unemployment

P. Adjournment

MOTION: Dr. Rick Rader moved to adjourn the meeting.

SECONDED: Rabia Belt

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye
James Brett: Aye
Rabia Belt: Aye
Mary Vought: Aye
Daniel Schreck: Aye
Andres Gallegos: Aye

Rick Rader: Aye

The meeting adjourned at 4:00 p.m.

Date Approved by the Council: March 11, 2021

Signature

Andrés J. Gallegos

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