**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 Amged Soliman

Wendy Harbour

**Absent**

Joan Durocher

Stacey Brown

**NCD Contractor**

Anthony Simpson

**Guests**

Shelley Richardson, Executive Director, State Ride Independent Living Center; Sylvia Flores, Deputy Governor; Karen Tamley, Commissioner, City of Chicago-Mayor’s Office for People with Disabilities; Kristi Kishner; Rehabilitation Doctor; Michel Greis; Denise Harmon, Certified Technology Specialist; Jessica Pederson, Specialist in seating and positioning; Angel Miles, Health Care Home and Community Based Policy Service Analyst; Sarah Ushkow, Social Worker; Rochelle Marceillars; Marca Bristo, CEO, Access Living; Rahnee Patrick, Director, Division of Rehabilitation Services , Department of Human Services; David Cur, Bureau Chief, Home Services Program; James Kadina, Chairperson , Illinois Human Rights Commission; Shelley Richardson, Deputy Governor, Health and Human Services; Debra Stein, Vice President of the National Federation of the Blind Illinois; Marcella Goodridge; Ethics Officer; Loren Harris, Outreach Director, Office of Senator Tammy Duckworth; Hugh Woodson, President, Chicagoland Black Deaf Advocates; Leandra Williams, nationally certified sign language interpreter; Rachel Arfa, Staff Attorney, Equip for Equality; Bryen Yunashko, President of Access 256; Tonia Bogener, Interim Director, Illinois Deaf and Hard of Hearing Commission; Corey Axelrod, founder and CEO of 2axend; Tom Wilson general commenter; Brandy Belford, public commenter;

1. **Welcome and Introductions**

Chairman Neil Romano called the meeting to order at 8:40 AM (UTC) and welcomed Council members, staff and the public.

1. **Approval of minutes**

**MOTION:** Mr. Romano moved to accept the minutes of the Puerto Rico minutes with the amendment which adds Wendy Harbour and Rabia Belt as being present at the meeting.

**SECONDED:** Ms. Wendy Harbour

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye

James Brett: Aye

Andres Gallegos: Aye

Daniel Gade: Aye

Benro Ogunyipe: Aye

Clyde Terry: Aye

Rabia Belt: Aye

Wendy Harbour: Aye

1. **Welcome to Chicago**

Sylvia Flores, Deputy Governor welcomed the Council on behalf of Governor Pritzker and Marca Bristo, CEO Access Living.

Ms. Shelley Richardson, Deputy Governor, Health and Human Services stated that Governor Pritzker is deeply committed to having voices of all levels of government represented in this administration and will continue recruiting people with disabilities to play key roles in state government.

Ms. Richardson stated that Rahnee Patrick, Director, Division of Rehab Services, David Cur, Bureau of Chief, Home Services Program and James Kadina, Chair of the Illinois Rights Commission all look forward to working with the Council.

Ms. Richardson stated that her role is to find opportunities to break down silos and create greater collaboration amongst the eight key agencies that are focused on health and human services and to advance the interests in improving the quality of lives with people with disabilities in every way.

Ms. Richardson stated that her agency was established the Rehab Act of 1973, Title VII, Section 705 and they work together in the state of Illinois 22 independent living centers.

She added that she has spent a tremendous amount of time going across the state getting public input on issues that are affecting them. She said that they are working with Dr. Susan Mengasse, University of Illinois, Ryan Prope, Network of Centers for Independent Living, and CIL’s to conduct public town hall meetings.

Ms. Karen Tamley, Commissioner, Mayor’s Office for People with Disabilities stated the role of her department is to advice the mayor and other city departments on disability issues and working make the city of Chigo the most accessible in the nation for people with all types of disabilities.

Ms. Tamley stated the key issues that he department is working on. They are as follows:

* Emergency preparedness;
* Transportation
* Pedestrian accessibility for blind and low vision individuals;
* Employment;
* Building a pipeline of young people with disabilities to obtain employment through internships;
* Emergence of E scooters and how they impact the disability community

1. **Chairman’s Report**

Mr. Romano the Council has two target dares and they are as follows:

* Employment
* Accessible medical care

Mr. Romano stated the Council met with various groups that have been distant from the disability community one being Ability 1 and the Source America.

Mr. Romano complimented James Brett and Amged Soliman on their work regarding accessible medical care.

1. **Executive Director’s Report**

Ms. Grubb reported the following:

* The Council included $200,000 increase consistent with the projected increase which is contingent on a continuing resolution if the government should shutdown;
* Finance team is preparing for a biannual audit;
* Continued discussing future actions and activities from the Puerto Rico meeting in regards to hurricane relief;

Ms. Grubb stated that on the legislative front the president signed the pandemic and all hazard preparedness and Advancing Innovation Act of 2019. The law established the new advisory committee on individuals with disabilities and disasters and makes NCD’s chair a member.

The legislation will fund money-follows-the-person for 2004 and preserve asset protections for the spouses of Medicaid beneficiaries who receive long term care benefits and extend the community mental health services.

Ms. Grubb stated the Council’s key report recommendations have been introduced and very excited when action comes from the recommendations.

The Disaster Relief Medicaid Act requires that states provide Medicaid to eligible disaster survivors through a streamline eligibility process when a person is forced to relocate from their home state as a result of a disaster.

The Council’s 21st Century Assistive Technology Act report seeks to ensure that all individuals with significant disabilities affecting communication have access to augmented and alternative communications.

The Expanding Access to Higher Education Act seeks to increase recruitment of students with disabilities into the program and grants for the creation of offices of accessibility on college campuses and also the reintroduction of the Higher Education Mental Act and the Safe Equitable Campus Resources and Education Act which are based in large part on the Council’s mental health coverage of college campuses report to monitor addressing the sexual assault on college campuses.

The Transition to Competitive Employment Act which would phased out 14C subminimum wage employment will also while also provide capacity building grants to states and providers to system work models.

NCD highlighted legislation to competitive employment house and senate briefing which incorporated many of NCD’s recommendations. The Council is currently exploring the possibility of hosting a congressional briefing in late July on the content of preserving and freedom report and involuntary institutionalizations.

Ms. Grubb stated that the Council upcoming report releases of the bioethics disability series working on a release date and looking on different rollouts which will highlight each section of the report.

1. **Finance Report**

Mr. Woods reported that the Council has $20,000 in reserve for unexpected spending which has the agency currently in the black.

He stated the importance for Council members to report their time in a timely manner and accurately.

Ms. Grubb stated that there are two open projects that will go to next year’s progress report and Ability1 reports.

MOTION: Mr. Altom moved to accept the Finance Committee Report.

**SECONDED:** Ms. Rabia Belt

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

Rabia Belt: Aye

Wendy Harbour: Aye

1. **Governance Committee Report**

Ms. Belt stated that there has been one approved vote electronically since the last Council meeting on the bioethics report with four approval votes and no votes from five Council members and one abstained.

Roll Call Vote:

Neil Romano, Chairman: Aye

Billy Altom: Aye

James Brett: Aye

Andres Gallegos: Aye

Wendy Harbour: Aye

No Vote

Clyde Terry

Rabia Belt

Daniel Gade

1. **Rehabilitation Technology Panel**

Ms. Kristi Kirschner, rehabilitation doctor stated that she focuses on the challenges and issues faced to get complex patients the needed equipment. Focus is placed on complex rehab technology which is defined as medically necessary, individually configured devices that require evaluation, configuration, fitting, adjustment and programming. These devices are designed to meet specific unique medical, physical and functional needs of an individual with a primary diagnosis resulting from a congenital disorder, progressive or degenerative neuromuscular disease or from certain types of injury or trauma.

Mr. Michael Grice reported that there are four areas of concern. They are as follows:

* Lack of communication between MCO’s and wheelchair companies;
* Technicians, physical therapists, and doctors need to listen to consumers more regarding their needs;
* Technicians, physical therapists and doctors will tell patients what they should have on their mobility devices;
* There needs to be more education for consumers requiring information regarding them getting a new wheelchair

Ms. Sarah Ushnow gave a synopsis of 3 cases and the lengthy paper process for obtaining access to seating and wheel mobility devices.

Ms. Jessica Pederson spoke on the role of the therapist during the process which is to provide a thorough evaluation as well as looking at several aspects of the individuals physical, environmental and functional abilities.

We want suppliers to work closely with the therapists to assure that the evaluation is done appropriately and that the fitting is done appropriately.

While Medicare acknowledges the need for specialty examination by a qualified therapist in the ATP, the documentation requirements are copious and get lost.

Mr. Angel Miles stated that she has experience in women’s studies and is currently working as a policy analyst at Access Living in health care. Her personal experience is her professional knowledge as a researcher.

Ms. Rochelle Marceillars reported that she sent 12 years obtaining her Ph.D, and gave a comparison between standard and motorized chairs and the requirements of each.

She stated that NCART is advocating for a bill called the house bill2293 which was introduced by Congressmen John Larson and Lee Zelden as well as other bills were to help appropriate Medicare payment reductions for critical components to complex rehabilitation chairs and to halt the competitive bidding process that has reduced the quality of products that people with disabilities get when they get their wheelchairs.

Ms. Marco Bristo welcomed the Council to Chicago and stated the Council was the original birthplace of the ADA and she was the was the first chairperson that came after that process. She urged the Council to push beyond its limits as a federal agency and to make sure to have people with disabilities at the center of everything that you do.

1. **Air Transportation Panel**

Ms. Loren Harris, outreach Director, Office of Sen tor Tammy Duckworth provided opening remarks and a letter from the senator’s office stating hope with a rule change would require air carriers to disclose how many wheelchairs and scooters they damage or mishandle and that that number will be lowered and to bring transparency for passengers with disabilities and help inform their travel decisions.

Ms. Karen Tamley stated her office has received many complaints from travelers regarding the poor experiences and the lack of accessibility at airports.

She stated that Chicago’s two major airports are undergoing major renovations to incorporate customer service, universal design principles, accessibility and communications that will go beyond the standards that exist.

She added that they are looking at issues of the concessionaires and how to make restaurants more accessible for people with disabilities including menus, seating, animal relief area and restrooms.

October 15, 2018, President Trump signed the FAA Reauthorization Act which contains numerous provisions regarding travel for people with disabilities. A study is required in consultation with the secretary of transportation, aircraft manufactures, air carriers and disability advocates. Also required is a report on the findings of the study to Congress.

Ms. Jessica Pederson stated one of the issues with TSA are as follows:

* Attitudinal;
* Changing stations;
* Boarding chairs

Ms. Dedra Stein, vice president, National Federation of the Blind, Illinois stated the obvious issues that blind people experience are different those that have mobility impairments wheelchair users. The main issue that confronts us is gathering information, getting information about where to get boarding passes, bags checked and how to get through security.

1. **Annual Ethics Training**

Ms. Marcella Goodridge, ethics officer, Department of Education gave the Council its annual ethics training.

Ms. Goodridge informed Council members that he role is to serve on the Council and that they are considered special government employees which is defined by statute. It stated that you are provide services for the government for a period of 130 days within

a 365-day period.

1. **Communication Panel**

Mr. Amged Soliman introduced the panel which will highlight the struggles of people who are deaf licensed sign language interpreters and their interactions with law enforcement as well as the shortage of interpreters and policy recommendations to help solve the issues.

Mr. Ogunyipe introduced and gave a quick vita of each panelist.

Mr. Hugh Woodson, Chicago Black Deaf Advocates stated that one of the issues that is noticed in black communities is that there are not enough culturally accessible black interpreters. The community prefer black sign language interpreters and others just don’t understand the needs of the community. He stated that they are invested in the use of providing interpreters when interacting with law enforcement.

Ms. Leandra Williams, certified sign language interpreter stated that she is involved in board and committee services to various organizations within the deaf community, including the National Black Deaf Advocates, the Chicagoland Black Deaf Advocates, National Registry of Interpreters for the Deaf, the state chapter, Illinois Registry of Interpreters for the Deaf and the National Alliance of Black Interpreters Incorporated.

Ms. Rachel Arfa, attorney Equip for Equality, stated she represents people with disabilities statewide and manages two PABSS which advocates for the beneficiaries of social security and chairs the Illinois ADA project which provides information and referrals to businesses who are in Illinois regarding ADA issues.

Mr. Bryen Yunashko stated he is trying to develop technology worldwide for better access and in doing so he has contacted the FCC, FEMA, IPWA and the commission IPAWS.

Ms. Tonia Bogener, interim director of the Illinois Deaf and Hard of Hearing Commission. The agency is dedicated solely issues related to the deaf, deaf-blind and heard of hearing.

Mr. Corey Axelrod stated that communication through interpreters is what would be successful. VRI is becoming more and more throughout health care where deaf people are not satisfied.

Ms. Williams stated there are challenges faced in higher education with interpreter education programs is being able to recruit and graduate. She stated there needs to be people from various communities of color to serve as sign language interpreters. Indigenous people are also struggling for there are no interpreters that understand their language.

Ms. Arfa stated the following:

* that hospitals are rather reticent in providing sign language interpreters which has a detrimental impact on services for deaf and hard of hearing individuals;
* emergency rooms should be prepared to provide communication access even if the patient is not deaf;
* training needed for criminal justice system staff and that deaf and hard of hearing people get the access that is needed while in prison;
* better communicant access and less reliance on family members to assist deaf and hard of hearing prisoners;
* challenges with the certification process and the licensure process.

**I. Public Comment**

Mr. Axelrod stated that the following needs to occur:

* training of the deaf health care;
* assertion that deaf people have the preferred method of communication;
* health care providers lack of cultural language competencies;
* funding for health care education, health care education programs, that includes medical school, nursing programs, and allied health.

A native Polish caller stated he had severe anxiety and a significant psychiatric disorder and stated that there are thresholds are the biggest mental health community organization in the state.

Ms. Susan stated that she didn’t want any institutional bias and that disability rights are constitutional rights as well.

Mr. Tom Wilson, former Access Living employee stated he wanted the Council to support Medicare for all and that the bill includes universal coverage of home care services.

Caller (unnamed) proposed that there be public access for all. The country needs to show the strength that people with disabilities to produce their own stories.

Caller (unnamed) recommends medical reforms for people who suffer from mental illness as well as employment for people with intellectual and mental health disabilities.

Ms. Brandy Bedford, deaf advocate stated that there are a lot of licensures who are not CDI’s.

**J. Unfinished Business**

JJ Hanley, Illinois State Treasury stated she has been a disability advocate for 26 years and have engaged in disability advocacy in numerous ways. She personally believes the ABLE account and ABLE Act is the most transformative and important act and piece of legislation that give people with disabilities opportunity since the passage of the ADA. It is a tool that can help to achieve the promises of the ADA.

The ABLE Accounts and ABLE act have a transformative capacity to help significantly give people with disabilities and the entire community a voice that it has not had.

**K. ADJOURNMENT**

The meeting adjourned at 4:23 p.m.

Date Approved by the Council: August 22, 2019