

**National Council on Disability
Council Meeting
July 12-13, 2023**

ATTENDANCE

Members

Andres Gallegos, Chairman
Hoskie Bennally, Jr.
Sascha Bittner
Theo Braddy
Shawn Kennemer
Risa Rifkind
Emily Voorde

Staff

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

Absent

Claudia Gordon, Vice Chair
Neil Romano

Absent

Anne Sommer-McIntosh
Lisa Grubb

NCD Contractors

Amanda Lowe
Anthony Simpson
Kadedra Walters

Guests

Zainb Dhanani, Executive Director, Medical Students with Disability and Chronic Illness; Dr. Susan Havercamp, Director, Health Promotion and Healthcare Parity, The Ohio State University; Matt Holder, Past President, American Academy of Developmental Medicine & Dentistry; Dr. Priya Chandan, Clinical Associate Professor, Division of Physical Medicine and Rehabilitation, University of Louisville School of Medicine; Chloe Rothschild, Board Member, ARC; Dr. Jonathan Perlin, President and CEO, The Joint Commission; Dr. Shepley; President Elect, American Medical Association; Dr. John R. Combes, Chief Communications and Public Policy Officer; Accreditation Council for Graduate Medical Education; Stephanie Meredith, doctoral student, Georgia State University; Julie Sowash, Disability Solutions; Ramonia Rochester, National Disability Institute; Lydia X.Z. Brown, SSI; Dahlia Shaewitz, CEO of Third Sight; Geoffry Young, Senior Director of Transforming Healthcare Workforce; President, American Dental Association; Bruce Scott, President-elect, American Medical Association; George Shepley, President of the American Dental Association

Public Comment

Kim Musheno, Vice President of Public Policy, Autism Society of America; Bart Devon, Senior Director of Eggleston; Vanessa Rastovic, Achieveva, Disability Healthcare Initiative; Chapman Bryant, National Down Syndrome Congress; Nicholas Lawson,, Charlotte Woodward, National Down Syndrome Society; Janet Parker, Executive Director, Medical Advocacy Network; Doris Ray, ENDependence Center of Northern Virginia; Beth Kenny, Elizabeth Kelly, Executive Director for the Alliance; Debbie Funk, Vice President of Education and Inclusion; Lisa Aquila, Kate Small, Erin Putman, Catherine Ivy Kennedy, Alex Alvarez, Meghan Schrader, Linda Riley, Javier Robles, President, New Jersey Action Network and Chair of the New Jersey Disability Action Committee

A. Welcome and Call to Order

Chairman Gallegos called the meeting to order at 9:00 A.M. (ET) and welcomed Council members, staff, and the general public.

B. Roll Call

Chairman Gallegos conducted a roll call of Council members, staff and contractors.

C. Acceptance of the Agenda

MOTION: Sascha Bittner moved to accept the agenda as presented.

SECONDED: Emily Voorde

Roll Call Vote:

Andres Gallegos, Chairman: Aye

Sascha Bittner: Aye

Theo Braddy: Aye

Shawn Kennemer: Aye

Emily Voorde: Aye

Risa Rifkind: Aye

Motion Passed Unanimously

D. Chairman's Welcome and Framing Remarks for Meeting

Chairman Gallegos welcomed everyone to the first in person Council meeting in 4 years.

He stated the council meeting will cover the following topics. They are as follows:

- Health disparities through educational curricula and training;
- Updates on the Council's projects in the areas of fetal medicine, germline editing and medical trials;
- Council's business meeting;

- Council member reports on their community contacts and updates since the May 2022 Council meeting;
- 33rd anniversary celebration of the Americans with Disabilities with a fireside chat with Bob Burgdorf, who drafted the original legislation.

E. Framework to End Health Disparities for People Across all Categories of Disabilities

Chairman Gallegos reported that the Council published the Framework to End Health Disparities for People Across all Categories of Disabilities which was its approach to end health disparities. The framework is composed of 44 components including several key components being the following:

- Enhanced data capturing;
- Designation of facilities especially underserved populations;
- Designating all people with disabilities as a health disparity population;
- Medical and diagnostic equipment standards;
- Developmental clinical care curricula and training

Chairman stated that there are many studies that compare to non-disabled individuals showing that people with disabilities have a greater risk cancer, diabetes, heart disease, obesity. Asthma, hypertension, kidney and liver conditions and experience greater adverse pregnancy outcomes. Also, people with disabilities have a harder time accessing medical services, routine healthcare services, dental care, screenings and further document that people with disabilities have significantly higher ratios of limited physical activity.

Chairman Gallegos stated the Association of American Medical Colleges which has 157 United States medical schools that are accredited and only 35 voluntarily require a limited disability-related curriculum. He added there are 400 teaching hospitals and health systems which include the Department of Veterans Affairs medical center, 96,000 plus medical students and 153,000 residents in the United States.

Chairman Gallegos stated that section 507 of the Patient Protection and Affordable Care Act of 2010 with the passage of the Patient Protection Care Act, permits the Secretary of Health and Human Services to issue grants to fund development and dissemination of a curriculum for cultural competency, prevention, public health proficiency, reducing health disparities and attitude for working with individuals with disabilities, training for use in health profession schools and continuing education programs.

Ms. Risa Rifkind introduced the panelist that spoke on health disparities through disability clinical care.

Chloe Rothschild, board member, of ARC and a medical student with a disability. Ms. Rothschild spoke about her medical experiences and how her needs were met. She encourages those with disabilities to be persistent with accommodation that they may need. She stated that it would be helpful if she had assistance in navigating her needs.

Ms. Rothschild stated mental health is another area of concern because it has been difficult to find a psychiatrist that can meet the needs.

Susan Havercamp as regards healthcare, people with disabilities have a lower quality of life. She teaches in health education that disability is a negative health outcome that should be prevented and cured. Health care providers perceive that having a disability is incompatible with good health. These beliefs contribute to the discomfort of many healthcare providers in caring for patients with disabilities and to the poor healthcare that is provided in terms of less preventive health services, fewer testing and less aggressive treatments. Caregivers feel uncomfortable caring for patients with disabilities that they do not communicate directly with them.

Ms. Rothschild stated that disability needs to be spoken of when speaking about health disparities, underserved populations, health equity and cultural competence. She added that it is necessary to build the next healthcare workforce to meet the needs of all people in society and to consider disability laws for other marginalized disabilities in education. She added that other factors would be as follows:

- Must be intentional, concentrated efforts to ensure doctors medical staff training;
- Doctors need to be patient and trained and be respectful;
- Medical community should take issues seriously and challenge themselves through the myths, stereotypes, and discriminatory behaviors;
- The medical community should adopt changes in their curriculum and professional training to address discrimination against people with disabilities;
- Greater recognition and discrimination ableism creates poor health outcomes;
- We want the medical community to support reforms to the healthcare system that can expand access to affordable, comprehensive healthcare for all people.

Ms. Priya Chandan stated that the primary audience of focus for these concerns and issues are the educators, clinicians and researchers. Dissemination has to reach further with the health services and to applied researchers.

Ms. Zainub Dhanani reported that medicine has made strides towards patients with disabilities with a long way to go. The history of medicine is full of discrimination and devaluing people with disabilities which alone has left a legacy that medicine still has not eradicated. There is a need for more disabled leaders in medical education and for dedicated training around ableism in healthcare for students as well as current providers.

Disability is a form of diversity, and we believe that disability adds a valuable benefit to the community in medical education trying to help institutions and communicates understand that further.

Ms. Dhanani pointed out the following issues. They were as follows:

- Reasonable accommodations for students with disabilities are often riddled with transparency and barriers that hinder access to those accommodations;

- Main challenges for people with disabilities is obtaining reasonable accommodations. Particularly in clinical rotations and medical school;
- Reevaluation and redesign of the accommodation process on all levels;
- Medical education at large has been intending with increasing evidence of racial and gender bias within clinical clerkship assessments for students;
- Licensing new physicians with under or unmanaged mental health issues is a concern far more detrimental to the profession and patients than supporting mental health for future providers and their licensing.

Mr. Matt Holder stated the medical and dental professions need to do the following:

- Barriers need to be broken between dentistry and medicine;
- Research in clinics have found 60% of patients were sent to routine dental care, with an interdisciplinary approach, which can be reduced by 95% which in turn a \$4,000 visit would result in a \$400 dental visit;
- medical insurers are paying for anesthesia but not involved in the dental insurance payment side;
- there needs to be a revamp to the training of healthcare providers;
- shift the paradigm of working with people with disabilities into a preventive fashion; focus on prevention and primary care, there would be savings of unnecessary spending and hospitalizations, drugs, and ER visits.

Dr. John Combes states there needs to be a faculty that can model the behavior of residents and medical students. Also, organizations need to be focused institutionally on providing equitable care.

Dr. Combes stated the medical education accomplishes work from two mechanisms. Quality Assurance Function and education and resources which is a quality improvement function. All residency programs must have an AGG accreditation to be funded by Medicare. Most of our time is spent supporting the improvement function which includes initiatives around diversity, equity, and inclusion.

Dr. Combes stated there is tool kit that is on his website that includes resources for programs to develop their training with the goal of promoting equity and diversity within in their program in addition to their approach to their patients to develop cultural competency in their residents.

Dr. Bruce Scott sated the American Medical Association (AMA) has a longstanding policy that all individuals should have access to appropriate healthcare which includes people with disabilities. The AMA looks to help create the future of medical education for changes in the curriculum.

Dr. George Shepley stated the AAMC has strengthened its standards of education by our commission on dental education, dental accreditation, CODA that graduates must be competent in assessing and managing the treatment of patients with special needs.

He added there is a principle of ethics and a Code of Professional Conduct where we added we cannot discriminate against people with disabilities.

Dr. Jonathan Perlin stated the Joint Commission is not currently an educational standard setting organization but could affect the practice of healthcare broadly across the full continuum of care.

Dr. Perlin stated that he led the VA as the undersecretary of health which specializes in a population with more challenges than the population at large.

The Joint Commission actually was jointly founded by the American Medical Association, American Dental Association, American Hospital Association, American College of Surgeons and has the ability to convene and work together on important opportunities.

Dr. Geoffrey Young that there is partnership with the Coalition for Disability Access in Health Science Education, and we are focused on helping students understand the ADA laws.

F. Public Comments

Kim Musheno, Vice President of Public Policy, Autism Society of America. She stated the following:

- Spoke on the vaccination education program;
- Autism Society of America believes improving vaccination experience is critical towards the achievement of a more equitable treatment of people with autism;
- Historically, people with developmental disabilities have lower immunization rates than their peers, leaving them vulnerable to vaccine-preventable diseases;
- Vaccine hesitancy is a longstanding issue within the autism community;
- New grants from the Aging and Disability Vaccination Collaborative to expand our initiative; and was an initiative funded by the HHS Administration for Community Living to provide outreach, technical assistance, and support to promote vaccine update;
- Creation of a path for increased vaccination rates for autistic individuals and those with complex support needs;
- The Autism Society is working with local affiliates and healthcare partners across the country to increase vaccine competence, promote vaccine education in the community, educate healthcare providers, and to create accessible vaccine clinics;

Bart Devon, senior director of Eggleston reported the following:

- 501 (c) (3) nonprofit based in Virginia whose mission is to empower the disability community;
- A nonprofit agency operating in the Ability One network;
- Offering services for people with disabilities, reducing disparities and combating stigma; creating opportunities for local partnerships to develop on their own;
- We work to develop relationships with local businesses to recognize each individual;
- Supports healthcare access and equality;

Vanessa Rastovic, self-advocate, a state leader in disability health equity and access to inclusive care for education, public policy, and government advocacy.

Ms. Rastovic stated that Congress must take advantage of current opportunity to quickly designate people with disabilities as a special medically underserved population; increase access to funding for preventive and primary care, training professionals, reimbursement incentives and health research.

Chapman Byrant, National Down Syndrome Congress addressed the following:

- Addressed the issue around individuals with down syndrome often face significant barriers and biases in healthcare;
- Shortage on down syndrome community and stakeholders have expressed deep concern for the shortage for personal care attendants;
- Family is forced to serve as unpaid caregivers, because people with disabilities are not receiving the care they need;
- Lack of medical professionals with lack of knowledge of Down Syndrome poses a significant challenge;
- Prioritization of training education for healthcare professionals to ensure they have the necessary skills to perform care;
- Limited access to oral healthcare with 30 million people not paying dental visits; affecting people of color.

Dr. Nicholas Lawson stated the following:

- Ableism cannot be addressed in the medical and health professions if you are not addressing the problem of the unbelievably low numbers of people who have been empowered as people with disabilities in the professions;
- Affordable Care Act not including people with disabilities in health inclusion sections;
- The Health Inclusion Partnerships Act and the Affordable Act excluded people with disabilities did not include them in training programs.

Ms. Charlotte Woodward, National Down Syndrome Society stated people with disabilities with Down syndrome want to be seen as people and deserve high-quality services. The government, families, the medical community, and people with disabilities bear the burden and responsibility to change the system and have the power to create a more diverse society.

Dr. Janet Parker, Executive Director, Medical Advocacy Network.

Dr. Parker addressed her firsthand experiences regarding barriers in healthcare and bias. They are diverse needs for someone born deaf and learned ASL as children.

Nora-

Stated the following:

- 400 physicians die by suicide each year due to depression;

- Rates of depression is higher across the board in all stages of training compared to the general population and compared to other people in graduate or similar levels of education programs;
- Accommodation needs to be addressed.

Doris Ray, ENDependence Center of Northern Virginia

Ms. Ray complimented the Council on its important work on healthcare for people with disabilities. More funds are needed for compliance with DOJ working to make things compliant and ensure that all society is accessible to people with disabilities.

Ms. Ray stated assistance is needed to help us at the federal level in getting guidelines on accessible diagnostic and medical treatment equipment and ensuring that there is access to medical information, making doctor's appointments and accessing medical records through the internet by assuring web accessibility guidelines and regulations are adopted.

Ms. Ray stated that problems and barriers continue to be in the physical environment and with access to effective communication and other accommodations in the healthcare environment due to the continued bias and negative stereotypes. All medical and healthcare facilities should be accessible.

Ms. Beth Kenny stated that COVID-19 policies are not based on scientists but are founded on the belief that disabled people are disposable. Healthcare needs to be more accessible. I am organizing a group to help disabled people make reasonable accommodation requests in healthcare.

Ellen Abberbock, independent living center, New York emphasized a greater need for accessible bathrooms, access to sign language interpreters and visual materials to be braille.

Ms. Elizabeth Kelly, Executive Director, Alliance. She wants to advance medical education and training in critical care and competency that benefits people with environmental disabilities. A presentation was given to the Council at its May 2022 quarterly meeting on the health disparities of people who are sensitive to chemicals and electromagnetic fields.

January 2021, the agency convened a conference for health practitioners designed to educate them on how to recognize, diagnose, and treat people who suffer from environmental illness.

Training for residents is important to understand the environmental sensitivities and how people are coping.

G. Fetal Medicine and Germline Editing

Ms. Stephanie Meredith reported that she spent several months reading literature, listening to presentations, and participating in public comment with bioethicists, science

and medical experts, and disability advocates on current' potential interventions to prepare the report. The interventions range from prenatal surgery currently in practice such as repairing lesions for spina bifida in the womb, to complex procedures.

Ms. Meredith covered the following in her report. They are as follows:

- Addressed background issues including different types of genome editing, prenatal surgery technologies; equitable access, some implications derived from the history of eugenics, social, medical, and other models of disability; and disability hierarchy and disability identity;
- The report will specifically evaluate genome editing pregnancy, changing the DNA of a fetus before birth;
- Report will focus on germline genome editing used for reproduction;
- Autistic Self-Advocacy Network have published their positions on these issues, saying they oppose genome editing because of the social and ethical impact for people with disabilities, due to potential editing out of people of disabilities as part of human diversity as well as the impact of future generations;
- Genome editing because of the social and ethical impact for people with disabilities, due to the potential editing out of people with disabilities as part of human diversity as well as the impact on future generations;
- 75 countries prohibit genome editing according to a global policy landscape analysis;
- Prenatal surgery report refers to the surgeries to repair medical issues of a fetus during pregnancy, technology currently used for condition like spina bifida;
- Report will address how many people with disabilities have published about heritage genome editing;
- Disability advocacy groups have been vocal including Little People America and ASAN;
- Literature review using disability studies articles, and science medical, and social science journals. I also researched nonacademic sources, i.e., popular media articles, documentaries, podcasts, and symposia featuring scientists, disability scholars, genome editing, prenatal surgery, and disability;
- Received comments from 20 participants ranging from prominent bioethicists, experiences of people with disabilities, advocacy organization leaders from the National Autism Congress and Little People of America;
- Broad representation from advocates with various disabilities and diverse racial backgrounds.

Chapter one will be the background on gene editing definitions, fetal medicine overview, some of the genetic conditions that might be targeted by some of the interventions and eugenics and how to address it.

Chapter two will address the ethical, medical, and disability rights perspectives.

Chapter three will talk about legal and policy considerations.

Conclusion will be recommendations that have been provided by members of the listening sessions and interviews.

Other recommended areas were as follows:

- Recommended disability core competency and anti-ableism training for medical and genetics professionals who are discussing disabilities as a potential on a life course and providing training for scientific professionals;
- Participants recommended disability rights education for people with disabilities themselves to advocate in the fields of science, genomics and medicine;
- Many participants cautioned about the potential for repeating mistakes of the eugenics are, where people with disabilities lives were devalued by those perceived scientific experts;
- Participants emphasized the importance of maintaining access to health equity if the technologies are agreed upon by consensus; concern arose around people with disabilities who are poor and/or experienced racial discrimination being able to get advanced fetal surgery or genomics in a health system which is also disparate;
- Spoke on the importance of social determinants of health and the community and social supports;
- Participants mentioned concerns about security and privacy of genetic information if genome editing is available and discrimination people with disabilities could experience if their conditions are perceived as avoidable;
- Importance of consent under the guidelines of the report.

H. Clinical Trials Report

Ms. Julie Sowash, Executive Director, Disability Solutions stated they are about 14,000 community-based organizations that work with around the world to help drive information, especially in employment and companies hiring people with disabilities around the world.

Ms. Sowash spoke on the patients journey through a clinical trial and some of the common barriers from participation for people with disabilities and discussed opportunities to increase participation through data collection and universal design principles and policy changes.

Ms. Sowash reported that they have been working with Bristol Myer and other incredible experts in the pharmaceutical and IRB communities and with healthcare organizations.

Ms. Sowash suggested recommendations were as follows:

- NIH and FDA to publish and distribute information about trials requiring that all patent-facing media, included but not limited to consent forms, websites are made accessible;
- Recommend that healthcare providers running trails should be trained on disability and inclusion;
- Teaching cultural competency; FDA to set standards for IRB boards to evaluate disability diversity competency study teams;
- Establish appropriate health literacy and reading level checks conducted by IRD's as a standard practice;

- Reducing subjective eligibility criteria if possible;
- Suggest that teams that are writing protocol address decision making capacity requirements within the eligibility criteria;
- Provide scientific justification for exclusion criteria and not allow the continuation of no exclusion;
- Need for better disability cultural competency training and a better understanding of the heterogeneity of the disability community;
- Acknowledging that there are misconceptions regarding cognitive ability that are applied regularly to all types of disabilities;
- FDA and Institutional Review Boards be required to include people with disabilities in their efforts, and develop guidelines specific to people with disabilities;
- Studies should be trained about consent and assent procedures with all consent documents and processes and procedures should be built with inclusion in mind;
- Encouraging leaders to think of a clinical trial as an experience.

I. Progress Report Update

Ms. Ramonia Rochester, National Disability Institute. She stated that the report looked at the impact on access limitations on people with disabilities with a view toward creating economic security. Specifically focused on whether the current states and programs can provide to create economic dependency. The first order of business was to define a basis on views from the disability community.

Ms. Rochester submitted the following highlights of the report. They were as follows:

- Looked at studies that discuss the impact of modifying versus eliminating asset limits;
- Looked at age of population;
- Healthcare;
- Medicaid;
- Cash assistance through SSI;
- employment-specifically the Workforce Innovation Opportunity Act;
- Looked at the Council's recommendations in its 2015 report as well as recommendations across healthcare and employment to make a comparison;
- Asset building and wealth protection program policies;
- Identifying states that are involved in best practices (Massachusetts, Virginia, Mississippi);
- Examining states with a higher rate of disability, percentage of poverty with a significant percentage of the disability population;
- Identifying states with large Medicaid programs or no Medicaid expansion program;
- Including national and state policy.

Ms. Lydia X.Z. Brown, director of policy, discussed the findings regarding SSI and healthcare.

Ms. Brown said the SSI program is particularly important for many of the poorest of people within the country.

Ms. Brown highlighted the following recommendations. They were as follows:

- Implementing a national coordinating system;
- Better integrating of benefits application and navigation for many safety net programs;
- Recommend Medicaid to remove the asset and age limits that are currently imposed in Medicaid covered services;
- Remove penalties that penalize people with disabilities who are married to other benefits recipients;
- Introduce premiums in order to make Medicaid coverage more affordable and accessible to a wider range of people;
- Funding research in the pathways for eligibility for Medicaid other than being qualified for SSI.

Ms. Dahlia Shaewitz, CEO, Third Sight discussed employment and spoke on competitive integrated jobs which is the number one way for people with disabilities to achieve financial independence.

Ms. Shaewitz's recommendations and reporting were as follows:

- state agencies receiving federal and state funds need to be held accountable for serving people with disabilities to help them achieve the education and the certification of the job;
- all public facilities to be fully accessible;
- subminimum wage and sheltered workshop and removing subminimum wage nationally;
- ensuring that people with disabilities understand their benefits, understand basic financial planning tools and processes, and understanding how to balance benefits with earnings;
- workforce access and accommodations and how the pandemic impacted all workers with the employment rates of people with disabilities recovering quickly during the recovery;
- technology access and access to broadband.

Ms. Rochester shared concluding thoughts on the project which were as follows:

- last point of discussion was around asset building and wealth protection for individuals with disabilities;
- looked at the issue of the ABLE Act
- 67% of the disability population are chronically financially unhealthy;
- Financial literacy and lack of information across providers;
- Medical recovery rules for individuals who are actually able to save;
- Making ABLE to work permanent, allow individuals who are employed to contribute directly from their wages to ABLE accounts;
- Research into the reasons for the low uptake currently;
- Strategic education and outreach to promote understanding of how these public these public benefits;
- Financial education and training, including a national technical assistance center for both direct service providers as well as for individuals and family members with disabilities on how to navigate ABLE and other kinds of asset busing and wealth protection programs that currently offer a safety net for individuals with disabilities.

MOTION: Chairman Gallegos moved to recess the Council meeting for the evening and to resume tomorrow's Council business tomorrow.

SECONDED: Sascha Bittner

Roll Call Vote:

Andres Gallegos, Chairman: Aye

Sascha Bittner: Aye

Theo Braddy: Aye

Shawn Kennemer: Aye

Emily Voorde: Aye

Risa Rifkind: Aye

Motion Passed Unanimously

July 13, 2023
10:00 am -12:13 pm ET

A. Call to Order

Chairman Gallegos called and resumed the Council meeting at 10:00 am et and conducted a roll.

B. Acceptance of the Agenda

MOTION: Emily Voorde moved for the acceptance of the May 4, 2023, Council meeting minutes.

SECONDED: Sascha Bittner

Roll Call Vote:

Andres Gallegos, Chairman: Aye

Sascha Bittner: Aye

Theo Braddy: Aye

Shawn Kennemer: Aye

Emily Voorde: Aye

Risa Rifkind: Aye

Motion Passed Unanimously

C. Update on Administration, Finance and Operations

In Ms. Grubb's absence, Mr. Woods reported the following:

- Changing accounting vendor to the Department of Transportation from USDA and have a meeting with them after this meeting;
- Reduction of office space from 1,750 square feet, meeting with GSA after this meeting.

D. Legislative Affairs Specialist

Ms. Eacobacci reported the following:

- The Council celebrated the 35th anniversary of the Americans with Disabilities Act last evening with a reception and in attendance were Hill staff and HUD, HHS, FEMA and other federal agencies;
- Fireside chat with the original author of the ADA Bob Burdorf;
- Speeches from Speaker of the House Kevin McCarthy as well as Senator

- Duckworth; co-chairs of the Bipartisan Disabilities Caucus stopped by and sent messages as well;
- House Ways and Means committee and the Commerce Committee advanced the protecting healthcare for people acts;
- HR 485 is currently pending budgetary score in the Congressional Budget Office before the House majority leader can bring it to a floor vote;
- HR 485 advances NCD's 2019 and 2022 report cautioning policymakers about the use of quality-adjusted life year-based cost effectiveness analyses for determining the value of prescription drugs and other health interventions;
- Jointly met with the policy director for the Senate Health, Education, Labor, and Pensions Committee;
- NCD policy staff and I met with the House Energy and Committee staff regarding questions regarding NCD's reported some of the recommendations from the impacts of extreme weather events on people with disabilities and our COVID-19 report;
- Discussion about reauthorizing the pandemic and All-Hazards Preparedness Act.

Mr. Nick Sabula reported the following:

- A large media on NCD's extreme weather and incentivizing oral healthcare reports;
- Joan Durocher and I met with the delegation from Tajikistan to talk about their policy and work they have been doing on CRPD for the UN;
- Policy briefing on extreme weather conditions;
- Expansion of NCD's social media with our LinkedIn account passing 10,000 with 76,000 followers across social media;
- Focused on community feedback and listening from the disability community on things that need improvement.

E. Policy Update

Joan Durocher listed the projects that are underway and Council members spoke on them.

Health Equality Framework

Chairman Gallegos reported the following:

Chairman Gallegos stated the framework was revealed in February 2022 the Council has continued to try and get the core components implemented. Being as follows:

- Designation of all people with disabilities as an underserved population;
- Adoption of enforceable accessible medical diagnostic equipment standards;
- Enhanced data regulation;
- Implementation/adoption of model healthcare disability clinical care curriculum.

Clinical Trials

Ms. Emily Voorde determined that there was nothing to add following yesterday's presentation.

Congregate Settings and Transition, Home and Community-Based services

Ms. Sascha Bittner reported the following:

- NCD released the report entitled, “*Strengthening the HCBS Ecosystem: Responding to Dangers of Congregate Settings.*” The report focused on the need to address the direct care worker shortage that worsened during the pandemic and threatened to institutionalize or re-institutionalize people with disabilities who rely on and unable to fund personal care services in the community;
- June NCD submitted detailed comments to the Centers for Medicare and Medicaid Services on its proposed rule to increase access to home-and community-based services. In the proposed rule, CMS proposes changes to address the direct care worker shortage including increasing the salary of direct care workers under Medicaid and creating new requirements on maintaining and reporting waiting list information;
- Housing-NCD staff are currently drafting comments to respond to HUD’s proposed rule to update its Section 504 regulation which prohibits discrimination against people with disabilities by federally assisted housing providers;
- Two federal agencies are taking action to address barriers to community living that the Council focused on in its recent HCBS report.

2023 Progress Report

Mr. Amged Soliman reported the report is undergoing a technical review and one last edit with a release date by the end of the fiscal year.

Tax Policy Project

Ms. Kimie Eacobacci stated the definition of employee under the FLSA does not guarantee the definition of employ for federal employment tax purposes. The Council is interested in how it affects employment benefits and employer-sponsored benefit plans.

Tribal Land Coordination Committee

Mr. Hoskie Benally reported the following:

- 2019 the Council signed an agreement with the National Indian Council on Aging to update its 2003 report;
- Completed report in March is 300 plus pages containing resources for Native Americans with disabilities;
- Recently, NCD agreed and approved funds for Executive Order which would be conduct a town all meeting in Indian country and where people will provide their experiences as a Native American with a disability.

HEAD’s Up Act

Ms. Bittner reported the following:

- NCD report designates people with I/DD as a special medically underserved population under the Public Health Service;
- NCD conducted research to determine how many people such a law would affect in hopes that such information could be obtained so Congress could move forward.

Quality-Adjusted Life Years Project

Mr. Shawn Kennemer reported the following:

- 2019 the Council issued a report calling for a ban on the quality-adjusted life year (QALY). Due to its discriminatory nature, the Council found that the use of QALY in standard cost-effective analysis has a discriminatory design and impact in that it undervalues prescription drugs that extend the lives of people with disabilities and has the potential to result in restricted insurance coverage;
- 20232 NCD released a follow-up QALY report describing less discriminatory or nondiscriminatory methods to put a value on prescription drugs that can be used by government health programs i.e., Medicare and Medicaid;
- Protecting Health Care for All Patients Act has been introduced in the US House of Representatives. The bill seeks to prohibit the use of QALY by all state and federal healthcare systems. Staff continue to track the progress of the bills.

F. Chairman's Report

Chairman Gallegos reported the following:

- 2010 the Access Board was required to develop technical standards for the manufacture and design of medical diagnostic equipment i.e., wheelchair accessible weigh scales, examination tables, X-ray machines, MRI machines and other diagnostic equipment;
- Department of Justice and Department of Health and Human Services Office of Civil Rights will be releasing standards in September rulemaking on Section 504 specific to the standards developed by the Access Board;
- the Council's comments have been reflected in the background of these regulations;
- honoring ceremony of Bob Burgdorf.

Executive Committee Report

Mr. Kennemer asked the Council to review and accept the spending plan and status of funds report for fiscal year 2023 through May 31, 2023.

Mr. Kennemer stated the Council's appropriated funds for FY '23 is \$850,000 which 46% was expended as of May 31, 2023. \$44,500 reallocated to policy and other areas, reallocating \$20,000 from Council member salaries to meetings and conferences and then reallocating \$4,500 from local travel.

Mr. Kennemer there is an additional \$20,000 needed for travel and we recommend that the amount from contractual services. \$1,00 is needed for security services.

MOTION: Sascha Bittner moved for the approval of the status of funds report through May 31, 2023.

SECONDED: Hoskie Benally

Roll Call Vote:

Andres Gallegos, Chairman: Aye

Sascha Bittner: Aye

Theo Braddy: Aye

Shawn Kennemer: Aye

Emily Voorde: Aye

Risa Rifkind: Aye

Motion Passed Unanimously

Mr. Kennemer presented the following allocations for a vote.

\$20,000 from contractual service to paroling travel;

\$20,000 from member salaries to program travel;

\$4,500 from local travel to program travel and ;

\$1,000 from contractual services to security services

MOTION: Emily Voorde moved for the approval of the allocations as presented. .

SECONDED: Sascha Bittner

Roll Call Vote:

Andres Gallegos, Chairman: Aye

Sascha Bittner: Aye

Theo Braddy: Aye

Shawn Kennemer: Aye

Emily Voorde: Aye

Risa Rifkind: Aye

Motion Passed Unanimously

Mr. Kennemer asked for a final vote for the recommendations to give the executive committee the determine a reallocation for \$20,000 that is available for meeting and conferences to policy work and/or government publishing office, the GPO deposit account for agency editing, printing needs from fiscal year '24 based upon the further input from the management team at the next executive committee meeting following this council meeting.

MOTION: Sasha Bittner moved for the approval of the recommendations to give the executive committee the determine a reallocation for \$20,000 that is available for meeting and conferences to policy work and/or government publishing office, the GPO deposit account for agency editing, printing needs from fiscal year '24 based upon the further input from the management team at the next executive committee meeting following this council meeting.

SECONDED: Theo Braddy

Roll Call Vote:

Andres Gallegos, Chairman: Aye

Sascha Bittner: Aye

Theo Braddy: Aye

Shawn Kennemer: Aye

Emily Voorde: Aye

Risa Rifkind: Aye

Motion Passed Unanimously

G. Governance Committee Reports

Ms. Bittner stated that she is memorializing the approval of the electronic vote of the Council to close the meeting held on June 15, 2023.

Ms. Bittner reported as follows:

- The bylaws are reviewed every few years to ensure that they are still relevant and that no changes are needed, with the latest version updating some areas showing a 15-member ;
- First quarterly meeting of each calendar year the Council shall actively solicit input from the disability community including but not limited to individuals with disabilities;
- Representatives of organizations representing a broad range of individuals with disabilities, and organizations representing a broad range of individuals with disabilities; and
- Organizations and agencies interested in individuals with disabilities to identify and prioritize the issues and concerns affecting the disability community;
- The council will consider the input received from the community during the meeting and engage in the deliberative process to determine the topic for the progress report.
- Few substantive changes that reflect how the Council operates;
- Executive committee revised section on selection policy reports and the annual progress report; determined topic for the progress report should be based on the issues and priorities identified by the disability community as well as the Council's assessment of the significance, urgency, and impact of those issues.

Ms. Durocher proposed the following processes in regard to policy reports. They were as follows:

- The executive committee shall determine with input from the Executive Director and agency staff the number of additional policy report;
- If the executive committee votes to approve the development of one or more policy reports in addition to the progress report, each Council Member shall have the opportunity to submit one or more proposal topics for policy reports that the Council can author during the next year;
- Council members are first to consult the disability community when arriving at these topics to ensure that the reports are responsive to the needs and concerns of the disability community;
- The proposals shall be submitted in writing to the chairperson and director of policy in a format as selected by the director of policy no later than the date established by the director of policy;
- All proposals timely submitted shall be included in the meeting materials for the council quarterly meeting and disseminated to applicable staff;
- At the council meeting, Council members will present the proposals to the Council Members for consideration and vote;
- Pursuant to the voting requirements set forth in the bylaws, Council Members will approve one or more policy reports for the subsequent fiscal year.

MOTION: Theo Braddy moved for a vote to approve the amended bylaws changes as presented.

SECONDED: Chairman Andres Gallegos

Roll Call Vote:

Andres Gallegos, Chairman: Aye

Sascha Bittner: Aye

Theo Braddy: Aye

Shawn Kennemer: Aye

Emily Voorde: Aye

Risa Rifkind: Aye

Motion Passed Unanimously

H. Council Member Report Outs and Outreach

Chairman Gallagos asked Council Members to give their activity's report since the last Council meeting.

Mr. Braddy reported the following:

- Many comments are from the disability community regarding consumer control. A number of constituents are feeling that a substantial number of federal agencies are not seeking input from the disability community;
- ACL, the aging community, and other departmental agencies are doing things without seeking input from people with disabilities.

Ms. Bittner reported the following:

- Her work with the California Council on Disabilities and regional centers, self-determination committee for people with developmental disabilities, are focusing on how to create more opportunities for self-direction and control for people with developmental disabilities and to develop methods of quality assurance that meaningfully include them;
- Main goal of the program is to give clients control over resources allocated to them by the regional centers of California and the program has achieved notable successes but has also experienced growing pains in terms of the new financial management services given the new rules including co-employers;
- Critical shortage of home care providers; governing board is looking to create public service announcements for worker recruitment;
- Increasing alarm among many disability advocates in efforts to gut diversity, equity, and inclusion programs.

Ms. Voorde reported the following:

- Community's concern of COVID-19 reaming a massive thing;
- Concern of the immunocompromised of color and impoverished communities are being forced to shoulder this burden.

Mr. Benally reported the following:

- Information has been submitted on the things that the Indian community is lacking;
- Many of the Native Americans with disabilities end up unnecessarily in nursing homes due to the lack of housing; has increased since COVID;
- Housing is a big issue.

Ms. Rifkind reported the following:

- Concern amongst the community regarding with the Supreme Court decision on overturning Roe V. Wade

Mr. Kennemer reported the following:

- Lack of benefit coordination with knowledge of how the SSI system works or staff in the social security department providing incorrect information for individuals that are working and wanting to retain more hours;
- Barriers in finding employment opportunities for individuals that we serve in maintaining those positions;
- Direct care staffing shortage;
- Waiting list of individuals wanting employment

Chairman Gallegos reported the following:

- Since the enactment of the civil rights statute in 1964, courts throughout the country have consistently recognized if an individual is deprived of their civil rights, discriminated because of their color, race, gender, religion and now disability, the emotional distress automatically follows;
- A small group of civil rights attorneys and disability rights attorneys have convened in Illinois to discuss what can be done at the state level resulting in a draft bill.

I. Old/New Business

Ms. Lewis gave a brief review of the reimbursement process. She stated it is federal policy that your reimbursement be submitted within five days after your travel. Travel days are defined as departure day from the traveler’s residence or official duty location and the return date of the traveler’s residence of their official duty station.

J. Adjournment

MOTION: Chairman Gallegos moved to adjourn the Council meeting.
There was not second to the motion.

The meeting adjourned at 12:15 p.m. (ET)

Date Approved by the Council:

Claudia Gordon
Signature

Claudia Gordon
Printed Name

