**ATTENDANCE**

**Members Staff**

Neil Romano, Chairman Lisa Grubb, Executive Director

Billy Altom Joan Durocher

Amy Nicholas Phoebe Ball

Rabia Belt Amged Soliman

Jim Brett Keith Woods

Wendy Harbour Netterie Lewis

Benro Ogunyipe Nick Sabula

Clyde Terry **Absent** Stacey Brown

**Via telephone** **Via telephone**

Daniel Gade Ana Torres-Davis

Andres Gallegos

**NCD Contractor**

Anthony Simpson

**Guests**

Jack Hayes, Nevada Disability Advocacy and Law Center and Community Representatives; Sandra Stanko, Nevada Program Director of MTM Services; Jerry Kappeler, Director of Nevada Community Enrichment Program (NCEP); Dan Holland, Regional Transportation Commission (RTC); Minerva Riviera, Independent Living Coordinator and Advocate for Southern Nevada Center for Independent Living (SNCIL); Jean Payton, Advocate; Morgan Whitlatch, Quality Trust for Individuals with Disabilities; Homa Woodrum, Aging and Disability Services Division (ADSD); Stephanie Wynn, Facilitator and Special Education Advocate; Karen Taycher, Nevada PEP; Bryan Hilbert, Director, Disability Resource Center, University of Nevada; Raquel O’Neill, Advocate, Parent Advocate and President, blindconnect; Karen Gray, Paralegal, Special Education; Natalie Filipic, Nevada PEP; Susan Williams, WCSD; Deborah Moran, SNHD-OPHP-MRC; Melissa Castro, DETR; Franshesca Soriano, NV Early Intervention Services; Cassandra Munoz, Congresswoman Dina Titus; Dawn Lyons, ADSD-NVSILC; Santa Perez, Nevada Governor’s Council on Developmental Disabilities; Janice John, NCDD; Katherine Siero, Vocational Rehabilitation; Sheena Childers, Nevada DETR-BVR; Victoria Oganian, Wellness Alliances; Tammy Counts; CLV-ADA; Kimberly Palma-Ortega, DD Council; Minerva Riviera, SNCIL; Antonetto Braddock, RTC; Don Howland, RTC; Kari Horn, NGCDD; Deb Reardon, RTC-Planning; Sandra Stanko, MTM; Tina Renthos, LACSN; Heather Boyce Ball, Pierce Foundation; Suzanne Doren, Pierce Foundation; Anita Franz, NDALC; Karen Taycher, Nevada PEP; Morgan Whitlatch, Quality Trust; Jeanne Pairman, Michaelson & Associates; Jennifer Kane, Nevada Department of Education; Tammy Serer, Division for Aging Disability; Kelly Gonzalez, Legal Ad Center of the State of Nevada; Kari Horn, Debra Bookart, Legal Ad Center; Christie Ackman, Aging and Disability Services Division; Robin Kincaid, Nevada PEP; Stephanie Vasick, Nevada PEP; Daniel Power; Brandy Novica, advocate, Hector Ramirez, Disability Rights CA; Jack Mayes, advocate; Gina Shoe, advocate; Jennifer Kenan, Nevada Department of Education, Office of Special Education; Mary Lamielle, Executive Director of the National Center for Environmental Strategies.

1. **Welcome and Introductions**

Chairman Neil Romano called the meeting to order at 9:11 AM (ET) and welcomed Council members, staff and the public.

1. **Acceptance of the Agenda**

**MOTION:** Ms. Wendy Harbour moved to accept the agenda of the January meeting.

**SECONDED:** Mr. Neil Romano

Roll Call Vote:

Neil Romano, Chairman

Billy Altom: Aye

Rabia Belt: Aye

James Brett: Aye

Wendy Harbour: Aye

Daniel Gade: Aye

Benro Ogunyipe: Aye

Clyde Terry: Aye

1. **Attendance and Roll Call**

Neil Romano, Chairman

Billy Altom

Rabia Belt

James Brett

Wendy Harbour

Daniel Gade, telephone

Benro Ogunyipe

Clyde Terry

1. **Approval of the Minutes**

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

**SECONDED:** Ms. Rabia Belt

Roll Call Vote:

Neil Romano, Chairman

Billy Altom

Rabia Belt

James Brett

Wendy Harbour

Daniel Gade

Benro Ogunyipe

Clyde Terry

1. **Welcome from Assemblywoman Ellen Spiegel**

Ms. Spiegel welcomed the Council and staff to Nevada. She stated there were facilities and programs in Nevada were children could get the help they needed before the economic downturn, and as the economy worsen, they were unable to pay providers what they needed to be paid, so they left.

She stated that children were sent out of state for treatment and returned there was nowhere for them to have the skills they learned reinforced.

Ms. Spiegel stated that she introduced AB307 to start a pilot program piecing services in the state back together to stop sending children to other states. This would be done by enabling Medicaid, the state and the counties to pull resources so that they could provide necessary services.

1. **Chairman’s Report, Neil Romano**

Mr. Romano stated that he met with the largest supplier of dental equipment the Henry Shrine Corporation and they will be looking at ways to bring our message clearly forward to all medical facilities across the United States.

Mr. Romano stated that during the 14c report the Ability 1 program stands as one of the most important in the middle of the entire 14 c question as they have many of the organizations they work with have some minimum wage employees.

Mr. Romano stated that Ms. Durocher and her team have been working diligently on international issues. He added that the president of Afghanistan has invited the Council to visit will be the agency’s first overseas trips.

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

Ms. Grubb stated the FY’20 budget has been submitted and the Council has received a pass back with a slight increase.

During FY’19 the Council will roll out SharePoint which is in its final preparatory stages. Staff has started initial training and will continue to work with the program to find any area that may need any further development as far as the sustainability and general operation flow. Within weeks there will be additional staff training with invites to train Council members. This platform will provide access to administrative forms, information for Council meetings and anything else that you need to access.

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

Mr. Altom reported that the Council is a quarter through and has spent 21% of its budget which 25% is usually spent by this time putting us under budget. There are some funds within research and training.

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

**SECONDED:** Ms. Rabia Belt

Roll Call Vote:

Neil Romano, Chairman

Billy Altom

Rabia Belt

James Brett

Wendy Harbour

Daniel Gade

Benro Ogunyipe

Clyde Terry

**MOTION:** Ms. Wendy Harbour moved to accept the FY’19 budget.

**SECONDED:** Ms. Rabia Belt

Roll Call Vote:

Neil Romano, Chairman

Billy Altom

Rabia Belt

James Brett

Wendy Harbour

Daniel Gade

Benro Ogunyipe

Clyde Terry

1. **Governance Report, Rabia Belt**

Ms. Rabia Belt had no report to submit.

1. **Policy Report, Joan Durocher**

Ms. Durocher stated the project that are underway. They were as follows:

* AbilityOne and the goals and outcomes of the program through the k=lens of current federal disability policy and law;
* ABLE convenings;
* Afghanistan trip;
* Newly enacted FAA Reauthorization Act of 2018-including the amendments to the Air Carriers Access Act;
* Addition of tool kit to be used at the state level

**MOTION:** Mr. Terry moved for the acceptance of the Ability 1 paper.

**SECONDED:** Ms. Rabia Belt

Roll Call Vote:

Neil Romano, Chairman

Billy Altom

Rabia Belt

James Brett

Wendy Harbour

Daniel Gade

Benro Ogunyipe

Clyde Terry

**MOTION:** Mr. Brett moved for the acceptance of the 14C and tool kit reports for local advocates.

**SECONDED:** Ms. Rabia Belt

Roll Call Vote:

Neil Romano, Chairman

Billy Altom

Rabia Belt

James Brett

Wendy Harbour

Daniel Gade

Benro Ogunyipe

Clyde Terry

1. **Legislative Affairs Report, Phoebe Ball**

Ms. Ball report that the government shutdown has ended. The Council was fortunate that it wasn’t affected. However, it did affect other agencies such as the Access Board.

Ms. Ball stated that these activities that are happening on the Hill. They are as follows:

* Medicaid Extenders Bill which has been passed by the President which helps to move people from institutional settings to home and community settings;
* Disability Integration Act has been re-introduced in both houses of Congress will end institutional bias of the Medicaid program;
* Pieces of legislation around 14 C program are being introduced;
* Legislation being discussed on guardianship;
* Reintroducing the Disability Employment Incentive Act;
* Parenting issues with people with disabilities

Ms. Ball stated that the Disability Integration Act has been re-introduced in both houses of Congress. This bill will end institutional bias of the Medicaid program which currently requires a waiver to get home and community-based services.

Ms. Ball stated that there is legislation being introduced that will issues around guardianship.

1. **Nevada Community Shares Education Opportunities and Challenges**

Stephanie Wynn reported that the panel will focus on self -advocacy, self- determination initiatives in Nevada and shared the progress that has occurred over the past several years and how we can progress through the next five to ten years.

Ms. Rachel O’ Neill stated that self-advocacy and self-determination are the hallmarks of her motivation. She stated that we must be able to express to our employers and self-advocate with self-determination how things will be accomplished a full-filled job at the end of the day.

She stated that she believes start promoting at an early age with programs on the start to assist parents and support systems that surround babies, children and individuals with the wording and the guidance on how to express themselves the best that they can. She added that transition comes in all aspects of life, there are so many life transitions and the one transition to disability and making that change in gaining independence.

Mr. Bryan Hilbert stated that an individual in early intervention services regardless of the severity of their need for support will have an adult life.

Mr. Hilbert stated that working with people to take a long-range view and to help them understand what they are doing well and what they are not will may help them to able to access the resources that they will need to build a long-term life.

Mr. Hilbert stated that he has expressed some students is that parents and the system has become foci=used on earning a high school diploma and exiting at 18 but would be better served with support services thought the age o f22. He added that the biggest misconception that people have about individuals with disabilities is that majority of disabilities are visible and physical but are that there are individuals with mental health issues as well.

Ms. Karen Taycher stated that she would like focus to be on working with service providers and services that are funded to help individuals with disabilities to understand self-advocacy and to celebrate it.

She stated that she believes that the rights that families and children have under IDEA have been long and hard-fought for and thinks that the public schools need to do a better job embracing their students and providing appropriate education and families should not be looking for alternatives if the schools were working in the best interests of the children.

Ms. Taycher stated that educators need to be educated that there’s more out there for graduates with disabilities than programs.

Ms. Gray expressed that when parents are given the opportunity to choose the programming that’s best for their child, they child becomes more successful. Parents know their children best and that there needs to be ways to expand opportunities for families to empower parents to do what is necessary for their children.

She stated that Nevada has taken great steps to encourage school districts to implement the multitiered systems of support.

Ms. Wynn stated that the panel submitted commented on the school districts which highlighted school choice and availability of vouchers for the community outside of the public-school system.

Ms. Gray stated that she thinks when parents are given the opportunity to choose programming that is best for the child and the child becomes more successful.

Ms. Taycher stated that the rights that families and children have under IDEA have been long and hard-fought for and stated that she is concerned when vouchers are taken by families that are not notified of the rights that they might be losing by taking their child out of the public schools and placed into a private system.

She added she believes that public schools should do a better job embracing their students and providing education.

Mr. Hilbert stated that parents and students are really focused on getting their high school diploma but believes that people would be better served with support services through the age of 22. The biggest misconception that people have about individuals with disabilities that their disabilities are visible and physical.

1. **Town Hall**

Ms. Novica stated that she is recovering from a third spinal infusion and has been denied disability three times. She is a single mother with a 10-year-old living off $318.00 per month and social services has denied her rental assistance.

Ms. Show stated there needs to be accessible housing, barrier-free showers and disabled parking.

Mr. Ramirez inquired how public policies could be implemented to assure that people with disabilities are better prepared and have access to evacuation and population assistance.

Ms. Kenan stated that she her partners from school districts and vocational rehabilitation would like to see a panel of education, vocational rehabilitation and other partners to speak specific programs related to things such as getting students to work experiences while they are still in the education systems.

Mr. Mayes stated that affordable and accessible housing is a tremendous challenge in Nevada.

Ms. Lamielle stated for 40 years the center has worked to protect public health and protect the lives of people disabled by exposure to chemical and environmental exposures.

Nearly a third of Americans report reactions to low-level everyday environmental exposures, 30% to 60% report unusual reactivities and a smaller percent have environmental intolerances. She stated individuals are underrepresented, underserved populations suffer greatly due to significant barriers to access to the most necessities of life.

Ms. Lamielle stated people disabled in this way continue to suffer from a profound lack of access to public and commercial buildings, housings, employment, health care and other necessities.

People with these disabilities are frequently denied civil rights and full participation in society. She added that federal agencies fail to address many issues that are basic to survival, and integration and inclusion, the mantra of independent living movement can be a threat to one’s health and well-being.

Ms. Lamielle suggested the Council and staff be provided the following;

* an opportunity for educational training on these disabilities;
* panel discussion for a future NCD meeting;
* continue a roundtable or listening sessions
* work with the Access Board and other agencies to develop an interagency work group on environmental sensitivities;
* convene a meeting with experts and advocates to formalize a plan of action to address proposed initiatives;
* work across agencies to develop policies and programs including technical guidance to ensure that people with these disabilities are assured access to the most necessities such as health care services.

The Council recessed at 4:45 pm

**January 29, 2019**

The Council meeting reconvened at 9:00 am with welcome and introductions.

1. **Welcome from Santa Perez, Nevada Governor’s Council on Developmental Disabilities Santa Perez**

Ms. Perez stated under the DD Act we engage in advocacy, systems change and capacity-building activities for people with intellectual and developmental disabilities and their families to promote equal opportunity, self-determination and community inclusion.

Ms. Perez highlighted other areas of her Council. They were as follows:

* accomplish their goals through activities carried out by staff and partnering with other agencies and organizations;
* address areas of mutual concern to develop infrastructure for the state;
* promote the concept of experienced-based informed choice, allowing people with disabilities to have the same real-life experiences ad everyone else before they can decide what’s best for them;
* operate in partnership with the Nevada Disability Advocacy Law Center in the Nevada Center for excellence in disabilities under the developmental disabilities network.
* The council established position statements based on its federal mandates, mission statement, and current policies-the mission statements address health care, community support, transportation, accessibility, guardianship, and supported decision-making, employment, quality assurance, and current policies;
* In-house projects are the production of many training materials life stages tool guide to help individuals with disabilities and their families plan for and to live the most self-determined life they can at any age;
* Expansion of cultural diversity, hiring a lingual self-advocacy coordinator, translating publications to Spanish and offering our partners in policy-making class in both English and Spanish;
* Youth are taught the curriculum and paid a competitive wage stipend to teach their peers;
* Planning a self-advocacy summit where self-advocacy groups will come together and talk about the issues that affect everyone;
* First state-wide summit in May which will address the transportation issues by people with disabilities in Nevada;
* Executive Order 2014-16 creating a task force to develop a strategic plan creating a more integrated work force and expanding competitive employment opportunities for individuals with intellectual and developmental disabilities.

**O. Welcome from Dan Liberman-Nevada Community Shares Transportation Opportunities and Challenges**

Mr. Jack Mayes, Executive Director of the Nevada Disability Advocacy Law Center thanked the Council for inviting his colleagues to share their stories.

Ms. Sandra Stanko, Nevada Program Director for MTM Services reported that people are using service and get to their appointment and it is a big challenge to transport individuals from Nevada to California.

In addition to providing transportation for medical appointments, they can also utilize services to get to other locations such as for social events. About 70% of the Medicaid trips in the state of Nevada are on public transportation, either fixed or via para transit.

Mr. Jerry Kappeler, Director of NCEP stated that one of his agency’s challenges is are the rural settings. He stated that they are always working with the state, county and cities to get services and transportation to more rural areas with the main concentration being on getting people transitioned out the hospital newly experiencing a disability. He added that there is a lot of talk about disability but little about brain injury and the cognitive disabilities that affect people which could be for life.

Mr. Kappeler stated that they are working with RTC and local state agencies who work on housing, transportation and accessible housing.

Ms. Antionette reported on Mr. Dan Holland behalf and stated that RTC has provided $1.3 million for para transit. Other services provided by RTC are as follows:

* not only provides public transit but also have traffic management as well as the metropolitan planning organization, streets and highways;
* senior services;
* veteran’s services;
* mobility training
* eligibility for para transit.

Ms. Minerva Rivera, SNCIL, reported that her agency assists all individuals with disabilities towards maintaining independent living, information and referral, advocacy, peer support and basic independent living skills.

Ms. Jean Peyton stated that transportation equals for people with disabilities. She has been working with RTC to help make independence a viable option for all people with disabilities.

She stated that Lyft is providing opportunities to assist with the challenges with paratransit.

Mr. Mayes stated that the Nevada has allocated close to a$1 million for home and vehicle modifications to assist people in becoming and maintaining independence.

Mr. Dan Holland, Regional Transportation Commission (RTC) stated that they have been working with vocational rehab in Nevada for individuals who are needing transportation to get back and froth from work. He stated that their mobility trainers work with those individuals to use fixed-route transportation.

Transportation companies have been using taxis to provide para transit services. He said that they are also working with the mayor’s office to establish grants to be used to modify vans to make them wheelchair accessible and to require wheelchair accessible built cabs.

1. **NCD Responds to the Nevada Community on National Transportation Challenges and Recommendations**

Mr. Altom stated that people love accessibility and shared his personal experiences when visiting Jackson Hole, Wyoming.

Ms. Nicholas stated people with disabilities are being pushed further away from the city’s center and the further you are out the more difficult it is to have accessible transit.

1. **NCD Shares Findings and Recommendations on Guardianship for Individuals with Developmental Disabilities**

Ms. Morgan Whitlatch, Quality Trust for Individuals with Disabilities stated that many states are not collecting concrete data to begin reforms that are necessary to promote responsible guardianship systems and to avoid overuse and abuse of guardianship.

She stated Quality Trust is partnering with ARC and will provide a comprehensive review of adult guardianship across disability from people with developmental disabilities who have mental health disabilities to people who have age-related disabilities and other types of disabilities.

Ms. Whitlatch stated the goal of the report is to scrutinize the impact of guardianship of people with IDD and the US policy implications under important federal laws including IDEA, the ADA the Rehabilitation Act and the Work Force Innovation and Opportunities Act.

The report consists of seven chapters. They are as follows:

* Orientation for the reader;
* School to guardianship pipeline;
* State laws impacting people with developmental disabilities in terms of guardianships;
* Tackling of data issues;
* Undertaken deep analysis of guardianships impact on IDD;
* Stakeholder feedback;
* Recommendations

Ms. Homa Woodrum, Aging and Disability Services Division (ADSD) stated that the state of Nevada has been on a god road of reform. There was a guardianship commission established by the supreme court that has been looking new legislation.

She stated one of the most crucial pieces of guardianship reform was guaranteed free legal representation of all individuals in all guardianship cases.

Ms. Woodrum stated in Nevada, there is a decision-making bill and the idea is to force banks, doctors and educational entities to recognize the informal supports of individuals with IDD so that we can stop the pipeline and the overburdening of the guardianship systems that are meant to be helpful for specific populations.

1. **Public Comment**

A mother of five stated that heir are not enough family components that are in place in Nevada, no sibling services and a delay of services for dual diagnosed children.

Ms. Gina Shoe suggested that suggested that the Council share information via Facebook and other social media outlets. Also offer easy to understand videos to educate people with disabilities will empower them to be self-advocates.

Ms. Stephanie Varsnick stated that she transports her son to work which is a half mile from the service area and she advocates that changes be made to accommodate his transportation needs.

1. **ADJOURNMENT**

**MOTION:** Ms. Wendy Harbour moved to adjourn the meeting.

**SECONDED:** Ms. Rabia Belt

Roll Call Vote:

Neil Romano, Chairman

Billy Altom

Rabia Belt

James Brett

Wendy Harbour

Daniel Gade

Benro Ogunyipe

Clyde Terry

The meeting adjourned at 12:00 noon.

Date Approved by the Council: May 24, 2019

Neil Romano

Printed Name