**ATTENDANCE**

**Members Staff**

Billy Altom Lisa Grubb, Acting Exec. Director

Andres Gallegos Joan Durocher

Wendy Harbour Anne Sommers

Benro Ogunyipe Phoebe Ball

Clyde Terry Amy Nicholas

Rabia Belt Amged Soliman

 Keith Woods

**NCD Contractor**

Anthony Simpson

**Guests**

Richard Petty, National Center for Aging and Disability; ILRU; Maria Town, Director, Houston’s Office for People with Disabilities; Hannah Mehta, Founder, Protect TX Fragile Kids (PTFK); Frederick Jefferson, Director, Man II Man Support for Fathers of Special Needs Children; David T. Hutt, Ph.D., Senior Staff Attorney< National Disability Rights Network (NDRN); Richard LaVallo, Legal Director, Disability Rights, Texas; Dawn Carlton, Advocate, Coalition of Texans with Disabilities, ADAPT, Texas Guardianship Reform and Supported Decision-making workgroup (GRSDM); David W. Slayton, Administration Director of the Office of Court Administration, Executive Director of the Texas Judicial Council; Dustin Rynders, Disability Rights Network; Kim Torres; TEAM Project at Partners Resource Network; Lisa Cowart, Project Director, Partners Resource Network PATH Project; Jana McKelvy, Texans for Special Education Reform; Steven C. Rhatigan, Founder and Principal, The Archer Consulting Group; Rita Martin, consumer; Paul Hippolitus, consumer; Thomas Diaz, consumer

**Welcome and Introductions**

Vice Chairman Benro Ogunyipe called the meeting to order at 9:10 AM (ET) and welcomed Council members, staff and the public.

1. **Attendance and Roll Call**

Billy Altom, Andres Gallegos, Wendy Harbour, Benro Ogunyipe, Clyde Terry

Note: Rabia Belt joined in the afternoon

1. **Acceptance of the Agenda**

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

**SECONDED:** Andres Gallegos

Roll Call Vote:

Vice Chairman Benro Ogunyipe

Mr. Billy Altom: Aye

Mr. Andres Gallegos: Aye

Ms. Wendy Harbour: Aye

Mr. Clyde Terry: Aye

Motion passed unanimously

1. **Approval of the Minutes**

**MOTION:** Wendy Harbour moved to accept the minutes from the March 8 and 29, 2018 Council meeting.

**SECONDED:** Billy Altom

Roll Call Vote:

Vice Chairman Benro Ogunyipe

Mr. Billy Altom: Aye

Mr. Andres Gallegos: Aye

Ms. Wendy Harbour: Aye

Mr. Clyde Terry: Aye

Motion passed unanimously

1. **Greetings from the Mayor’s Office**

Ms. Maria Town welcomed NCD and stated that Houston is seminal in the history of the disability rights movement and to leaders Lex Frieden, Justin Dart and Bob Kafka. She added that Houston was critical in its history of the disabilities rights movement. Houston is a city where disability rights must include immigrant and refugee rights, it has experienced five natural disasters in the past seven years and it is home to the second largest population of aging people in the nation.

1. **Greetings from Lex Frieden, Former NCD Chair**

Mr. Lex Frieden thanked the Council for coming to Houston and shared his experience as executive director and chairman of the agency. He stated that Joe Dusenbury was the first chairman of the Council who later became a member and that Congress requested that the Council have its report entitled, *“Toward Independence”* by the end of January when they had no contractor to print the report. However, the Federal Prison Industries printed the report and it was presented to Congress’ by the deadline.

Mr. Frieden stated that the Council has a long history of producing work that has had an impact on everyone in the United States, particularly people with disabilities. He encouraged the Council to capture the imagination of people with disabilities, advocates and friends and think toward the action and make practical recommendations, one that can be achieved together.

1. **Executive Reports**

**Chairman’s Report, Neil Romano**

The Chairman’s report was tabled until the next Council meeting.

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

Ms. Lisa Grubb reported that the Council was operating under a continuing resolution until March 30th and until that time she was meeting frequently with OMB senior staff to prepare for a lapse in appropriations. She added that the Council received its appropriation and could move forward with its priorities for the remainder of the fiscal year.

Ms. Grubb stated the office is scheduled for carpet cleaning and that we are in the final stages of preparing for a dedication wall honoring past NCD chairs.

Ms. Grubb stated that the five-year strategic plan has been updated under Anne Sommer’s expert stewardship and that it is a roadmap to success.

Ms. Grubb stated that mid-year personnel performance evaluations have been completed and interviews and selections have been made for the public affairs specialist and administrative support specialist positions.

Ms. Grubb stated that planning is underway for an ADA celebration swearing-in ceremony for the new chairman.

**Financial Representative Report, Billy Altom**

Mr. Billy Altom stated that the committee met on May 29th by teleconference and the Council has been operating under a continuing resolution until March 30. The Council has spent 35% of its budget. The Council has its full funding of $3.25 million and is moving forward with its policy work.

**MOTION:** Mr. Andres Gallegos moved to accept the financial representative’s report.

**SECONDED:** Billy Altom

Roll Call Vote:

Vice Chairman Benro Ogunyipe

Mr. Billy Altom: Aye

Mr. Andres Gallegos: Aye

Ms. Wendy Harbour: Aye

Mr. Clyde Terry: Aye

The motion passed unanimously.

**Governance Representative’s Report**

Vice Chairman Benro Ogunyipe stated that there has been one vote since the last Council meeting that needs to be memorialized for the record and that will be for the governance report. The vote was to approve the personnel and operational priorities for the recommendations and requirements in the amount of $122,400.00

**Director of Policy Report, Joan Durocher**

Ms. Durocher submitted an update on the following:

* Bioethics project
* Post-disaster Institutionalization Project
* 14 (c)
* Guardianship Report
* Follow-up to dental report
* Task force of the Administration on Community Living

**Director of Legislative Affairs Report, Anne Sommers**

Ms. Sommers expressed a special thanks to Johnna Carlson, District Director for Congressman Michael McCaul as a guest to the Council meeting.

Ms. Sommers stated the guardianship report was released March 22nd at the tenBroek conference in Baltimore, Maryland and was very well received. She added that there is also interest from Capitol Hill in following up on the recommendations of the report. Ms. Sommers stated that there has been very exciting opportunities and developments on many reports and Senators Casey and Hasson along with Representative Dingell have written the Safe Equitable Campus Resources and Education Act (SECURE Act) which came out in March and was a direct result of *“Not on the Radar”* report release January 30th. The targeted improvements would ensure that the needs of students with disabilities are included in campus planning in response to sexual assault, domestic violence, stalking and all materials provided are accessible.

Ms. Sommers stated recently Congresswoman Dingell published an op-ed in the Hill which praised NCD’s work directly and attributed her legislation as an impetus for her action.

Ms. Sommers stated that in December the Council published the dental brief. Ms. Phoebe Ball has been on the Hill making people aware of it.

Ms. Sommers stated that through the collaborative efforts from the LAO and policy teams, the Council offered amending legislative text for the Public Health Services Act that would expressly include people with intellectual and developmental disabilities as a special medically underserved population.

Ms. Sommers stated that Chairman Romano is scheduled to meet with Hill staff to talk about HR 1377, the TIME Act by Congressman Gregg Harper. The TIME Act seeks phasing out the Fair Labor Standards Act of 14(c).

Ms. Sommers stated that Chairman Romano was interviewed by the *Daily Mail* and the *Washington Post* on 14 (c). In addition, Chairman Romano participated in a radio show in Minnesota.

1. **Hurricane Preparation, Response Recovery**

Vice-Chairman Ogunyipe introduced the panelist.

**Richard Petty**, Director of ILRU and Director of the National Center for Aging and Disability (NCAD) moderated the panel.

**Maria Town**, Houston Mayor’s Office for people with Disabilities,stated the Mayor’s Office for People with Disabilities functions are like the National Council on Disability but on a local level. The role of the office is to advise the Mayor and City Council on policies and program issues to make Houston more accessible and inclusive for people with disabilities. Few direct services are provided such as the placement of visual fire alarms for deaf and hard of hearing populations and they engage in many awareness-raising events and campaigns.

Ms. Town stated that slightly before Hurricane Harvey ‘s devastation, the Mayor’s office began convening daily calls of local advocates to monitor the for people with disabilities.

Ms. Town stated that METRO has deployed numerous special services throughout the immediate response of the disaster that is a model for what other local transit authorities should be doing.

**Hannah Mehta**, stated that the Mayor’s office worked with families who relied on supports through Medicaid and medical assistance providers such as home health and other types of supports to remain in the community with their children and being able to keep them at home.

Ms. Mehta said during Hurricane Harvey there were innumerable challenges that survivors faced which included unique circumstances of caring and proving for a child with conflict medical needs. Many were without nursing and attendant care during the preparation for the disaster, which limited the family’s capacity to prepare.

Ms. Mehta stated that when families were asked to evacuate, it was recommended that their child be admitted to the hospital for the lack of medical accommodations.

1. **Progress Report**

**Amy Nicholas**, Attorney Advisorstated that a draft of the progress report is due on May 22nd with the final draft being June 25th. She added that all interviews and research have concluded.

**David Hutt**,Ph.D., Senior Staff Attorney, National Disability Rights (NDRN) stated that the progress report will be an overview of NCD’s 2000 report entitled, *“Promises to Keep”*. Mr. Hutt highlighted the report. They were as follows:

* Reviewing the enforcement activities of the EEOC, DOL and the Access Board;
* Reviewing the 11 elements used in the report *“Promises to Keep”* to look back at the EEOC, DOL and the Access Board and its recommendations;
* In the process of re-editing and editing many may sections for those individuals that were not familiar with the history of ADA and federal disability rights laws;
* Providing clear explanations and descriptions of federal laws and the role of the federal enforcement agency;
* Providing clear explanations and descriptions of federal laws and the role of the federal enforcement agency, with simplifying the language per recommendation of the advisory group.

Mr. Hutt stated that there is progress with the ADA Amendments Act reauthorization of 2014 which led to changes in Section 503 regulations and significantly for the wage and hour division, the enactment of 511 of the Workforce Innovation and Opportunity Act.

Mr. Hutt stated there were regulatory changes since the 2000 report, being the EEOC made good steps when drafting the ADA Amendment Act’s regulations, focusing on major life activities and including a list of disabilities that is covered under the ADA.

Mr. Hutt stated regarding other regulations, the US Department of Labor’s Office of Federal Contract Compliance Programs initially proposed many strong enactments to 503 affirmative action regulations but pulled back many proposals in the final regulations after federal contractors raised concern that many of the proposals were too burdensome. He added that several proposed regulations, not adopted, included a requirement that federal contractors create a written reasonable accommodation plan and offer more frequent requests for voluntary disclosure of disabilities to better track progress to achieve affirmative action progress.

The Wage and Hour Division has slowly but gradually taken aggressive enforcement activities with four recent revocations of 14 (c) certificates in the past several years. Researchers are concerned about the extent they are allocating resources to property implement Section 511 of the Workforce Innovation and Opportunity Act which place more restrictions on the 14 (c) certificate holders.

1. **Guardianship Panel**

**Ms. Phoebe Ball,** Legislative Affairs Specialistintroduced the panel.

**David Slayton**, Administrative Director of the Office of Court Administration, Executive Director of the Texas Judicial Council stated that Texas courts are charged with closely screening guardianship proceedings beginning at the point when a guardianship is sought and lasting throughout the life of the individual under guardianship. The courts regularly review reports from guardians about the well-being of the individual inventories of the assets in the estate at the inception of the guardianship and detailed accounting reports about the revenue examine expenditures from the estate.

Mr. Slayton stated that there are over 50,000 active guardianships in Texas with 60% active guardianships in Texas are elderly, under the age of 65 and most of whom have a disability or traumatic injury. Mr. stated there were over 27,000 cases in the state of Texas in which his agency found that 40% of the cases did not have the required reports and that 3,100 individuals had died under guardianship without the Court’s knowledge. Mr. Slayton stated that in 2015 the Texas Judicial Council recommended statutory changes to require attorneys and judges in guardianship cases to ensure the following;

* that there were no appropriate alternatives to guardianship available to avoid the guardianship, the goal to keep those that didn’t need to be under guardianship out of it;
* consider the ability of the ward to make decisions about residence;
* require regular review of the necessity and continuing need for the guardianship
* create a new alternative guardianship (supported decision-making)
* the judicial court has sought and obtained pilot funding to provide resources to judges to monitor the guardianship cases.

**Richard LaVallo,** Legal Director, Disability Rights Texas stated he’s agency was the first to enact the supported decision-making statute. Mr. LaVallo stated that in doing reforms the agency was able embed its reforms of the guardianship system into the statute. He added that most resistance receive legislatively was changing the term from” ward” to “a person under a guardianship” or “a person in a guardianship” and attempt has deemed unsuccessful.

Mr. LaVallo stated that there is mandatory training for attorneys representing people in guardianship proceedings to get training on alternatives to guardianship as well as supports and services.

**Belinda Carlton,** Coordinator, Texas Guardianship Reform and Supported Decision-making Workgroup (GRSDM) stated that the Texas laws lists guardianship explicitly as the only method for parents of children with disabilities to maintain a decision-making role when their child turns 18.

Ms. Carlton stated that a small work group has examined the education code and during the transition planning, we inserted supported decision-making and added things that schools should do when a person does transitioning and a list of things that are required for schools to do such as support services. She said for supported decision-making and other alternatives to work, their needs to be housing.

1. **Education Panel/IDEA**

**Wendy Harbour**, Panel Moderator, Council Member, introduced the panel.

**Jana McKelvy**, Texans for Special Education Reform stated that her group helps people with disabilities which focuses on special education and that she would like to see the Texas education Agency draft a student and family centered mission statement that is directed at families and students with disabilities.

Ms. McKelvy said that value should be placed on federally mandated state advisory panels. She said that her agency’s panel is called Continuing Advisory Committee for Special Education. She stated that their strategic plan contains a lot of details which will focus issues related to student data privacy and safety.

Ms. McKelvy stated that there are discussions revolving around the Texas School Finance Commission and working with TKs to try to build relationships between students, parents, educators and administrators.

**Kim Torres**, TEAM Project at Partners Resource Network stated that her agency is responsible for helping parents learn to advocate on an individual basis as well as provide parents free training to help articulate to schools.

Ms. Torres stated that he McKinney-Vento Act that guides homeless children came in handy during Hurricane Harvey due to the temporary displaced children. There was also new focus on communication skills training from the school to parents.

**Lisa Cowart,** Project Director, Partners resource network PATH Project spoke on resources, policies and programs to help deal with children in crisis. She added that there needs to be the following:

* frontline coordination and training;
* a special education disaster response task force- one that has a single repository for that information;
* help with distribution of information to parents, in cases of immigration reform, parents, regardless of citizenship status, that their children have a right to a free and appropriate education

**Dustin Rynders,** Disability Rights Network stated that the McKinney-Vento Act nor only allows for one to maintain their enrollment in your home school and receive your transportation as well, even if one moves to a different district.

McKinney-Vento also addresses the right to immediately enroll, with or without completed documentation. Disability Rights Texas has received 200 intakes from full enrollment denials at school.

Mr. Rynders stated that upon investigation they have found that their high-performance-based monitoring system form the state education agency, TEA, included an indicator of special education performance that gave schools the best possible score of zero If they kept their special education population to below 8.5%

1. **Bioethics and Disabilities**

**Steven C. Rhatigan,** stated that he had provided information prior to the meeting for review. They were as follows:

* organ transplant
* medical fertility
* quality-adjusted life years
* physician assisted suicide
* genetic testing

Mr. Rhatigan reported that the central philosophical concepts regarding disability were constructed by disability rights activists, not philosophers. Mr. Rhatigan stated that disability is a social problem that involves the discriminatory barriers that bar some people but not others from the goods that society offers. This view is often called the social model of disability. It contrasts with the traditional vie, sometimes called the medical model, according to which disability is a problem of individuals whose biomedical conditions disadvantage them. The medical models depict disadvantages are natural and inevitable outcomes of simple biomedical facts.

The social model depicts disability as a problem experienced by a class of people that is caused by social organization and that can be remedied by social change. The medical model is an individualistic rather than social theory. Quality -adjusted life years (QALYs) is common in rationalization and prioritization.

Mr. Rhatigan stated the medical model usually poses a direct and tangible threat to disabled people. If healthcare funds are prioritized to maximize quality, then funding for people with low quality of life should receive a lower prioritization for the same type of care than people with a high quality of life.

Mr. Rhatigan studies show that states with higher ratios of primary care physicians have lower rates of general mortality and morbidity from conditions across the board. Also reforms in California that provided all Medicaid recipients with primary care physicians, in a 7- year study, resulted in lower hospitalization rates. Also, private Medicare plans that increased co-payments for primary care visits and the thereby reduced such visits have seen increased hospitalization rates.

Mr. Rhatigan stated that there are four kinds of information that one should be concerned regarding their health and well-being over time. They are as follows:

* information about the state of your internal systems;
* state of living conditions;
* housing;
* community;
* economic and environmental circumstances;
* state of care received;
* type of practitioner that is working with you;
* state of your behavior;
* sleep pattern;
* exercise;
* stress;
* adherence to treatment
1. **Public Comments**

Mr. Thomas Diaz, parent with a child with a disability, and stated that I/DD should be considered during guardianship. He stated that the I/DD population is a heterogeneous group and those with severe profound I/DD, the definition of choice in the guardianship process must consider an individual’s right to the services where they can best thrive.

Ms. Rita Martin tanked the Council for commissioning a new report on the subminimum wage follow-up regarding the use of 14(c) with the for-profit supply chains, and this study is critically important with the announcement by OMB on May 9th on notice to amend regulatory definitions in the Rehabilitation Act.

Mr. Paul Hippolitus thanked the Council for allowing him to share the concerns from the World Institute on Disability regarding minimum wage jobs to competitive employment. He stated that the agency has an evidence-based suite of materials designed to support and provide education and training around how to represent itself in a competitive world and how to understand what is expected that is vital to this transition.

1. **ADJOURNMENT**

**MOTION:** Clyde Terry moved to adjourn the Council meeting.

**SECONDED:** Rabia Belt

Roll Call Vote:

Vice Chairman Benro Ogunyipe

Mr. Billy Altom: Aye

Mr. Andres Gallegos: Aye

Ms. Wendy Harbour: Aye

Mr. Clyde Terry: Aye

The motion passed unanimously.

The meeting adjourned at 4:18 p.m.

Date Approved by the Council:

Signature

Neil Romano

Printed Name