Gulf Coast Adapt
Lydia Nunez Organizer

The Honorable James B. Frank
Chairman of Human Services Committee
Texas House of Representatives
P.O. Box 2910
Austin, Texas 78768-2910

Re: Human Services Committee, Interim charges

Examine the long-term services and support system of care in Texas. Study workforce challenges for both institutional and community services, with a focus on home and community-based services in the state's STAR+PLUS program. Review what impact funding provided by the 86th legislature to increase the base wage for community attendant services and the increased funding for rate enhancements have on workforce retention and quality. Consider options to both stabilize and expand the workforce. Review long-term care programs and services available to Texas' seniors, including community alternatives to institutional care available through programs like the Program of All-Inclusive Care for the Elderly. Examine the adequacy of current funding mechanisms, including Medicaid reimbursement rates and supplemental add-on payments, to incentivize high-quality care. Consider mechanisms to promote a stable, sustainable, and quality-based long-term care system to address current and future needs of the state.

Dear Chairman Frank,

Adapt of Texas is a non-profit grassroots disability rights organizations representing people with disabilities of all ages in Texas. Thank you for the opportunity to provide written comments on the abovementioned interim charges during the coronavirus pandemic. Please accept our input on charge No. 4.

I ask you to bear with me as I provide a bit of background information on these important issues. For many years prior to the pandemic, I served as a certified volunteer long-term care ombudsman in Texas. In that role, I witnessed firsthand the substandard conditions in Texas nursing homes and the pronounced systemic failures of the agencies tasked to regulate them. The neglect, abuse, incompetence, and regulatory dysfunction I observed led me to dedicate my life to opposing the segregation of disabled people in institutions. Disabled people must be afforded the same human rights as anyone else; we have the right to remain *living* in the homes of our choosing, with our families and in our communities.

I want to emphasize that despite the abundance of laws regulating nursing homes and other congregate institutions, states and committed advocates throughout the nation have continually worked, for over a century, to enact further reforms. The good intentions of reformers aside, little

has changed for nursing home residents because institutional reform is neither practically nor morally feasible.

Profit comes before all else. Seventy percent of nursing homes in the U.S. are for-profit facilities; they receive, by far, the lowest quality ratings; they have, by far, the highest occurrences of neglect and abuse. Yet, notwithstanding countless congressional hearings, public testimonies, graphic video evidence of abuse and neglect, medical studies, and reform recommendations, congregate institutions have proven themselves impervious to calls for rehabilitation and regulatory compliance. Rather than expend energy and resources on care for residents, many nursing home corporations dedicate their time and resources to fighting against regulations and lobbying for increased taxpayer funding. A common nursing home talking point complains that the regulatory requirements protecting residents' health and safety consumes too much time, that it bogs down their understaffed facilities with administrative tasks. I assure you that this is not a matter of regulatory excess. This is not a matter of low reimbursement rates. This is not a matter of excessive paperwork. It is solely a matter of profit over humanity.[i] The coronavirus outbreak exposed the systemic understaffing and poor care in these facilities.

Institutionalization, however well regulated, violates both the civil and human rights of disabled people; it demeans their lives and dignity through regimented control, and swiftly leads to despair, abject loneliness, and failing health.

To the above we can add an economic dimension. Nursing home corporations incessantly demand increases to government funding. Since their demands are usually met, they have become a bottomless drain on limited state funds, funds that could be more efficiently used for home and community-based services. In just the past six months, nursing homes have received $10 billion in federal funding, $2,500 per bed from states, taxpayer subsidized PPE and COVID testing, and now volunteer labor provided by Doctors without Borders.

Also since the pandemic, a flurry of reports attesting to the horrible reality of these facilities has continued unabated.

- Corroborated reports of bodies stacked in nursing home morgues and left in rooms;
- Disabled people dying alone in fetid and soiled beds;
- The recent U.S House Ways and Means report detailing the drugging of residents to keep them restrained.
- Twenty-one states providing billion-dollar nursing home corporations legal immunity.
- The Office of the United States Attorney General report detailing the prevalence of unreported abuse and neglect.
- The waiving of basic regulations during the pandemic.
- Coercive nursing home arbitration agreements.
- Widespread evictions of significantly disabled Medicaid residents—those considered too time consuming—for replacement by more lucrative Medicare patients.
- A revolving door of poorly trained and improperly screened staff.
- Consistently dangerous understaffing and manipulation of staffing levels to government agencies.
- Persistent violation of resident rights despite the superficiality of 'person-centered care.'
- The United States Government Accountability Office report on widespread infection control deficiencies in facilities across the nation (Texas was particularly bad).

- CMS data revealing the 21,000 COVID-19 cases in nursing homes in Texas, with over 4,000 deaths.
- CMS data attesting to Texas's low ratings

Now, when reflecting on the magnitude of this human rights catastrophe and the neglect detailed in government reports and media accounts, is it conscionable to continue to fund inhumane practices that, according to Kaiser Health News, have resulted in the deaths of over 70,000 disabled people nationwide (over 54,000 alone in nursing homes) since May 8th?

It is for the reasons outlined above that I stress to you the necessity of expanding Home and Community Based services (HCBS) and providing community care attendants livable wages for their hard work (and other wage enhancements). As it is now, especially during the pandemic:

- Because pay for personal attendants are poverty-level wages, disabled people living in the community struggle to retain qualified staff and, as a result, many are forced into nursing homes. Poorly paid attendants who fail to show up for work jeopardize disabled people's health, and the fear of solitary confinement in a nursing facility induces untold psychological duress.
- Families must often miss work or school to assist with caregiving duties when poorly paid attendants do not show up for work.
- With underfunded HCBS, parents often have no other choice than to place disabled children in congregate institutions.
- Because of underfunding of HCBS, families/spouses are often separated when a disabled member must be institutionalized.
- Struggling attendants are forced to juggle multiple jobs, some of which are in congregate settings. This makes the six month lockdown of nursing facilities ineffectual and cruel. It also endangers the public health by spreading the virus and, in turn, results in hospitalizations, long-term health effects, and increased state Medicaid costs.
- During the pandemic, it is safer and more economically sound for attendants to choose work that pays higher wages than to work multiple jobs as attendants.
- It is safer for attendants to collect unemployment than go back to their jobs.

Recommendations:

- Fundamental change and budgetary reorganization from institutions to HCBS.
- State funds squandered by fiscally irresponsible nursing home corporations (to increase *their* profits) could be:
    a. reallocated to increase the starting wages of community attendant care workers from $8.11 per hour to $15 per hour.
    b. used to train and employ other disabled people to engage in community attendant work.
    c. invested in community attendant wage enhancements.
    d. used for the expansion HCBS.
    e. used to reduce consumer wait lists for HCBS (reallocation of these resources would reduce preventable deaths and the health effects of institutional neglect and abuse).
- With a reduction in nursing home populations, HHSC regulatory and ombudsman workloads will be significantly reduced.

- Increased funding for relocation specialists to move people back into their communities (most residents and volunteer ombudsmen are unaware of this option).
- An acknowledgement that nursing home staff and social workers have a vested interest in resident retention and regularly misinform residents of their rights and HCBS options. The state should require relocation specialists to routinely inform residents about HCBS.
- Despite CMS and state regulations, resident rights, safety, and health cannot be ensured without adequate state oversight *free from corporate influence and coercion*. Under our current patchwork system, this is untenable. Rarely are regulations followed. Without uniform implementation of regulations, substantive penalties for violations, and *sincere* oversight, human rights violations will continue unabated.
- *All* ombudsmen, particularly state and county head ombudsman should be required to have a basic knowledge of disability rights, the Supreme Court *Olmstead* decision, the ADA and why these are necessary.
- Certified volunteer ombudsman are regularly harassed and prevented from doing their work. This results in oversight so weakened as to be mostly ineffectual; ombudsmen end up being little more than friendly visitors. Substantive penalties should be imposed on both individual staff members and facilities that obstruct ombudsman work and retaliate against ombudsman for doing their work. The misdemeanor charge itself is rarely if ever applied and a charge more severe than a misdemeanor is needed. As a LTC volunteer ombudsman, every single week for years I had to countenance retaliation and obstruction, and despite notifying the county head ombudsman, nothing of substance was done. Retaliation by LTC staff against residents who speak to ombudsmen is far more prevalent, punitive, and swift.
- Ombudsman programs and HHS regulatory exhibit *severe* goal displacement. Rather than prioritizing the best interests of residents and the disabled people they serve, these positions have become career opportunities for technocrats. The main goals seem to concern achieving and maintaining career advancement. I suggest an outside evaluation on the efficacy of the state's ombudsman program and HHS regulatory through annual audits of these programs (free of corporate or other influence).
- A separate citizens' commission consisting of relevant stakeholders needs to be appointed to monitor these agencies.
- Because funding depends in part on efficaciously achieving their goals, ombudsman programs want the appearance of high rates of case resolution. And, in fact, most cases are resolved or partially resolved. But the appearance of resolution is false, as certified volunteer ombudsmen have been explicitly instructed to not record unresolved cases on 8620 forms. This means that officially no cases are left unresolved, while in reality, most are unresolved. The mere appearance of efficacy has troubling consequences. Since everyone assumes that the ombudsman programs are representing residents' rights and effectively resolving issues they have with facilities, they believe that residents are protected. The nursing homes themselves know that this isn't the case, and this false sense of efficacy feeds into their belief that they can violate the rights of residents with impunity.
- Residents and ombudsmen should *regularly* be informed about HCBS options. Unfortunately, most residents and their families are unfamiliar with these programs and nursing home corporations and their staff undermine efforts to help residents connect with Centers for Independent Living or other resources that would enable them to live in their communities. Staff and head Ombudsmen are remiss in informing residents of their rights about community living options and relevant programs. Moreover, many volunteer ombudsmen are unfamiliar with the *Olmstead* Supreme Court Decision and the importance of the ADA. There is quite a lot of overt ableist bias within the ombudsman program and this should be rectified with education. More disabled people (with knowledge of disability rights) should be encouraged to become ombudsman and adequately supported in this role.

- The occurrence of former HHS regulators or paid ombudsmen becoming nursing home administrators significantly harms residents. Administrators have professional and social connections to regulators and ombudsmen and firsthand knowledge of how to manipulate the system to their advantage.
- HHS regulators frequently fail to communicate with volunteer certified ombudsmen. They disregard our firsthand knowledge of systemic issues occurring in substandard facilities. We are told that if regulators didn't "see" a given violation, there is nothing that they can do.
- The Ombudsman program desperately needs role clarification. In numerous newspaper interviews, a county head ombudsman discussed their role as investigators and likened ombudsmen to "Sherlock Holmes." Ombudsmen *need* to understand that they are *resident advocates* first; they need to take seriously what residents, their families, and certified volunteer ombudsman tell them. In one CE training, the county ombudsman advised volunteers that we should be cautious about believing residents because their anxiety made them paranoid. On numerous occasions he said that people with anxiety were paranoid. Since the widespread discounting of what older and disabled people report helps abuse and neglect to continue, the undermining of residents' credibility should be forcefully prohibited rather than endorsed.
- Sincere oversight of nursing home administrators and their licensing is necessary. Currently representatives of the nursing home industry are appointed by states to oversee nursing home administrators. As a result, few administrators (and there is a revolving door— the average administrator lasts approximately six months) exhibit competency with regard to disability and resident rights.
- Rather than give increased funding to nursing homes, increase the number of ombudsmen, incentivize volunteer ombudsman work. Presently, in my county, we have roughly one paid ombudsman for every *fifty* facilities. The program relies heavily on volunteers, as it should. However, a head county ombudsman conveyed to me that some nursing home administrators were so truculent with certified volunteers that they could not retain volunteers in those facilities. Knowing this, nursing home staff and administrators regularly harass and intimidate certified volunteer ombudsmen, with the result that volunteers are not placed in these facilities and, as mentioned above, because there are not sufficient numbers of paid ombudsman to replace them, these facilities have little oversight.

[i] Many for-profit nursing homes themselves run deficits, but still make money. Corporations with interests in the facilities own the property through a separate company, supply medical supplies through yet another pharmaceutical company, and so on. They earn millions by skimming the money meant for resident care through these other companies. One company in N.J. owned the land two poorly run nursing homes where 60 COVID-19 patients died; 17 bodies were found hidden in a tiny on-site morgue. They received $8 million a year in rent for the two places.