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     >>ELISSA: We will give it another minute or so to let more people in. I will do some housekeeping stuff and we will get going. We're going to give it another moment or two and make sure all of the speakers are here. We will get started in just a moment.

     >>ELISSA: We are a couple of minutes past noon here so we will go ahead and get started. We do have a couple of other speakers who should be joining here momentarily. I am going to go through just a little bit of housekeeping. First of all, I want to thank everyone for being here, welcome. I am Elissa Ellis the director of operations with the Association of programs for rural independent living. First, if when you scroll over the screen, a menubar will pop up on your computer which shows the microphone, video camera at the bottom. You can select video to join by WebCam if you can, there is a microphone, you will want to unmute and mute, you can press to join the discussion. There's a chat feature with the word bubble at the bottom and you are welcome to use that for any comments, we will be monitoring that and will come at the appropriate time get your questions in. We are providing closed captioning for today's session, but you can view the captioning by selecting the CC tab at the menubar. You can also make a larger box by clicking the three dots at the top right hand corner of the box. If you would prefer a larger font or to change the contrast, you can change the carbon view by selecting full transcript in the same CC box. We do have sign language interpretation for today's meeting. The interpreter can be found in the box named, where are you? Interpreter (laughing). If you would like to view them in a larger display, you can go to the top right corner of their box and select the three dots, a drop down menu will show you the option to pin. Select this option and go to the speaker view for them to show on a larger screen. For those of you on the call today, we ask that you press start six to mute and unmute. We ask that you keep your phone on mute when you are not speaking to keep the background noise down and be respectful to those that are speaking. If you need anything during the call, please feel free to message in the chat or you can certainly email me at. APRIL is so pleased to be hosting this webinar today. COVID 19 is still in institutions, dying in place, staying saving lives during emergencies. Our intent is to acknowledge. (Laughing) thank you. Our intent is to acknowledge that people with disabilities have been disproportionately affected by COVID 19. We want to highlight the vital roles that we all play in the fight to save lives, and we want to start the conversation about how we can collectively respond better in the future to the needs of people with disabilities. We see this as a starting point, we are planning planting the seed with the intention of nurturing and growing the relationship between all of the entities on this call. So that moving forward, the boot is on the ground folks that will be at the top of your list of resources to contact when emergencies arise. With that, I will turn it over to Fran Tobin to give you a bit more of an update.

     >>FRAN: Thank you so much Elissa Ellis, and everyone who is a part of this gathering. I am Fran Tobin, I am with the alliance community services which is a unique community partnership of people with disabilities, seniors, poor people, frontline public services workers and we are part of the institutional rescue and recovery coalition, and the SILVER program. Saving Institutional Lives Via Emergency Relocation. Just a little background on how we got to this point, you may recall that over a year ago from the very beginning of the pandemic, many disability rights advocates across the country weren't correctly that can't get institutions would be petri dishes for COVID. By March and April 2020, national and local disability rights advocates have developed calls to action to safeguard the disability community and those in congregate facilities in the pandemic. The advocates met with and pressed state officials and a number of settings to convene the various agencies that could develop functional rescue plans for folks left in these facilities. By May and June, as it became undeniable that congregate settings were the most COVID dangerous places to be. Being very conscious of failures, past failures to safeguard persons and institutions during Hurricane Katrina and other disasters in the past, there are more and more groups that joined in the call to the governors to develop emergency plans to save lives. Including reducing the density of congregate facilities by relocating some residents into safer non‑congregate settings. Keep in mind, that the groups, many of the groups involved in this advocacy have years of practical experience and expertise in transition. In moving people out of nursing homes and other facilities into non‑congregate settings. This came from real experiences. As the death toll grew, the institution of rescue and recovery coalition which includes current and former nursing home residents, organized protests and marches, meetings with officials and press conferences. But the media reports and the government responses were mostly long and sorrow and short on solutions. Demonstrating what many advocates sought as a combination of systemic able‑ism, a lack of vision or indifference to the industry. Officials and frankly many well‑meaning allies claimed that safely relocating anyone at any scale was simply impossible. One presumably unsympathetic official reportedly said, what am I supposed to do? I don't have a helicopter. The reality is, that throughout this period local groups in the coalition were doing what officials said was impossible. Very few resources but many bureaucratic obstacles, small numbers of people were being safely relocated on emergency temporary basis out of facilities where COVID risk was the greatest. Safely and effectively but on a very small scale and we will hear more about this very soon. There are other groups in Illinois across the country that were very interested in doing emergency relocation, but the complexity of piecing together funding buckets and lack of policy support were major hindrances. As Congress took up its COVID relief packages, and obviously complicated politics and all of what that might have been and where it ended up coming down. It only made sense to those of us that some portion of federal funds for COVID relief should be dedicated to the rescue and recovery for those people that were most at risk of COVID infection and death. That is persons in congregate institutions. Working from the experience and expertise of local groups already doing this work, groups with experience and other nonemergency transitions. Coalition leaders from adapt, APRIL, the world of disability and others outlined the silver framework for saving institutionalized via emergency relocation, and called for a small pilot that would accomplish that goal. Groups from across the country signed on to the SILVER proposal asking Congress to hear more support from the pilot SILVER program which would provide funding and technical assistance so as to expand the emergency relocations that some folks were already doing. And to determine best practices and guidance for future disaster relief. By increasing the numbers of emergency relocations and evaluating the work that was being done, or any place to inform future in public policy and future protocols for disasters. This coalition is still advocating for those kinds of responses. That is some of the background and we will get more into where we go from here.

     >>MARCIE: Thank you very much, I really appreciate those opening remarks. I am Marcie Roth, the executive director at the world Institute disability prayed and a member of SILVER. I really appreciate APRIL and all who have worked so hard on behalf of people seeking emergency relocation. We asked you to join us today, because we need you and we want to work with you. We are here seeking common ground. We are meeting in the middle to save lives. I am filled with a deep sadness over my own failure to find the right words, do the right things to convince decision‑makers to work with disability organizations to provide a safe alternative for millions of disabled people in congregate facilities over the past 18 months. For the many months and years that preceded them. SILVER has not brought us together to pontificate what some advocates are pushing. The right to live in the community is settled in the U.S. civil rights law, and in trying to gain international human rights treaties. However, due to collective inaction over the past 18 months, 200,000 or more disabled people of all ages have died in the U.S. despite civil rights protections as a direct result of the failure to keep them safe, and give them the option to shelter in a safer place than a congregant institutional setting. Many who hold the keys to the kingdom found it easier to deny them emergency protective measures and other efforts for regions we just don't understand. Maybe it is because these people are family friends, neighbors, coworkers who were routinely dismissed as bold, vulnerable, frail, fragile, with comorbidities and underlying conditions. Rather than simply as our fellow human beings. Many decision‑makers told me directly that they believe that these disabled people were safer, better off where they were. That they knew better than the experts from independent living centers who had been successfully relocating people for many many years. Maybe you have convinced yourself to see this differently. For many of us, that the deaths of hundreds of thousands of disabled siblings is nothing short of the genocide. Although thankfully, no longer dying at a rate up to– three every minute for weeks on end, these deaths persist today, hundreds of them with no end in sight. Most people agree that nursing homes come along care facilities, psychiatric hospitals, large group homes, detention and other commercial facilities and other congregate facilities, or not desirable places to be. Nobody signs up to go into an institution. There are reams of data that document the dangers of these settings, this data also documents that a very high percentage of institutionalized people are disabled and that the vast majority are Black, brown, indigenous and other multiply marginalized people of color. Poverty and all that comes with it, is also a common reality among the 2 million people in long‑term congregate facilities and the 2 million in personal facilities. Many of us began coming together under the leadership of the partnership for inclusive disaster strategies on February 28, 2020. Within days the partnership, the world Institute on disability and the national Council on Independent living issued a call to action to protect the rights and the lives of 26 percent of the U.S. population, people with disabilities. Amid the unfolding horrors of the COVID‑19 pandemic. Within days, almost 200 organizations had signed on calling for immediate federal action to ensure that over a quarter of the population entitled to hard‑fought disability civil rights protections would be prioritized throughout what was shaping up to be a devastating and deadly virus. We didn't just call the government to figure it out, we provided specific actionable solutions to reduce the disproportionate impact COVID was raking on disabled people. As we always do, in our commitment to be a part of the solution, following our nothing about us without us motto, we offered to bring our considerable lived experience and emergency management expertise to the table. We had continued to come together, each and every day, weekends and holidays without exception. In our commitment to contribute to saving disabled lives. We have not missed a single day. Yesterday at six p.m. Eastern time, we met for the 500th day in a row. We have had regular attendance from local, state, and federal allies. The American Red Cross joins us every day, no longer a glaring symbol of failure to plan for and accommodate disabled people and disasters. Now a source of information, and a partner in efforts to save disabled lives. The DHS office for civil rights and civil liberties, and a representative from the Center for disease control and prevention are regular attendees two. We are grateful for their commitment to work alongside us against untenable and surprising opposition. Over a year ago, we were thrilled when we learned that FEMA was rightfully providing states with access or public assistance category B emergency protective measures funding to offer non‑congregate sheltering to people who are on house. We thought surely this meant the same resources could be used by states to relocate people in congregate facilities with the New York Times refers to as death pits. Two non‑congregate shelter. Many of us had decades of experience in disability rights and in the rights of people with disabilities and disasters. Many from independent living centers are experts in nursing home transitions led by folks that you will hear from today. They did all they could to work with their county, state and federal emergency management and public health officials to allow them for people asking for help to move from clear and present danger. To the relatives safety of the non‑congregate day. Unfortunately, even though we went to everyone at FEMA, the department of Health and Human Services, who might be in a position to help, the only resources provided to hundreds of thousands of disabled people desperate for help was funding to cover their funeral expenses. In other parts of the world, July 14th is a day of significance. It is best field day, commemorating the storming of the Bastille in the 1779. We are not here today to storm the institutions, though some might like to. But rather to commemorate what happened one year after the storming of this the steel day. Senator Martin who wrote France's national law commemorating the steel day, 100 years later said and I quote, after the day of 14 July 17, '89, there was the day of 14 July 17, '90, this latter day cannot be peeling for dividing the country. It was the concentration of the unity of France, whatever difference which might part us, something hovers over them. It is the great images of national unity which we all desire for which we would all stand. Our goals clearly implementing and enforcing the rights of millions of people have not been enough. It is time to stop fighting for the rights of denied disabled people for far too long, equity is quite the buzzword these days. We must move from rights to justice. In a just world, people don't all get the same thing. They get what they need to live in freedom. We ask each of you to stop admiring the problem of institutionalization as a horribly failed experiment. Join us in putting an end to the institutionalization of people with disabilities starting with during and after disasters. We will now be hearing from some of the folks who have experienced the very significant impact, more than words could even begin to describe. I am first, I see Ebony has joined us. I am first going to turn to ebony who is currently in her own nursing home transition journey. Ebony has a very powerful story to tell, and we have really appreciated her partnership throughout the SILVER journey. Ebony?

     >>EBONY: Hi, good morning. Imagine being paralyzed from the neck down, living in a nursing home, depending on someone else for your daily needs, and to keep you safe. My name is and I'm a resident at worst edge in Chicago, Illinois. This is my reality. I have been a quadriplegic for 18 years. I became paralyzed in January 2003. I was a victim of a violent crime involved in a car accident at the same time. Since then, I have been in and out of nursing facilities, I didn't begin to self advocate right away, but after years of having to endure and witness and on. The moral and potentially illegal treatment, I felt I had no other option but to begin advocating for myself and others. Specifically, it was after contracting a near fatal blood infection. Due to the receipt of improper care that I began to self advocate. A nurse at the facility, aware of and worried for my safety seeing that the facility was not listening to my concerns regarding my treatment, introduced me to the (name) who served as an advocate and go‑between for the residence. (Name) is a vital tool for me as I directly traverse advocacy on behalf of Bob residence as well as when I would assist them as they attempted to advocate for themselves. The October before it was announced as a pandemic, my facility which houses 200 + residents experienced an outbreak of residence with flulike symptoms. I personally experienced several severe cough for several weeks that progressively got worse. Chills, body aches and an abnormal temperature. My symptoms increased so severely that soon after they had begun, I was admitted to the hospital and diagnosed with what they can only describe as an upper respiratory infection. I remain hospitalized for approximately two weeks. Having to receive two different antibiotics with two different breathing treatments every four hours around the clock. Two weeks after my symptoms began, the CNA that worked very closely with me began experiencing the same symptoms and was quickly admitted to the hospital and diagnosed with the same upper respiratory infection. Once it was established that there was an impact virus spreading, COVID‑19 as we have come to know it, minimum steps were taken by the facility to lessen the spread in congregate situations. Given the result, we have steps including unnecessary forced isolation, lack of proper PPE gear and staff who weren't observing the mandated isolation or social distancing rules. Just to name a few, one must only wonder how effective and thought about these steps really were. Initially, the severity of the pandemic didn't really affect any of us but after a few weeks, the grimness of our situation began to set in. I in turn became really worried. I wondered about the effectiveness of the facilities cleaning procedure, and just how sanitary it actually was. Especially given the facilities response when the CNA asked or masked. The facilities initial response of "this is a mask free facility ", truly frightened me. I was in fear of my life. As an immunocompromised resident, and fearful of the lives of those other residents that depended on the facilities to keep them safe. Even the nurses at the facility soon became fearful enough to act. They organized and protested on national news. Once the broadcast was held right in front of the facility, CNA's spoke out about the facilities neglect to inform them about the virus, the infection rate within the facility, the COVID related deaths in the facility, and also about not having proper PPE gear. Real was in the news during this time and segments providing information on facilities with the highest number of outbreaks. Real was ranked number three. Here I was, stuck amongst 200 + other people with no way out and no way to truly isolate or social distance. To my knowledge, as the facility continues to be regarding to the actual numbers real has experienced five COVID related deaths including two staff members and three residents. One of the staff members provided me with up close care and assistance only a few days before she was found deceased. One of the residents who passed was hospitalized with COVID and past soon thereafter. Their family had not even knowing they were in the hospital. To this date, Maria refuses to keep the staff and residents updated on new outbreaks or the number of patients. Already testing positive for COVID. To add insult to injury, while the residents were forced to remain in what had become a proverbial petri dish of infection, facility also staffed, I am sorry come at the facility allowed staff to travel across the state on leisure, with some not taking precautions traveling to "hot states ". Such as Georgia, Florida, California, and Nevada. I experienced severe mental health ramifications from the facilities lackluster response to the COVID 19 pandemic. Having to, among other things, deal with prolonged isolation. Prior to the pandemic I was accustomed to visits from family, every other day if not every day. I was also accustomed to being able to leave the facilities to see my family, sometimes multiple times a week. Not counting the occasional surprise visit and outings with friends. Needless to say, my mental health was affected. So much to the point I had to begin telehealth therapy sessions. The facilities will response and the pandemic continued to lessen. To this day, remains in position to the CDC and IEP age guidelines in the industry practices and other facilities and even the fact contrary to certain other real facilities. Brea has announced itself as a "vaccinated " facility, however there is no course for residents like myself who cannot vaccinate due to medical issues. I, myself have one working kidney and the multiple issues I have experienced with the kidney has left me compromise. My question is, how do people like me protect ourselves? Being in a congregate care facility, I have to interact with people from social workers and administration, to kitchen staff, activity aids, nurses and CNA's. Each of these people have to interact with each other as well as other residents. Now isn't that the opposite of isolation and social distancing? Why not make a way for people to truly isolate, a way that a resident can interact with one person giving them the total care that they expectedly need, a way for dire emergencies and life‑threatening situations such as this. In an ideal world, does residents like myself who wish to leave congregate facilities will be able to do so. It is much easier to control who you interact with, not being in places like these. This way if you do become infected, you would know exactly who caused you to be exposed. I would love to be able to leave the facility and be in a place where I can control my environment. Can currently am working with the covert program to transition out of the nursing home but COVID response to it has caused a backup in their ability to get and keep the process going in a timely manner. Due to COVID and the facility not providing a safe social distance opportunity for visitors, it has become near impossible for the covert program to properly conduct interviews and to perform assessments. I personally had to rely on assessment which the facility making document had to be re‑performed and corrected. I interviews have now had to be moved update to Google or resume. All of which and other items, nursing homes have gone into a 3 to 4 months process into a six‑month and counting ordeal. If you can, imagine being paralyzed from the neck down. Depending on someone else for your daily needs. To keep you safe, living in a nursing home fearful every day the next person that enters your room could be the one to infect you and cause you death. The stressed depressed and desperate to get away. My name is and am a resident at Forest at Chicago and this is my reality. Thank you.

     >>MARCIE: Ebony, this is Marcie speaking. We cherish your leadership and I hope that you have gained more allies today in a shared commitment to get you and all others who want to relocate to safety, to be able to do that. I want to point out that Eric colleague, Lily Greenman shared in the chat and after looking up vaccination rates, it looks like only 41 percent of facility staff are vaccinated as of about two weeks ago. Where are the rights of people like to be safe and protected from the kind of horrific circumstances that folks are experiencing? Unfortunately, our next speaker, someone who I have come to have tremendous respect for, I can imagine that we would never have crossed paths. Although, I am so glad that we have. Her next speaker is someone who I am quite sure didn't plan on being a national spokesperson, didn't plan on taking on the most difficult of leadership messages. But Melissa Hickson, the widow of Michael Hickson and the mother of five beautiful children, found herself facing a doctor speaking the most unbelievable words about her husband. Then having to deal with the loss of her husband, Michael. Many of you know some pieces of Michael's story, but I am so glad that Melissa is here to speak with us today. Melissa?

     >>MELISSA: Thank you, Marcie. I apologize, I am sitting outside and there is an airplane going by right now. Give me one moment here. All right, I think you for the introduction Marcie, when he first started talking I thought who is this person that she is talking about? It can't be me. What? As he progressed in talking, I said I think she is talking about me? Because I don't obviously necessarily give myself any credit for that. You are right, it was a situation in which I never saw it coming. To begin with, first of all my husband Michael passed away June 11th last year. In a hospital in Austin, Texas where he was denied care. He was not given medication, he wasn't given hydration, he died six days after admission to the hospital. It was a recording that has been made public which I had with a doctor in the hallway, he told me that the reason he would not be continuing treatment for my husband was because he was not walking and talking. He goes into more detail about the fact that the patients that had survived were all walking and talking, my husband didn't fit that same ability. Based on that, he had no quality of life. We went back and forth in the hallway about it and he told me it was up to the state and the hospital. To make that decision, but they were going to transition him to hospice. At that point. So they did, and less than a week later, he passed away. That story, to me, it doesn't sound like it is mine. But it is. The reality, when I go back and I want to talk a little bit about this about how Michael became disabled, but I do want to say that Ebony, you are strong and hearing you talk about it and being in the position from the facility, the strength of your voice is so strong. You are doing a great job, I applaud you for doing that because that took courage. It was well presented. I am praying for you, and I know I hope that things work out, but I do really applaud your strength. It does take strength, it really does. Let me begin, Michael, in May 2017, a typical day, we started out preparing to go to work with a regular routine, we dropped the kids off at school and he would drop me off at work and continue to his job. On this particular day, it was no different, we dropped the kids off and are on our way to my job. Right at the service road where my job was located, Michael passed out at the wheel. The paramedics came, they worked on him for hours. Took him to the hospital, they immediately put him into a induced coma and they told me that he had gone into sudden cardiac arrest and that he suffered brain injury based on the extended length of time that he had been unconscious, which had been at that point, over one hour. They resuscitated him after maybe 30 minutes, then he went out again. Then they resuscitated him again, then they put him in an induced coma to preserve whatever brain activity he had at that point. I want to say that from the beginning, they encouraged me to discontinue medical treatment for him. That was a conversation we had, I think on day two. The neurologist came to talk to myself and my family members to tell us that Michael essentially would never be the same person again. He would potentially be paralyzed, and would have little or no brain activity or function and that his personality would never be the same again. He encouraged us to switch our treatment. They kept asking me the question and persisted daily with that question for me and they said he would never be the same person, what he would want, not what you would want for him but what would he want? I pondered that question and I thought Michael is the kind of person, that love life, he wanted to live and he loved his family, and he loved me, he would never want me to give up on him. I knew that that was what he would want. I gave the information but that didn't stop, they persisted with it continuously. That was a reoccurring theme, that was 2017 and I would say the reoccurring theme for the next three years was always leading back to that same point. Withdraw care or in some ways, not give any type of treatment, therapy. It was all rejected. We come to a point in 20/20 last year where he, Marcie knows about this, the guardianship was an issue and was contested between myself and my sister in law, the guardianship organization took over, court‑appointed. They decided just what I had been trying to avoid the entire time, they wanted to move him to a nursing facility. That wasn't the first time that it had come up. In the beginning in 2017 they continuously tried to push skilled nursing and all through the three years that was the first thing they wanted to do was put him in a skilled nursing facility which I kept rejecting because I wanted him in rehab and have therapy. I wanted him to have love, and care and support at home is what I really wanted. I think about what you just talked about. I know since Michael's passing of come in contact with more advocates that support community care. I wish I had access that information, back then. I had no resource or any type of support during that period of time that he was home, which was four months or so. I was pretty much figuring it out on my own. What to do. Who to call. It was pretty much just me. Michael was 300 pounds, 6 feet tall, he was paralyzed from the waist down and had also lost his sight, he was blind and suffered short‑term memory loss. Here and there. The primary caregiver for those once he was at home was me, by myself. I could not get an age to come, when I finally did, they were unpredictable. She would come sometimes, or late, just not continuously present. The one thing I missed was the resource of someone to help me at home. He looked good at home, he got the best care at home, he needed to be at home. But all the time I kept being pushed back on that, that he needed to be in a facility and that was a reoccurring theme pushing the facility, then he would have bouts of pneumonia and different things. People who are quadriplegic experience and that that would force me to the hospital. Of course the conversation in the hospital would always be discharged to a skilled facility, pushback from caseworkers, social work is as far as that was concerned, fighting insurance was another issue. I had to continue to fight that for him, to make sure he got the best care. I was his advocate, his person, communication wise I understood every movement he made, his body language. We had been together for so long with five children, and I was an advocate. When he went into the hospital the final time in 2020, they took that away from me. The primary person that was an advocate that was his eyes, ears, mouth, they removed from the situation. They became fully in charge of his care, and they made the decision to not offer him care. What I would like to say on that, is as you all are aware, the disability, there has always been a biased for people with disabilities, it didn't just start last year during COVID. When COVID opened the eyes and ears of a lot of people to see exactly what goes on behind the scenes of what has been, for so long. I hope that we all use this opportunity to really really press in on this to make people understand, people that are not familiar with the life of either someone with a disability or the family of someone with a disability that they are overlooked. They are considered less than human, there is biased whether it is unconscious or conscious, there is bias. Unfortunately, it happens quite frequently with the medical community. That is something at this point that we use to our advantage and make sure we make sure people see this. There is bias with intersex Nellie, Michael is a clear example of the Black male with a disability, clearly intersex Nellie there. Accessibility as well, we are talking about lately and Texas, the voting rights in the fact that the Democrats left you to go to DC to fight for that and one of the issues of course, was accessibility. For people with disabilities. The other issue is going to be support for people with disabilities, that is almost nonexistent as well, and it is because not enough light has been shined on the fact that there is a need for support, there is a need for accessibility. Those are really important things that we need to stress. Marcie was aware of the bill that I attempted to go through Texas legislator, the legislative session that was the HP 363 and that would essentially cover people that don't have advanced directive that are under guardianship and we know a lot of people that are disabled or under guardianship of some type. When they do that, you lose your rights. This bill was supposed to be a place for families to be able to make a decision if there is an end‑of‑life or critical care decision. It didn't even pass the house and that is important, passing legislation is key, as you can see that just issuing the guideline of some sort doesn't work, there needs to be legislation in place to keep people accountable for what they are doing and what they are not doing correctly. I hope that will stick with that, I know I am in it for two when it completely at this point. I did not become an advocate at the beginning by choice, but since I have been, since Michael's accident, since the issues, the numerous issues I have had over the past four years, it is my commitment as far as as long as I live that we will continue to fight for that. I won't stop. I want to thank you Marcie, for giving me the opportunity and I know I have talked quite a bit. Thank you so much for the opportunity. If you ever need anything, let me know.

     >>ELISSA: Thank you so much Melissa, we appreciate you being here. Next, we are going to move into our boots on the ground folks, best practices, first up is Misty Dion she is the CEO of the roads to freedom in Pennsylvania. Go ahead Misti, thank you.

     >>MISTY: Hello everyone, this is Misty Dion. Thank you for the introduction and it is a pleasure to be here with so many of you who actually work and spend time to try and save lives, in many cases save lives during a pandemic. I was fortunate enough to have connections with many of you and make connections soon after learning of COVID with many of you. Which help us to provide the emergency relocation services that are agency provided. I work for the roads to freedom Center for Independent living up north central Pennsylvania. We have transitioned individuals for many decades successfully and in many cases, watched them, their quality of life improve and the length of their life improve. It has been a blessing and it is what has kept me interested and a part of this SILVER program. Although we have provided many services, in addition to the nursing home transition services, we also provide attendant care services. Also, advocacy services. Those three services are what allowed us to relocate individuals who are on our nursing home transition list, and those family members who themselves have contacted us here saying that they were facing that they were seeing death knocking on their institutional doors. We worked to request the assistance of our local emergency management, era state Department of human services, the office of long‑term living which provides our Medicaid services, and a few managed care organizations. We requested that they assist us in helping to save the lives of these individuals by allowing and collaborating with us, to move these people into hotels and dormitories where we could provide the services they needed to keep them safe to allow them to be socially distanced, and to avoid them contracting the COVID‑19 virus and dying. In many cases, we received pushback, we received pushback from the state from our local County emergency management, from our commissioners. From the very officials in the hospital and nursing facilities that we were requesting to coordinate with, we were told that the hotel rooms were not safe for people who lived in nursing facilities, and in many cases, in all cases we proved them wrong. We moved individuals into these facilities and provided them with the attending care services, the durable medical equipment, the transportation and food, any other service that they needed. We coordinated with families so that they weren't isolated so they have the support and the connection that they needed to continue through this very hard time. We were told by our local emergency management agency, that this isn't something that FEMA helps support, FEMA is therefore natural disasters. In many cases, that means moving people from nursing facilities into another facility. When I explained that these facilities were on fire, that I needed them to help me rescue them, we were told we don't know how to do that, we don't have the mechanism to support you in doing that. You will have to explain to us how to support you in what you need from us. Working with many of these advocates on this call, mercy, with a similar program he has done, we were able to develop the memorandum of understanding is that we had to provide to the emergency management agency so that they would be able to apply for FEMA, and FEMA reimbursements. We are still waiting to see if we will receive any reimbursements, but we decided that whether or not we were going to move forward, relocate these individuals, make sure that they had the services and support that they needed in a safe environment, and I hope that today those of you listening and those of you that are in positions where the departments that have any interaction with emergency response and with assuring that individuals living in institutions will follow this with providing action. With putting support in place so that others who provide emergency relocation services have the finances, have the supports, have the connections needed to make it possible so that we can save more lives instead of sitting back and watching this horrific genocide continue. Thank you again for having me.

     >>ELISSA: Thank you Misti for everything you do. We are going to move on to Anaya Robinson with Atlantis in Denver, Colorado.

     >>ANAYA: I am Anaya Robinson, my pronounce or he/him. I am at the Center for Independent living covering the area in Metro Denver, Colorado. Thank you Melissa, I am excited to speak with advocates and the whole community and our whole selves and is saving as many lives as possible during a time many continue to not prioritize those dying at highest rates. Much like Misti Ambrose to freedom we saw so many of our community members imprisoned and dying congregate settings during the pandemic. We saw it severe need that was not being met by any other entity so we can together with several state and community partners to create a pilot program using cares active dollars and other funding streams to build and implement an emergency transition and diversion program. To move folks immediately and to supporting them into permanent housing in the community with the services they need. We have been utilizing this pilot not only for transitions from skilled nursing facilities but also assisted‑living's, the acute care hospitals rehab hospitals and congregate shelters for folks who are on house and at risk of being and institutionalized. After failed conversations with our local emergency management agencies, we quickly realized FEMA funds were not going to be made available to us to support our siblings in congregate settings. Our local agencies informed us time and time again that they were already contracting with providers who support people experiencing homelessness and did not have the ability to take on anymore. We quickly shifted to cares dollars, grant funding and individual notations to begin our work. It took us months to get confirmation from ACL that we were able to use cares dollars for this type of work so we had to leave in other funding options as we raise them which created significantly slower start than we had wished for. We partnered with our state division of housing to get access to state‑funded housing vouchers for those consumers transitioning in diverting through this program. To ensure that after their time in the hotel, they could have access to a affordable accessible in integrated housing. Our pilot center not only around supporting people with disabilities getting into spaces where they were able to safely distance and shelter in place, but also people experiencing homelessness who needed the same safe spaces and connections to employment. We partnered with two local downtown Denver hotels to provide significantly discounted room rates and comfortable, clean and safe hotels. Where closely with the case management agencies and state Medicaid office to expedite eligibility for agents. One of our main partners is a local nonprofit that provides employment supports for people experiencing homelessness. Through this partnership we were able to identify individuals who wanted to be in the workforce as care attendants. We as Colorado's consumer directed service delivery models, to hire these individuals to provide care for those transitioning and ensured they had safe shelter were also were able to live in the hotel. While they were there the attendant had a period of time with no living expenses while receiving income so they were also able to get themselves house, once the individual transitioning moved into their apartment and housing. While we have been told by our local EMA that they were not willing to help us fund this program, three of the individuals we transitioned through it were referred by the contractors working with the city and counties because they were unwilling to provide support for the individuals ADL despite the fact that they were obligated to do so while in these FEMA category fund. Though our pilot had some bumps along the way, as they always do, we have been able to support six individuals getting into permanent housing, for others working to get into their permanent homes in the community, for attendance have been house and not a single individual in the pilot contracted COVID once they enter the program, even after moving into the apartment housing. Imagine what we could have done, had we had clear and earlier guidance on cares funding, less restrictive funding, more funding streams and more partners connected and committed to doing this work throughout the nation. We need to find sustainable ways to continue this work, we need to find divergent programs throughout the country and we need to find divergent programs throughout the country and will ways to ensure no one has to end up in a nursing facility when the next pandemic hits. We have to ensure that what we have seen happened in our community, who have fought for decades to free our people from institutions does not go unnoticed were unremembered. It is a catalyst to create systems that make it easier to live in the community with the services folks need to thrive than it is to get stuck in institutions.

     >>ELISSA: Thank you so much, Anaya Robinson for all that you continue to do. Next up, is Sydney Breslow. Then Vicki Smith from the ABA Center for Independent living in North Carolina.

     >>   My name is Vicki Smith, I am the executive director of a center in the Raleigh/Durham area of North Carolina. Like other centers, we have already shared, we also focused on using our cares dollars. The big difference with us is that we didn't wait to ask for permission, we just started working and relied on our ability to link it. To the COVID‑19. We temporarily housed in hotels, 40 eligible consumers who were homeless because they either lost their housing because they couldn't afford it, they were not homeless or people who were being released from state prisons after a big outbreak of COVID in those facilities and other places. We were focused on providing the warm and dry, safe sheltering during the winter months. In particular, we wanted to save enough of our cares dollars to be able to help remove financial barriers to get into housing, which we immediately started working looking for when they became a consumer. We did all of this through an automated process, which Sydney helped develop because she was getting all of the calls, because she is our information and referral specialist. I know we are on short timeframe here, so I wanted to give Sydney an opportunity to talk a little bit about the process, and how we document it because I think that was key to justifying the use of money. But we did get about a quarter of the people that we put in the hotel program permanent housing. That is quite a fee in our area because affordable accessible housing is almost nonexistent. Sydney?

     >>SYDNEY: Thank you, Vickie. As Vicki mentioned, I am the policy manager. I have disability advocates. The first step in the hotel program was that application, the initial application. We asked all the families for support, budgeting money and the current housing situation. In the initial application, we were looking at resources and looking at the options. We wanted this to not have funding restrictions. There were all the resources that were there, with official fill out the initial application for the program. Then Vicki and some would pay to schedule the reservation to pay for the hotel. When the reservation was up, then they felt that another form which reassessed their eligibility for the program and asking what their current housing was. Once those steps were taken to get permanent housing, the consumers wanted to be in control of their decisions. We wanted to make sure that we follow that. It was just a simple form where we ask the goal and also for the hotels and how long they wanted to be in there for. That is the process that we took and I think it was a very great program, I wish we had more funding to continue but unfortunately the funding is running out and the goal is to get people into permanent housing now. Thank you for your time and I will pass it over to–.

     >>   One more follow‑up, the reason why we had a renewal process every few weeks which was key, is that we wanted to focus the community inclusion specialist on really working hard on finding permanent housing. So they constantly had to be checking in and documenting their attempts and where was going. It also gave us an opportunity to be able to find out what was working, and what wasn't working. Thank you.

     >>ELISSA: Thank you both, and thank you for the work that you guys do. Next on the list, is Kiersten Onanga. She is at the access to independence, I think the Eastern corridor of Iowa, it has been a long time. I will turn it over to you.

     >>KIERSTEN: Yes, it is a long title. When we say access to independence, we have also shortened it to. Thank you so much for inviting me to share what our agency has been doing. With transition and diversion services. As a very small agency in Iowa, and prior to cares act, it was not possible for us to have somebody focused 100 percent on transitions, it just was not possible. We did not have the funding to do that. Because of this, our time was torn between the independent living specialists, our time was torn between all of the five core services. With cares act, we have been able to hire somebody full‑time to strictly work on transitions. That person is me, I applied for it and I was able to get it because I was the one who was transitioning before hand. Anyways, with our transition services, we had to figure out what we were going to spend the money on to help people get out. Some of the examples of things we decided were very crucial was anything that had to do was transitioning. Examples would be storage facilities that people were renting that housed their things while they're in the facilities, transportation for appointments to engage in the transition process, this would be an example of the individuals having to have home accessibility and the estimates of them, them going there and being a part of it, following that philosophy. Technology to help individuals while they were in the facility and also outside of the facility. So a lot of times individuals get in there and they want to have access to Internet, they don't have access to cell phones, they are dependent on who is able to get them the phone at the moment in time. We were able to provide them with some technology to be able to communicate with, not just their family, but also us. To keep us updated. Then initial housing costs, furniture, rent, application fees and etc. I will say that a bulk of our referrals have been actually divergence and we talked about moving people out of the facilities in the first place. We want to make sure that that happens. The easiest way for a person to be in a community is to stay in the community and not have to enter a facility. Some of the examples that we have used for the cares act have been stair lift ramps, major home repairs where the house was not safe, and long term it would be a financial burden for the individual to stay there. Deposit, rent, utilities, moving expenses if they have to move to an accessible housing or housing, we have been able to help pay those moving costs. This didn't come without any type of community collaboration. We collaborated with several other agencies in our community. The money falls program, I am sure you have all heard of that. Our agency does not, did not get the contract for that, so we do not run that program. But we've been able to collaborate with them to be able to fill in the gaps where they are not able to help individuals. MFP, their eligibility for individuals is extremely limited and in Iowa, and those, the only people that qualify for those are with ID or FBI waivers. A brain injury or developmental disability is the only way you could qualify for it. That leaves a whole lot of people that aren't able to get out of the facilities and the hope was that we could fill in that gap for the other individuals. MFP allowed me to train with their new hires to be able to see how they run their programs, and hopefully increase education to the state on what we are doing. It has been a really good collaboration so far. They have also shared with me, all of their community resources that they have that I wouldn't have always, a lot of times individuals are wanting to move outside of our service area. I know what I have in my service area, but on the other side of the stage, I am kind of lost. Luckily they have been able to help me with that. Also, we were able to fill in the gaps for some of the individuals for first month's rent because MFP is not allowed to pay for first month's rent. That was something that we felt like we could help with that, that is something we needed to provide with the cares act and we have been doing that. We also collaborated with Habitat for Humanity. Since the majority of our referrals have been divergence, it has been crucial for us to develop this relationship. To offer contract build services for homes, we have made a wonderful connection with our local Habitat for Humanity and they referred individuals to us in need as well as serving as contractors for the built amp service area. That is kind of a low cost and back and forth referring people to each other. It has been pretty awesome to be able to connect with them. A large part of my role has been education and outreach to build community knowledge of the services at capacity. That we have, prior to this, we work prior to the full‑time position, it was not something that I was able to do. Luckily, I have been able to focus 100 percent on transition including education part. From pre‑existing relationships we have through our AAA, we were invited to present at all seven of their County task force meetings on transition and divergent. Informing them of the program and operator services, this was a great way for the people in the rural parts of our service area to learn about the program. We utilized our summer interns, gotta love those interns, to send out surveys to identify the facilities in our service area to get more information on the transition needs that they had in those facilities. It's also been very crucial for us to be in connection with the managed care organization, case managers and facility. One of the first things I did was reach out to those MCO facility case managers who worked in our service area, and let them know about our services, how we can support their consumers. To date, I will tell you they have been our largest referral source, 100 percent. They are quick to say, I have this person, please help us with it. I love the fact that they are a great, it was a great thing to do to reach out to them, they are on top of it. If they can. That doesn't mean that the cares act is great, but it doesn't mean that there weren't various, it did not take away all of them. Communications from facilities is an ongoing issue, we rely heavily on those MCO case managers to facilitate communication and to assist with accountability to keep this process moving. Systematic figures also continue to make it difficult to help individuals transition with long wait lists for waiver slots, and staff shortages for service providers. Also, affordable and accessible housing is a major barrier we have found. It doesn't seem to be getting any easier to find that affordable accessible housing. Lastly, I don't want to sugarcoat everything, this is a true barrier and I hope I'm not the only one that has ran into this. Lastly, we have seen consumer barriers to transition, the consumers themselves are the barriers. Some individuals don't want to take the necessary steps to help guide the facilitate transition and be a part of the process. When this happens I do my best to educate and empower the individual that this is their opportunity to decide what they want to go next. Often times we see the consumer is struggling with the idea that smaller steps may be needed to reach that end goal. Ultimately though, it is the individual's choice and I will respect that choice, and we do what we can to support the consumer with planning the steps to set them up for long‑term success. Thank you guys so much for allowing me to share about what our agency is doing, and if you have any questions, feel free to reach out to me.

     >>MARCIE: Thank you very much Kiersten Onanga, this is Marcie Roth speaking. Thank you to all the folks that are leading the way nationally, navigating through a real scattershot of bits and pieces of money and resources, programs. We have got to put an end to this lack of any sort of cohesive approach for people with disabilities to be able to live in freedom along with everybody else. Our next speakers are they are the very powerful leaders of the partnership for inclusive disaster strategies. There is so much I could say about them, but I will turn over to them in just a moment to let them tell you themselves. You can count on the fact that you know where they have been each and every one of those 500 days, because they have been leading a large group of people day in and day out as we have tried in every way we can think of to put an end to the horrific exclusion of institutionalized people, and people with disabilities in general. From being able to get the supports and services they need before, during, and after disasters. Shaylin and German?

     >>   Hi everyone, thank you so much Marcie for that great introduction. My name is and a quick image description of myself as I am a younger like complexioned woman with shoulder length or past shoulder length curly brown hair. Wearing a Black top. Alongside me,–.

     >>   My name is German, codirector of the partnership with disaster strategies. I am a Puerto Rican brown man sitting in my wheelchair wearing a red polo shirt with Black long hair pulled back.

     >>   This is Shaylin and again to come up behind us is a multicolored Mandela tapestry and a cluttered desk behind us as the mail still piles up even throughout the pandemic. This is Shaylin and again, I just want to thank everyone for organizing this great webinar and really bringing us all together to continue this important discussion as Marcie mentioned at the beginning and just recently the partnership has been holding a daily COVID‑19 disability rights call, each and every day since February 28th of 2020. As Marcie mentioned, and tallied up, 500 days straight, it is hard to imagine that we have been truly meeting each and every day, the weekends, holidays, all seven days of the week and it is where partners across the nation come together to share good and promising practices, systemic rising issues and just engage with one another across the nation, and share those resources and tools that we are all using in our localities to save lives and transition folks out of these deadly institutions. Really, what spurred this daily call is when the COVID‑19 pandemic started hitting the United States, first notably the Kirkland nursing facility in Washington state, and really drew our attention and said that's going to be a disaster. We know this, and when each disaster occurs whether it is a hurricane, a tornado, earthquakes or fires, we call on our local folks that are in those impacted areas and bring as many folks together to see what the issues are, address them. To make sure that we save lives during disasters. Because people with disabilities are 2 to 4 times more likely to die or be injured than nondisabled people in any disaster. COVID‑19 pandemic has certainly shown to be no different, and that is largely due to the lack of resources, information and accessible information to our communities throughout these times. During our daily call, we have really come together to not only identify what these urgent needs are and continue discussing them, but also addressing them to a national focus as well as within localities and many thanks to all of the folks here today, and beyond that it continues to do that could work throughout our nation. I'm going to share in the chat and later on I will also set share some other resources as well but as I mentioned, institutionalization and disasters is not new, it is not something that is just a public health emergency. Or a deal. It is something that happens throughout each disaster in in the national Council and disabilities preserving our freedom ending institutionalization of people with disabilities during and after disasters really highlights those ongoing issues that continue to impact our communities. As we have heard our fellow speakers like Ebony, Melissa Hickson shared of the ongoing systemic barriers throughout what we call blue times guys, just navigating these complex systems as a disabled person and understanding what resources are available during disasters and after disasters, that information and access to that information is just that much more exit exacerbated and often times, many times people with disabilities fall through those cracks. We continue to bring these issues out, I will also continue in a few moments to add some additional resources in the chat. Because as we have been meeting each and every day to address these issues, talk about these issues, we have also been cross pollinating information and resources locally that have been working as solutions, as you have murder heard Missy from roads of freedom and Anaya Robinson. Some anywhere that continue to work on transitioning folks out of institutions during this pandemic is just so vital during these times and there are solutions out there, one of the biggest barriers that we see during disasters including now, is the 1135 waivers that truly is what expedites these nursing home placements during disasters. Pretty much eliminating all of the red tape that is usually there during blue sky times and just allows for those very quickly. We see that in a typical disaster like a hurricane or a fire after sheltering. Often times folks are being institutionalized during leaving shelters and we are seeing now and folks are entering things like hospitals for treatment, they are most of the times getting placed into skilled nursing facilities ask Melissa really emphasized what kept happening to Michael as well. These are things that they are not new, they continue to happen and they have been here long before this pandemic. There are solutions that would certainly make a difference for our communities, one of them being if centers for independent living were explicitly written in the public and policy guide for FEMA Public assistance subcategory the funds that would allow for reimbursement to go directly to these nonprofit organizations that are doing the hard work as we all heard today, and will continue to hear. It would allow for that reimbursement to go directly to them rather than having to navigate the complex systems of being in a good relationship with your local emergency management agency, and being able to get through all of those processes that can often take so much time that we see people with disabilities continue to die in nursing facilities while they wait to get transitioned out and while they wait for the red tape to disappear. These kind of solutions, as well compensating with the local solutions that have been identified today and beyond, is what we need moving forward.

     >>   As Marcie opened up, institutionalization that congregates setting phenomenon is a failed experiment. This country, the United States had a massive explosion of deaths during large amount of time. The United States still has twice as many more deaths as the next country because of our institutions, because of congregate settings. The gamut of care industry is putting us in placements where like Ebony will describe well described is killing us during disasters and the CDC report clearly states, this has been ongoing and during this pandemic, it has exacerbated why we need to close the front door. We need to create spaces where each home community‑based services are the first option, so people like Michael Hickson and Melissa Hickman do not need to go through the suffering and the death that occurred. In El Paso, we saw crisis standards of care creating segments of a hospital to be called the pit. People with disabilities have been in the expandable population through this pandemic. Every other segment of the population, every other industry is looking at not going back to previous pandemic times. How are we going to move forward? This country, decision‑makers, policy need to see how people with disabilities being the most affected, have been murdered the most because the lack of resources, needs to change. We cannot go back to 2019 and how it was before. Every report from the GL is clearly clearly states how infection control policies have not been put in place, the disability community who are the stakeholders, people live in these institutions have been stating for decades, and we have report after report, how it is inhumane situations. Moving forward, we need to create a space where home and community based services is the first option with all the resources and critical support needed, this is not going to be the last pandemic. Climate change is gearing disasters to be increasing in intensity and frequency. It is on the news every day. If nothing else, let's create a path forward with people who have disabilities have real decision‑making power and the options they take in their lives.

     >>MARCIE: Thank you very much German and sailing. We are now going to hear from somebody who has been a longtime friend and a partner in crime, somebody who has stepped up many times, and most recently into a leadership role as part of the White House COVID task force. Andy Imparato who has worn many hats over the years and is currently the executive director of disability rights of California. Thank you for joining us, and A.

     >>ANDY: Thank you, Marcie. I will be brief because I really want to listen to others and I really appreciate this opportunity. Let me just start with the disability rights of California had this morning, I was a little bit late because we are engaged in a mediation to try to resolve a homestead lawsuit that Alameda County, and I don't know if we have mentioned homestead yet on the call. I think everything we are talking about relates to the right to receive services in an integrated setting. As we think about kind of an after action analysis of the pandemic and I know this was an important thing for the report that was referenced earlier, it is really worth thinking about the homestead failures that we have experienced before the pandemic that set us up for the failures of the pandemic and what we can learn from that if homestead is going to be real close pandemic. I will just mention one thing we did, we worked on crisis of care in California. Some of you know that our state came out with draft crisis of care. Melissa, thank you for your compelling testimony and advocacy, and leadership. The first draft in California was seriously problematic, it was basically encouraging discrimination of disability and age. We pushed back hard in a coalition in Calais for California, the disability rights with aging and others, every state change their draft standard significantly and came out with new standards in June which were much better. Post pandemic I think there's an opportunity for the civil rights and human services and other civil rights enforcement agencies to give national guidance to the whole country on how to do crisis care and in a way that does not discriminate. There is a lot of inconsistencies and a lot of lack of knowledge on how to do that within the public health and the kind of medical and hospital world. That is one opportunity that we are hoping to see leadership on coming out of the pandemic. I also wanted to mention, we had to sue the California Department of state hospitals to try to get people who were immunocompromised or otherwise at high risk of dying from COVID, moved into a safer setting. You would think that the state, these are folks who have been kind of sent to these hospitals that have no choice, you would think the state would understand that they have a responsibility to help keep them safe and keep them alive in the pandemic. The state was very proud of the fact that there were no outbreaks for six weeks, then there started being outbreaks and as you can imagine, they expanded very quickly. The state basically fought a lawsuit, rather than addressing the problem. This is a progressive state. I just think that is an example of the scale of the problem that we have. I appreciate on this health equity task force that Marcie referenced I got appointed to in February, we have home mortgages on their who is a physician that is focused on basically the health and safety of people in cars will settings, that is his expertise, his traveling around the country. He is coming forward with good recommendations on how we do it better post COVID. That is really the purpose of the task force, we are advisory similar to the national Council on disability, we don't make policy, but we are advising the White House and the COVID 19 response team on things that they can do to learn lessons from the pandemic, promote equity, the chair of our task force (name) Smith I think has been very consistent that disability is a part of the equity conversation, the executive order that created this callout disability. I know you all have done a lot of work around data and trying to prove data and noted the contributions in the chat. I want to say that is one of the subcommittees that a monitor called data analytics and research. We have come out with a number of interim recommendations to try to improve and disaggregate data for subpopulations including people with disabilities. I am very confident that there will be recommendations like that in our final report and I look forward to working with the folks in this coalition on what recommendations would be most meaningful. I know that Tom Owen reached out to me and participated in our last meeting, and I look forward to getting more recommendations from Tom and others who he has collaborated with. The other committee am honest communication and collaboration. One interesting thing that came up in the last several weeks that I know given Marcie's history with FEMA, is something that Marcie has thought a lot about but the emergency preparedness world has grown in part, because of all of the increasing disasters that we are all facing as a country. At a time when the public health world has shrunk. Every public investment and public health has gone down over time. Our investment and emergency response has gone up. I think as we think about learning a lesson from a disaster, it is worth thinking about, one of the earlier presenters mentioned that FEMA kind of didn't see it as their job, I think it was that brought the sub, the state version of FEMA or the state emergency response folks didn't see it as their job to respond to a pandemic. I think what we are learning is that we need a government response in the public health infrastructure is not strong enough, and certainly doesn't have deep enough connections to the disability community to make the decisions that are well‑informed and are going to be effective so from my perspective, we have to get these different groups to collaborate. What we were told in our subcommittee meeting, was that in a lot of states, the top public health official and the top emergency health response official didn't even know each other as we were going into this pandemic. That feels like a serious opportunity for collaboration and certainly we will have recommendations to that effect. I don't want to take up too much time Marcie, I appreciate the invitation. If folks are interested in seeing our interim recommendations from the task force, they are all posted on the office of minority health website for the U.S. Department of Health and Human Services and I will put the URL for that in the chat so you can see what we have already recommended. The final report will come out sometime in September, October. That is the timeframe that we are running on right now. I do want to just say, I really appreciate that the folks that the president appointed to this task force have all been very supportive of integrating disability into all of our equity conversations. I am very optimistic that the final report will have a very strong disabilities seem to it which I'm hoping will get some attention and reinforce some of the things that the SILVER coalition and various groups that are represented on the skull have been asking for. Again, thank you Marcie for the opportunity.

     >>MARCIE: This is Marcie, thank you very much Andy. I am glad he specifically called out homestead, when I said that the law is settled. That is exactly what I was referring to and yes, we absolutely need to redouble our focus on what the homestead decision could possibly mean as part of the path forward. I also wanted to point out, your observation about the disconnect between emergency management and public health. In fact, in the national preparedness system, which came out of law. The emergency support functions for the two areas, there is a gap between them and people with disabilities Paul between the work of the emergency managers, and the public health officials. Thank you for bringing that up. One of the smartest things that President Joe Biden has done, has been to appoint our next speaker as the chair of the national Council on disability. An incredible leader before he was moved into the role as chair of the Council. We are really very grateful that he said yes, and looking forward to hearing what you have to say, Andres Gallegos.

     >>ANDRES: Marcie, thank you. That will ruin the president's chance for reelection, I will tell you. I am Andres Gallegos and proud to be the chairman of the national Council of disability and also proud to be a person with a disability having to say I have a spinal cord injury resulting in– I am joined by mycolic, Senior staff Attorney at the national Council of disability, Amy Nicholas. Amy is our resident expert on all things emergency planning, emergency response and is our liaison with FEMA. When Marcie invited us to be a part of this, Marcie's instructions to me were absolutely clear. She said just shut up and listen. I am listening, and it has been a sobering discussion. By the fact that we are having this discussion, means that we at the national Council of disability haven't done enough. To push our partners in FEMA and in other federal agencies to do what needs to be done and do that expeditiously so that we are not having these conversations. I can tell you that we had a conversation with the new administrator of FEMA yesterday, and with her staff. We are committed to strengthening that relationship and continuing to be a stronger voice, not only for this coalition, but for people with disabilities in general to address these critical needs. One of the things that we are doing at the Council, that I think is critically important here is we are looking at the lost opportunities over the last four years or so, determining what reports of policy recommendations we've made in all areas, particularly in the areas of institutionalization during emergencies. To see what recommendations have not been, did not take it there was Congress or whichever agency that we deemed would have primary jurisdiction. For taking it and implementing it. We are really looking at those issues and we are looking at different strategies to engage them, to ensure that our policy recommendations are considered and followed through. We can assure you that our 2019 report on ending institutionalization during emergencies was not the last that we have to say about that issue, and we will continue to focus on that. As a priority. I also want to say, with respect to Melissa Hickson, when you look at the definition of strength and, in the dictionary, you will see pictures of both of them. I am proud to be representing Melissa and her family as a disability rights attorney to just issues that she experienced in Texas, and also proud to say Melissa is a friend of mine. Just incredibly blessed for having her advanced issues that she is addressing in Texas and throughout the country. I'm going to let Amy and Nicholas speak to this as well please.

     >>   Good afternoon everyone, thank you for having us. As he said, we did meet with the new administrator of FEMA on Monday to discuss some of the recommendations from the 2019 report. We also just discussed some of the concerns regarding the category B funding and eligibility of independent living centers. In receiving the funding. We were assured they were going to look into it, and that they would have a response to us and that they would respond to us in regards to what their findings were. They also had even suggested that we hadn't provided them with sample language to update their guidance to the state so that will be something as Andres Gallegos said, I wear the hat of the emergency management liaison at NCD. That I will be reaching out to the partners that I have worked with for the last number of years. To get and rely on your expertise to help with that language and what needs to be changed, what language needs to be provided. So that local state emergency operators have a clear understanding that these funds are and should be made available to ILC. Be ready, I'm sending the email out shortly. We will be convening again as we have in the past to try to get answers to this issue. I agree with everyone on this call, it has taken way too long and needs to be resolved as soon as possible. Thank you.

     >>MARCIE: Thank you very much Amy, much appreciated. I know that Allison, I will ask folks to meet themselves. We have a variety of folks you might like to weigh in but I am really pleased that one of the first presidential appointees that we reached out to, Allison Park off said yes, she would join us today and when I asked if there was anything she would like to say, she said yes. Without further ado, Allison who is the acting assistant secretary for the administration for community living.

     >>   Great, thank you Marcie and thanks for having me on the call again. It was really helpful to hear from so many folks about the barriers that continue to exist. I have worked alongside so many of you throughout the COVID pandemic and so switching into this new role inside of the administration, I really come in with urgency that I know we all share and addressing the long‑standing institutional biases that we face and that have just had a spotlight shone on it throughout COVID. I think some things that are really important that I just want to highlight, is I think the opportunities that we have two really leverage some of these resources and would really like to partner with all of you, in making sure that we are doing that in the best way possible. I think in ACL and working with the administration I am putting together a budget going into fiscal year 22, the crucial role that centers for independent living play and transitions, it can't be understated and that is why we work so hard to include increased funding very significant increase funding to the CIO. We saw this morning the House Appropriations Committee moving that and we think that really the urgency over the next several months of helping people transition out, diverting people from going and has never been stronger. We heard a number of people on the call talking about the fact that the lack of affordable accessible and integrated housing continues to be a barrier. I am not sure if our colleagues from HUD are on but that is one place where HHS and HUD have really from the beginning of this administration, started thinking about how can we partner and leverage our shared resources. There are housing resources that are out there, and use. I think Misti we have been on several calls where we talked about the fact that there are housing choice vouchers targeted to people at institutions that are sitting unused and we are really working on how to build that relationship to make sure those referrals are happening, there are far too many people stuck in nursing homes and other institutions because they can't access housing. That is a key issue. Just the two other things I want to highlight, we heard from folks in Iowa around Money follows the person and we are working closely with our colleagues in CMS, there has not only been with authorization and expanded reach of those programs and expanded eligibility, but actually about to follow‑up with you because there are some things that sound like Iowa could be doing in their MFP program that they are not doing that are various. Again, we are really interested in building partnerships between state MFP programs, the centers for independent living, and the public housing authorities on the ground. So we can really have all the pieces that we need to transition out. Finally, I'm sure I'm not telling people things that they don't know when you have been involved in advocacy on the ground in your own states, because of the incredible work of all the advocates on the phone. There was a huge infusion of funding to states, home and community‑based service systems through the American rescue plan, it is really an unprecedented opportunity and in the allowed uses is divergent, transition. Working on connections between services and housing, a whole list of things that we have talked about and I think ACL is incredibly interested in working with all of you, lifting up best practices that are happening across the country in making sure that the $7 billion is put to incredible use and keeping people out of institutions, returning people back home. Finally, we are working incredibly closely on the full range of issues that MD framed out around COVID crisis standards of care, visitation policies and hoping to move not only best practice guidance, but regulations of partnership with office for civil rights. This is not dependent on who is leading administration but really it becomes the path forward and not just the law, but very clear set out and regulations. With that, I will end by saying thank you to everyone on this call again. I have been a part of many of those calls in my prior life, and again, so many people who literally every evening, try to identify the issues and really work on saving lives. I think we have some opportunities before us, and really looking forward to partnering with all of you to really bring those to fruition. Thank you, Marcie.

     >>MARCIE: Thank you very much Allison, we really appreciate that and will take you up on working together in every way we can. It is the only way we are going to move forward. We have about ten minutes, are there other federal folks who would like to respond? I think if you would like to respond, you can either raise your hand, or put a note in the chat.

     >>FRAN: Either way, we will make sure that we can get you turned on, get your microphone turned on. So you can comment.

     >>MARCIE: I see a bunch of federal representatives. On the call. I will give it a minute and see if anybody would like to make any comments. Linda says she would be happy to jump in for a moment. If we could please promote her.

     >>   She is good to go.

     >>MARCIE: Go ahead, Linda.

     >>   I am trying to unmute myself and turn my video on. Here we go, here I am. Good afternoon everyone. Linda with FEMA. I wanted to thank you all for the opportunity, I have been listening and taking careful and copious notes and appreciate the opportunity to listen and to hear everyone's concerns and take respect for action as he heard from Andres Gallegos and Andy. We had a productive discussion with the FEMA administrator the other day to talk about a way forward to address this issue that has come up time and again about category refunds and how we can most effectively use those in disaster and emergency situations to assist people with disabilities. Though the answer hasn't been the one that folks have wanted to hear, for many months prior, we have been working to figure out how to appropriately address this and move forward. I think we are cautiously optimistic that we are inching closer to an answer that I think will get us where we need to go to get people to be of assistance that they need. Again, cautiously optimistic on that. But I want to thank you for posting this really important discussion and for giving me the opportunity to listen in. I will be taking all of the feedback to the administrator and having a follow‑up discussion with her on a way forward. That is all I have for now, thank you so much.

     >>MARCIE: Thank you Linda, and thank you for joining us and for speaking up. Rebecca from the office of civil rights and civil liberties at the Department of Homeland Security would like to respond as well.

     >>FRAN: I am not seeing her. Rebecca, are you on the phone?

     >>MARCIE: Maggie is Becky with you?

     >>ELISSA: Is it Maggie Frederick?

     >>MARCIE: Margaret Schaefer. I am not sure. Let's promote Maggie Schaefer, Margaret Schaefer, and see if that.

     >>ELISSA: Done.

     >>FRAN: All right.

     >>MARCIE: Maggie, go ahead. Maggie, go ahead please. Let's see if we can get that straightened out, in the meanwhile if someone else who would like to speak.

     >>FRAN: Luis Ryan?

     >>MARCIE: I see Luis Ryan has their hand up.

     >>FRAN: All right.

     >>MARCIE: Go ahead Luis.

     >>   Hello, I just wanted to thank you for this very informative and compelling presentation. Also, I work at the administration for community living and work with our state long‑term care programs. Just wanted to mention they have been involved, I am assuming a lot of you are engaged at the local level with your programs. Just to kind of put out a reminder, that they are a resource on transitions and in responding and have been responding to all of the issues that you have raised so eloquently. I just found this just a great synthesis of everything and kind of in one session. It is really helpful, thank you very much and I know Allison is certainly carrying the message forward and likewise, the (name) program is equally concerned and supports certainly of course transitions and rates. The people can live wherever they wish, with dignity. In the way that they want to live. Thank you.

     >>MARCIE: Thank you very much, Louise. This is Marcie speaking, I really appreciate it. Let's see, here we go. I see that Becky is now able to speak. Go ahead, Becky.

     >>   Hi, good afternoon everyone. Marcie, can you hear me okay?

     >>MARCIE: We can hear you great.

     >>   Great, wonderful. I am Rebecca to Sato with the office for civil rights and liberties at the Department of Homeland Security and I am, I only have a minute but I wanted to send regards and regrets from our office of civil rights for civil rights and civil liberties. Kathy (name) is appointed by the president and arrived on day one. To lead our office, and to integrate civil rights and civil liberties. Everything that the department does and especially to uphold and including two uphold the rights of people with disabilities and everything that we do, and whatever recipients do. It is wonderful being on the call with our federal partners, state partners, advocates and I just wanted to say that while it is so hard to hear about some of the hardships, burdens and really just the loss of life, it is really important to have this discussion, please consider as an ally and despite. We want to continue to work with all of you, to better uphold the civil rights in disasters, whatever kind of disaster it is, we have worked with FEMA and other federal partners since the beginning of the COVID response. We are here to help find the solutions and work with all of you, we have a direct line to our office. Maggie Schaefer and just very happy to be a part of this conversation here today. Thank you so much, Marcie.

     >>MARCIE: Thank you, Becky. Thank you to the office for civil rights and civil liberties for always making time on the calendar to work with us. I am going to turn it back to Elissa Ellis for closing comments. Before I do, I just want to say I would like to think that we have turned a page. I would like to think that this was an opportunity for folks to come together, talk about what has gone wrong and we will look to the SILVER leadership and to APRIL to bring us all back together again for specific next steps.

     >>ELISSA: This is Elissa Ellis with APRIL, I want to thank everyone who took time out of their day to be on this call and participate. I love when a plan comes together. We hope that this is one of many next steps. I want to reiterate that the people you heard from today, we are your allies. At the federal level, we want to be a first card in your Rolodex. When you are looking for resources to respond to people with disabilities, and disasters and other related issues, we are here, that is what we do and we hope that this is the very first step. In the words of (name), lead on! Thank you everybody so much for being here.

     >>MARCIE: This is Marcie, I believe Fran, Billy, also APRIL wants to say a last word.

     >>FRAN: Let me bring Billy in.

     >>ELISSA: You're good to go, Billy.

     >>   There we go. For some reason, I cut out for a second. Since we are at the end of time I wanted to make sure that we kept everybody extra for just a moment. All I really wanted to say is that as a person with a disability, I am so thrilled that each and every one of you are my advocates, I value everything that each and every one of you do so thank you so much for doing all of the heavy lifting a lot of times. I just wanted to make sure that you knew how much my I appreciate all of you. Thank you.

     >>ELISSA: With that, we are going to end the call. Thank you guys, have a great rest of your day.

     >>MARCIE: Thank you everybody.