

**BEFORE DISASTER STRIKES:
PLANNING FOR OLDER AMERICANS
AND PEOPLE WITH DISABILITIES
IN ALL PHASES OF EMERGENCIES**

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Thursday, June 15, 2023

U.S. SENATE
SPECIAL COMMITTEE ON AGING
Washington, DC.

The Committee met, pursuant to notice, at 9:29 a.m., Room 106, Dirksen Senate Office Building, Hon. Robert P. Casey, Jr., Chairman of the Committee, presiding.

Present: Senator Casey, Blumenthal, Kelly, Braun, Rick Scott, Vance, and Ricketts.

**OPENING STATEMENT OF SENATOR
ROBERT P. CASEY, JR., CHAIRMAN**

The CHAIRMAN. The hearing will come to order. Thank you for being here everyone. The Senate Special Committee on Aging will come to order today. We welcome those who are here for our fifth hearing of the 118th Congress, and this hearing will focus on including older adults and people with disabilities in emergency management and response. In the two years since the Committee held a hearing on this topic, we have witnessed devastating emergencies and disasters across the country.

While all Americans are affected by disasters and emergencies, older adults and people with disabilities are disproportionately affected. The most devastating of recent disasters, of course, is the COVID-19 pandemic.

More than 75 percent of COVID-19 deaths, some 850,000 Americans, were adults over the age of 65, so 75 percent of the deaths were in the age category over the age of 65, and while those with—and at the same time, I should say, those with developmental disabilities were nearly three times more likely to die from COVID-19 than those without a disability.

While the pandemic has had a disastrous effect on older adults and people with disabilities, natural and man-made disasters also have a disproportionate effect on them, as well. Last year, Hurricane Ian killed at least 150 people in Florida and North Carolina, with nearly two-thirds of those who lost their lives were over the age of 65.

As you will hear from one of our witnesses, the train derailment in East Palestine, Ohio, which caused about 5,000 people to flee their homes in both Ohio and Pennsylvania, had a profound impact

on people with disabilities. In this Committee's recent joint report with the Senate Finance Committee, this is a copy I am holding up entitled, "Left in the Dark", we recommended that older adults and people with disabilities be included as an essential part of the entire emergency planning process.

In the report, we stressed the importance of making the resources to prepare and respond to emergencies available to all who need them, including, of course, older adults and people with disabilities.

As we will hear from our witnesses today, one of the most essential resources during an emergency is, of course, information. People with disabilities and older adults need accurate, accessible, and comprehensive information to plan for and to respond to emergency situations.

That is why I, along with 11 of my colleagues, including Senators Gillibrand, Blumenthal, Warren, and Fetterman from this Committee, have introduced the Real Emergency Access for Aging and Disabilities Inclusion for Disasters Act, for short, thank goodness we have an acronym, the REAADI for Disasters Act, R-E-A-A-D-I, REAADI for Disasters Act.

This Bill would ensure that people with disabilities and older adults are included in both disaster preparation, and that their needs are considered during both response and recovery efforts. It would also ensure that the civil rights of older adults and people with disabilities are not violated during disaster emergencies, so whether it is a pandemic, a natural disaster, or a human made emergency, older adults and people with disabilities need to be considered in both planning and response. I look forward to hearing recommendations from our witnesses about how we can ensure disaster planning, response, and recovery are truly, truly inclusive.

I will now turn to Ranking Member Braun for his opening statement.

OPENING STATEMENT OF SENATOR MIKE BRAUN, RANKING MEMBER

Senator BRAUN. Thank you, Mr. Chairman. Disaster can strike anyone anywhere. Just this past April, we had over 20 tornadoes hit the ground in Indiana, causing damage and devastation in communities across the State. I witnessed the disaster firsthand in Sullivan, Indiana, not too far from where I live, when I met families that lost their homes and offered Federal assistance to the mayor in that case.

Older adults and people with disabilities were particularly vulnerable in the aftermath. We must do more to plan ahead, before disaster strikes. When I ran a business for 37 years, we budgeted for things outside the ordinary. We didn't go on a kind of disorganized spending spree. We had it in place.

That is why you have insurance. That is why you have rainy day funds. This isn't something special because most other places do it, and the scale, even to the size of the ones that attract Federal attention, you could still be doing the same thing.

Most Americans are very practical. They try to save and prepare for that rainy day, for that unforeseen event. My home State of Indiana has had over \$2.5 billion in reserves. We are always pre-

pared, and if you don't do that, you have to dig your hole even deeper, because right now this Federal Government is borrowing, borrowing \$0.30 on every \$1.00 we spend, and it is going the wrong way because it was just \$0.20 when I got here four and a half years ago. It was \$18 trillion in debt, now \$31 trillion. That is a terrible business plan for the future, including how you confront disasters. We talked about COVID earlier. You are throwing money at the problem does not necessarily stop the course of a tornado or the spread of viruses.

This is an expensive lesson that we have learned, and we have—Chairman Casey mentioned how it ravaged senior citizens. Always senior citizens seem to be in that place of most peril when there is a disaster that comes along. We spent \$4 trillion on COVID alone. We borrowed every penny of it.

We lost more than 1.1 million lives to it. Instead of prioritizing the highest risk groups, which we should have because we knew the science of the disease very quickly, we ended up just following the political science, and what did it do? More money borrowed, more money spent, and it really didn't do a great job on protecting those that needed it most.

The record inflation that we are dealing with now does not bode well for putting emergency funds together, which we need to. At the heart of this is big government. From 2019 to 2023, the Federal spending grew by 40 percent. We cannot adopt the model of panicked crisis governance as a standard response for emergencies.

After three years, it took two measures by Congress to end the COVID-19 national emergency. Why should Congress have to fight to end an emergency? We should have to fight to keep it in place. The American people are simply looking for things that make more sense, like they see in their own lives, in their State Governments.

They see a place here run by bureaucrats that generate generally decisions that are counterproductive. Last week, I joined Sanders, Lee, Blumenthal, Crapo, Risch, and Murphy as a broad bipartisan effort to introduce the Article I Act. This Bill would automatically terminate national emergencies if Congress does not renew them. The Federal Government should do more to plan ahead for emergencies and change the trajectory of emergencies, especially to protect older Americans and those with disabilities.

I look forward to learning from you, advice on your end in terms of what to do, but generally it is going to have to be housed within a system that doesn't take us deeper in debt, that actually would do a big rainy day emergency fund here and quit borrowing money from future generations for whatever we do.

The CHAIRMAN. Thank you, Senator Braun. Now we will introduce our witnesses. Our first witness is Dr. DeeDee Bennett Gayle, who is an Associate Professor at the University of Albany's College of Emergency Preparedness, Homeland Security, and Cyber Security at the State University of New York at Albany.

Her research focuses on emergency management, socially vulnerable populations during disasters, and communications during emergencies. Thank you, Dr. Bennett Gayle for being with us today and for sharing your expertise and experience with the Committee. Our second witness is Annie Lloyd from Darlington, Pennsylvania,

in Beaver County. She lives roughly five miles from East Palestine, Ohio.

Ms. Lloyd and her family were directly affected when a train carrying dangerous chemicals derailed in East Palestine just a few months ago. Thank you, Ms. Lloyd, for sharing your experience and your story with us today, and now I will turn to Ranking Member Braun to introduce our third witness.

Senator BRAUN. Mr. Jonathan Bydlak is the Director of the Governance Program at the R Street Institute. He is focused on fiscal budget and legislative branch policy. Jonathan received his bachelor's degree in Economics, with Minors in Finance and Political Economy from Princeton.

In May, Mr. Bydlak published "the Known Unknowns, Planning for the Next Emergencies". The report calls for planning ahead for emergencies rather than relying on off budget emergency spending. Thank you for agreeing to testify today, Jonathan. I Appreciate it.

The CHAIRMAN. Thanks very much, Senator Braun. Our fourth witness is Dr. Mahshid Abir. Dr. Abir is a Senior Physician Policy Researcher at RAND Corporation and a practicing Emergency Physician.

During the pandemic, she led COVID-19 related projects, including identifying strategies to increase critical care capacity in intensive care units and strategies to boost COVID-19 vaccine acceptance.

Thank you for sharing your expertise with us, Dr. Abir. We will start with our first witness, Dr. Bennett Gayle for your opening statement.

**STATEMENT OF DEEDEE BENNETT GAYLE, PH.D., PROFESSOR
OF EMERGENCY PREPAREDNESS, HOMELAND SECURITY,
AND CYBERSECURITY, SUNY, ALBANY, NEW YORK**

Dr. Bennett GAYLE. Good morning. Thank you, Chairman Casey and Ranking Member, Senator Braun, for having me here today. It is an honor to testify before the Committee. This is such an important issue.

Most marginalized members of our society are often disproportionately impacted during disasters, and negatively so. These populations include older adults and people with disabilities, racial and ethnic minorities, low-income populations, LGBTQ communities, among others, and in fact, there is some research that estimates the marginalized members of our society or socially vulnerable populations account for nearly 50 percent of our population or more. Some of the concerns for older adults and people with disabilities are the lack of inclusion across the life cycles of a disaster, lack of understanding about the social conditions that contribute to their vulnerability, a focus on agent specific rather than an all-hazards approach, trying to change our culture of preparedness and a dearth of sponsored research to address many of these concerns.

We are aging, healthier, longer, and more independently living. Our older adult population is also more racially and ethnically diverse, overwhelmingly women, and is rapidly increasing. For example, my grandmother lived to be just over 96 before she passed away just this past October.

Though her mobility slowed as she aged, her health was far superior than most in my family, without common physical ailments outside of arthritis. Plus, her memory was completely intact. The vulnerability of older adults is not merely the result of their pre-disaster health or direct injuries sustained.

Social factors that contribute to their increased vulnerability. These factors include being left out of emergency planning, preparedness, response, recovery, and mitigation efforts. This also includes the increased isolation that many older adults and people with disabilities face in the aftermath of a disaster.

Our culture of disaster preparedness is more reactive than it is proactive. Legislation often follows an extreme event and is agent specific. However, we see very similar disproportionate impacts across all hazards concerning more vulnerable populations. Federally sponsored research has underscored the importance of investments in infrastructure related studies, and more recently, health related medical studies to tackle disaster preparedness.

Research should also proactively fund social, human behavioral factors, and workforce related studies pertaining to disaster vulnerability. The Real Emergency Access for Aging and Disability Inclusions for Disasters Act has the potential to focus our attention on fixing known challenges and ensuring the inclusion of older adults and people with disabilities.

With potential investments in research centers, this Act can fund necessary empirical studies related to the impacts of our marginalized populations, and I have some recommendations. We need to address how our citizenry rethink about and understand disasters. For one, disasters are not natural.

The term natural disasters can be misleading, encouraging individuals to dismiss the notion that there is something they could actually do to reduce their risk. To empower individuals, we need to encourage people to be aware of their local hazards and to prepare for them appropriately.

The whole community approach to disaster requires a dedicated focus on building capacity. However, we often focus on the deficiencies of our marginalized populations instead of understanding their strengths and capabilities. This leads us to talking at people instead of listening to people.

Our focus on deficiencies is likely related to our preconceived notions about aging and ability. We must shed these biases. With older adults living longer, healthier, and independent lives, it is important to consider their unique needs, include them in developing preparedness plans, listening to their experiences, and learning from them.

We need to also consider the heterogeneity of these populations, as older adults do not all reside in nursing homes and may have informal caregivers who are members of their family or spouses of a similar age, or they very may well live alone. This is similar to every older adult in my family currently.

People with disabilities are often also discussed as a homogenous group of people, however, they are of all ages and have differing abilities. Furthermore, these populations also vary in their racial, ethnic, and cultural background.

As we plan for and study populations, we must factor in that we are not all just a member of one group. We must make investments before a disaster occurrence. We should proactively induce—introduce legislation to increase preparedness, such as the REAADI For Disasters Act.

Additionally, these investments should follow an all-hazards approach rather than an agent specific one. The issues and lessons learned across most of our major disasters are similar. After action reports tell a particular story where communications, coordination, community engagement, and reaching vulnerable populations are significant issues.

This means that sponsored research should also focus on remedying these challenges and increasing knowledge transfer with the workforce. We are only as resilient as our most vulnerable populations. Again, thank you for inviting me to speak before the Committee, and I welcome your questions.

The CHAIRMAN. Thank you, Dr. Bennett Gayle.

Ms. Lloyd, you may begin your testimony.

**STATEMENT OF ANNIE LLOYD, DISABILITY POLICY
ADVOCATE, DARLINGTON, PENNSYLVANIA**

Ms. LLOYD. Good morning. My name is Annie Lloyd, and I would like to tell you about my family's experience with the East Palestine train derailment. We moved to Darlington, Pennsylvania, after my husband served in the Navy.

My toddler son, Teddy, was showing signs of developmental delays, so we felt a quiet rural life would be beneficial. He would later be diagnosed as being on the autism spectrum with additional symptoms of anxiety and ADHD. Now, nine years old, he is incredibly active, imaginative, and very funny.

He can land a punch line like no one I have ever met. He is also dependent on special education services that include access to his school's autism resource room, a special education teacher, a paraprofessional, therapies, and special transportation.

Immediately after news broke that a train derailed in East Palestine five miles from our house, it became very clear to me that finding reliable information to keep our family out of harm's way would be difficult. You see, I have a journalism degree and I have worked at multiple media outlets over the last 15 years.

Living in a rural area places us in a news media barren desert. Residents of my community often end up relying on social media neighborhood watch groups to try to figure out what is going on, and as you can guess, the posts and comments can be riddled with rumors and false information.

The pressure building up in the derailed train cars was becoming increasingly concerning. At the time, I concluded that the major concern was shrapnel from the anticipated explosion, so sending my kids to school that day, to a school that was further away from the derailment than our home seemed to be the sensible thing to do.

Not long after we got the call that our kids were being evacuated, and officials blocked off all westbound roads at my street, something I didn't realize until I saw the barricades. My son ar-

rived home with a note from his special education teacher that she told him he was being evacuated because a train was stuck.

She often responds to Teddy's anxiety and meltdowns, and her precise, subtle explanation met Teddy's needs and was greatly appreciated by all of us. He was totally stoked to be off school early, so he immediately took to running in the yard, as he often does after school, to help him regulate his emotions, anxiety, and need for movement.

Today, I said, would not be a day he could get his running in because we have to stay safe from the stuck train. It wasn't long after that the black cloud erupted from the controlled explosion, igniting concern of chemical contamination.

Those concerns continue to this day as no testing has been available to us and no one has told us about the conditions of the air, well water, and soil around our property. Senator—Senators, we desperately need more reliable information.

We needed clear communication from authorities with intimate knowledge of the train derailment, of what the danger was, and who needed to take active steps in protecting themselves. Evacuating disabled kids from their schools and hoping that they will navigate their way out of harm's way in an emergency is simply not enough.

No disaster is ever truly expected, but everyone should be prepared for by our local and county emergency response authorities, and first in those preparations should be the needs of our most vulnerable.

At moments like these, I am reminded as my child's caretaker that I will not live forever, and there will be a day where he will be navigating emergencies on his own. It is a perpetual feeling in the pit of my stomach, having struggled myself, a non-disabled person, with figuring out what to do to stay safe during the explosion, to know that someday my son will be doing this without me.

Senators, I am asking you, as a mother of a son with a disability and a friend of many disabled people, all of whom make unique, remarkable contributions to our communities, to put forth a comprehensive accommodation plan for our disabled citizens for times of emergencies and disasters.

There is nothing more fundamental to a dignified life than the capability of preservation. What is freedom, if not equal ability to survive. Thank you for your time.

The CHAIRMAN. Ms. Lloyd, thank you very much for your testimony. We are grateful you bring your own personal story. Next, Mr. Bydlak, for your opening statement. Thank you.

**STATEMENT OF JONATHAN BYDLAK, DIRECTOR
OF THE GOVERNANCE PROGRAM, R STREET
INSTITUTE, WASHINGTON, D.C.**

Mr. BYDLAK. Thank you. Chairman Casey, Ranking Member Braun, and Members of the Committee, very much appreciate today's hearing and the opportunity to testify before you.

My name again is Jonathan Bydlak, and as I mentioned, my specialty is in budget policy and improving Government efficiency to better serve constituents. The pandemic and its response imposed

significant hardship on Americans, particularly the older and disabled.

Being better prepared for the next crisis, whether public health or otherwise, can help ensure that no Americans are left behind. Smart planning preserves resources and ensures that any Federal response benefits those who need it rather than furthering waste and abuse. Emergency events affect vulnerable segments of the population the most, and so do the unintended consequences of poor planning and irresponsible budgeting.

In everyday life, we understand that a car accident is an emergency. It requires a rapid response and temporarily special powers like letting ambulances run red lights or speed on their way to the hospital, but increasingly, in the context of national emergencies, the Executive continues to use special powers long after the crisis.

Just as we don't let injured drivers run red lights on their way to physical therapy, so too, must we limit emergency powers to the time of actual crisis. In recent years, the number of federally declared emergencies has increased dramatically, and so has Federal spending in response.

Officially designated emergency spending has totaled more than \$3 trillion since 2000, but the true impact on the U.S. economy and the Federal budget is much greater. The Federal response to the COVID-19 pandemic costs more than \$5 trillion. Spending overseas expanded dramatically during the two decades after 9/11, and disaster supplementals in our response to the financial crisis in 2008 also contributed to our increasingly tenuous Federal balance sheet. Put simply, emergencies have added up, especially since this spending is typically enacted without any offsets. There are also substantial private costs, and I am thinking of closed businesses, on and underemployment, and more recently, higher inflation and interest rates.

Many economists at the Federal Reserve and others have written about the relationship between expansive pandemic related spending and persistent inflation. I have with me an article from CBS News, the headline of which reads, "Inflation is Slamming U.S. Seniors". "It is a scary time", one disabled widow said.

Unchecked spending poses real costs to Americans who are lower income or on a fixed income. With each additional unexpected expenditure, vulnerable populations are threatened further by trust fund insolvencies, crowding out other budgetary priorities, and potential benefit cuts if nothing is done.

As a recent Social Security trustees report warned, the odds are rising of a 23 percent benefit cut as soon as 2033 without a change in the status quo. Fortunately, there are reforms that Congress should consider. These include limiting the length of emergencies and restoring the proper role of Congress.

The executive branch must often act quickly, but the legislature should not allow emergencies to extend unchecked for months and years. The recent bipartisan effort to end emergency declarations after 30 days absent congressional action is a good idea, and when an emergency has been declared, Congress should target funds and demand transparency.

For example, instead of trying to claw back pandemic funding after the fact, Congress could have required States to publish how

they spent funds as a condition of aid in the first place. Most States were able to respond to the pandemic thanks to the strength of their budget stabilization funds.

We should explore such options at the Federal level to alleviate fiscal strain in times of crisis. As we now reenter a world of Federal spending limits, such mechanisms could ensure that adequate funding for emergencies is immediately available, rather than relying on off budget spending and gimmicks.

Well-designed fiscal rules in other countries should also be considered. Sweden's entitlement program guardrails have become a worldwide model, just one example, instituted to safeguard their safety net programs, and finally, we should help people continue to save. The Federal Government can incentivize individuals to prepare for emergencies and make existing savings vehicles more flexible.

Efforts enacted in last year's omnibus, including the chairman's Able 2.0, should be expanded to further increase savings opportunities for Americans with disabilities. Thank you again for holding today's hearing and for your consideration of these important issues, and I look forward to any questions that you may have.

The CHAIRMAN. Thank you, Mr. Bydlak. We will turn next to Dr. Abir.

**STATEMENT OF MAHSHID ABIR, M.D., EMERGENCY PHYSICIAN
AND HEALTH SERVICES RESEARCHER, RAND
CORPORATION, ANN ARBOR, MICHIGAN**

Dr. ABIR. Thank you, Chairman Casey, Ranking Member Braun, and distinguished Members of the Committee for the opportunity to testify today. In addition to being a health services researcher at RAND, I am a practicing emergency physician and worked on the frontline during the COVID-19 pandemic.

The views I share today reflect my clinical experience in the emergency department for nearly two decades and an expertise as a health services and public health researcher. On a typical day in the emergency department, many older adults and individuals with chronic diseases present for care.

Many of these patients have multiple co-morbidities and long list of medications, and some are dependent on life sustaining medical devices. The process of getting to the emergency department itself can be a massive feat for these individuals, often necessitating transfer by ambulance or dependence on family or transportation services.

During emergencies, these population's challenges in seeking health care are compounded by the uncertainties presented by these events. Disruptions in access to food, shelter, transportation, electricity, health services, and medications can put older adults and people with disabilities in an even more vulnerable position.

Any one of these disruptions can lead to acute exacerbations of chronic illnesses and the need for care in the emergency department and inpatient settings. The routine challenges faced by health systems and social services in the U.S. are also amplified during these events.

For example, during the COVID-19 pandemic, health care workforce shortages strained the emergency department and hospital

capacity, and emergency department boarding of hospitalized patients, where admitted patients may stay in the emergency department for days waiting for an inpatient bed worsened.

This strained health system capacity during emergencies can adversely affect outcomes among older adults and people with disabilities, because of this two prong exacerbation of vulnerabilities among these populations and in the health and social services systems. Mitigating the needs of older adults and people with disabilities requires special consideration distinct from the rest of the population.

Given that preparedness, response, and recovery is likely most challenging in the context of these groups because of the intensity of their health care and social services needs, framing related policies and practices based on them are likely to improve the processes for all Americans.

In order to effectively plan for the response and recovery needs of older adults and people with disabilities, a data driven approach and leveraging technology is imperative. For example, the size of these populations and the nature and degree of their health care and social services needs need to be routinely measured in every community across the United States to inform mitigation plans and anticipating the needed resources.

Paired with a national all-hazards surveillance system, such data could inform planning for the needs of these groups based on the nature of the event. Further, because many older adults may live alone and may not have a reliable source of communication with response entities, advanced knowledge of the locations of these individuals and plans for outreach during emergencies will be critical.

Beyond leveraging data and technology, Congress could take steps to advance the health and safety of older adults and people with disabilities in emergency contexts, such as requiring Medicaid payments to be made out of State for older adults and people with disabilities during public health emergencies and disasters.

Extending Medicare 20 percent increase for inpatient COVID-19 care to all Medicare eligible adults and people with disabilities during future incidents. Requiring the development of resources and capabilities within public health departments to address the needs of older adults and people with disabilities.

Another opportunity is the currently in progress reauthorization of the Pandemic and All Hazards Preparedness Act, otherwise known as PAHPA. PAHPA reauthorization offers an opportunity to modernize preparedness, response, and recovery capabilities at all levels of Government through investing in more effective and efficient strategies.

Part of redefining our preparedness, response, and recovery framework is planning for the worst case scenario that affects the most vulnerable in our communities, including older adults and people with disabilities. I thank you again for this opportunity and look forward to your questions.

The CHAIRMAN. Thank you, Dr. Abir. I Appreciate your testimony and your experience. I wanted to start a round of questions. I will start with Ms. Lloyd. You are a journalist, and you have to get the

facts right, and you know the importance of accurate information, especially in the context of an emergency.

I am sure you are also sensitive to how, and you made reference to this in your testimony, about how disinformation or rumors or other misleading information can put families at risk and put a whole community at risk in the aftermath of the train derailment in Ohio.

News organizations got facts wrong. You shared in your own testimony that you and your neighbors could only find information through local Facebook groups and that these became rumor mills, to use your words, that cause unnecessary panic.

Why is it important for families like yours that include people with disabilities and older adults to have access to accurate, trustworthy information about both emergencies and disasters as they are occurring, and of course, in their aftermath?

Ms. LLOYD. Yes, I think not everybody has discernment. I think a lot of people who are new to technology, especially in our rural area, think because it is printed on a website, that it is official, and it is true, and in this case, it obviously was not necessarily the case.

I know of people who lived 20 miles out that were getting hotel rooms that probably the people who lived within the one mile radius of the explosion desperately needed. There seemed to be no information czar or no information manager who was managing the information coming out from our, like town supervisors, our local State representatives. It just seemed to be a free for all.

The CHAIRMAN. Nothing that was centralized?

Ms. LLOYD. Not that I could find.

The CHAIRMAN. That is one of the challenges in this area of policy to get—to try to improve that. We will talk more about that. I wanted to turn to Dr. Bennett Gayle. In your testimony, you talk about the importance of the whole community approach to emergency preparedness.

The REAADI For Disasters Act will create a commission that will have on the commission people with disabilities, older adults, and experts to provide guidance on inclusion, inclusion of those Americans on such a commission so that they are prepared and were prepared during disasters.

These particular citizens of ours have specific needs before, during, and after disasters that are often ignored. Dr. Bennett Gayle, what specific challenges do older adults and people with disabilities face after a disaster strikes? Why is it so important that they have a seat at the table throughout all phases of emergency preparedness?

Dr. Bennett GAYLE. Thank you for the question. I believe it is not just in response and recovery that they have their challenges.

What happens during preparedness, and I think we should invest more money in preparedness, is that they are often left out of the exercises and simulations when we are thinking about and planning for people with disabilities. There needs to be some proper inclusion, so sometimes you may see someone without a disability being a mock actor trying to figure out what their needs might be, and that doesn't necessarily cause anyone to figure out what their actual needs are. They should be included in planning.

In response during warnings and emergency messaging, there needs to be consideration for American Sign Language and prominent languages in the area. Reaching out to populations only gets us halfway there. Did they understand the message, and can they actually comply with that message is something that we really haven't looked at as much.

We are starting to think about that, but we are doing a lot of research on making sure that we have clear, consistent, clear, and accurate messaging going out, and trying to reach the populations, but often just having numbers on how many people that receive the message doesn't actually get us to know if they are able to understand the message and if they are able to take the necessary precautions. In evacuation, we can figure out how to maintain their social connections and social networks.

That is extremely important because if they are unable to, then they fare way worse than if they actually are able to keep up with their social connections, and then in search and rescue, we have problems with trying to figure out where people are located. These groups are not necessarily geographically located all together.

How do you figure out where they are? Registries have not worked in the past. Registries only pick up about five percent of our population in a particular area, and—at best, and then when we do have registries, you have a number of people who don't want to be on them, especially those who are people with disabilities and some older adults, and we have to take that into consideration.

With recovery, there is early evidence, especially even recently from Hurricane Harvey, of the paperwork being very detailed and being very difficult to navigate, and that also hinders people from filling out the paperwork or getting information so that they can recover, and it may not consider unique household dynamics.

Some of the paperwork does not consider the fact that families living in a particular area have passed on their houses from person to person and then you don't have a deed, or it doesn't consider the fact that you may have grandparents, and a number of them are, taking care of young children and how do they actually navigate that system, and then mitigation, it is costly at the individual level. A lot of our older adults are on fixed incomes, and it is not easily explained. That takes some time to do. We have evidence of it working where people have been able to mitigate and do it at the household level, but that has taken way more than 30 days. It has taken quite—like a year or so.

A good example of that is in Greensburg, Kansas, after tornadoes. They did get a chance to get individuals to start thinking about green living or changing their household structure so that it would be better off, but that took a lot of community engagement and explaining to individuals what was happening so that they can buy into the system.

The CHAIRMAN. Doctor, thanks very much. I will turn to Ranking Member Braun.

Senator BRAUN. Thank you, Mr. Chairman. Mr. Bydlak, earlier, we talked about on all emergency spending, we basically borrow the money, done nowhere else through insurance, through any other Government entity.

They have to deal with emergency funds and rainy day funds, and I think you said that over the last two decades, it is north of maybe \$10 trillion that have been added to the Federal debt. Can you explain why a rainy day fund, an emergency fund, would actually be a better way of doing it?

Mr. BYDLAK. Yes. Thank you for the question. I think if I start I mean, if you just consider, you know, a quick back of the envelope calculation, I mean the cost of war project at Brown University estimates that we have spent around \$8 trillion in total on the war on terror, and that was spending that was not expected pre-2001.

If you consider the money that we spent on the pandemic, that is another \$5 trillion. That was obviously not really expected prior to early 2020, and then if you consider the \$3 trillion in sort of officially designated emergency spending, that is alone, is you know, \$15, \$16 trillion out of an increase in the national debt of \$26 trillion over that time.

You are talking well north of 50 percent, so I think that the impact, you are correct to point out, of emergency spending, whether officially designated or otherwise, has been very significant. You know, in the context of emergency funds—and I think to some degree it speaks for itself.

I mean, if we look at how States were able to respond in the pandemic, they had, you know, their emergency funds were pretty much flush with cash in the early stages, and, you know, that put them in a very strong position. I think that there has been a lot of sort of, you know, misinformation maybe that it was a requirement that they get funds from the Federal Government to replenish their emergency funds, but their emergency funds were in very strong shape early on, and the same was true even going back to the 2008 financial crisis, and so the value here is that, you know, you have actual funds put aside for these types of expenditures, which look is the kind of thing that we all do in our own private lives and that we expect even businesses to do to plan for unforeseen events, and the other underappreciated part, I think, of emergency funds is just the speed. You know, as we learned in the context of the pandemic, the ability to respond quickly to an emergency or disaster situation is incredibly important.

It is not just that you have money, it is that you also are able to respond in a much quicker fashion, and so, I think it is something that we should definitely consider at the Federal level, especially when we consider that, you know, in many points in time, the Federal Government has served as sort of a de facto backstop.

It is very important that we have our Federal finances in as strong of a position as possible, and an emergency fund could very well be an important component of that.

Senator BRAUN. I think sooner or later, when you have any understanding of fiscal policy and macroeconomics, you are going to pay the piper with inflation and other things that happen due to that approach, so when it comes to, how would you—what policy proposals are out there? Is or anything else other than creating a rainy day fund, which is probably unlikely here?

I don't think we will do that until you hit the ditch fairly hard. Any other policy proposals that would make it a more sane approach rather than—we know the need is there, but it is the ap-

proach in this place that defaults to the, to me, shameful process of just putting more and more debt on to everybody that is in a future generation, kids and grandkids.

Mr. BYDLAK. Yes. I mean, I like to be a little bit more optimistic perhaps, and hope that we might be able to go and implement an emergency fund. Look, I think there are a lot of lessons from the States and from other countries.

I mean, I referenced in my written testimony the Swedish case where Sweden was actually found themselves in a very similar situation in the 1990's. They had a generous social safety net. They don't sit on a large amount of oil reserves like their neighbor to the West, and they had to really think about, how can we ensure the sort of programs that many people are reliant on, and they implemented statutorily, you know, budget caps that put some level of restraint on their expenditures, and you see very effectively that countries like Sweden or Switzerland, perhaps being the other example that is often used, those countries have tended to respond far more effectively to crises and done so in a way that didn't result in just blowing up their budgets.

Senator BRAUN. They have a fairly—they have got somewhat larger central Government, probably budget, but they don't borrow money to spend what they want to spend, and they are taking the responsibility of putting savings into emergency funding, which again, is what all other places have to do. This is the only place that seems to try to violate that rule routinely.

Mr. BYDLAK. Yes. I mean, you know, in this country, we just went through the debt limit fiasco, crisis, whatever you want to call it, and I think there is a lot of acknowledgment from people on both sides of the aisle that the way that we deal with our sort of expenditures in this country is not ideal.

There are virtually no other countries that have this exact same process. I think Denmark is the only other one, and instead, what they do is they cap their expenditures as a function of expected revenue, which is itself a function of what they have taken in recently and what they expect in the short term, and that is a much smarter way of doing it, and it gives you a lot more flexibility to respond to unforeseen events. I mean, in the Swiss case, they don't have a—they don't have an emergency fund explicitly, but they are able to engage in emergency spending, and then it sort of—that impacts what they are able to spend in the coming five or six years, and so, again, these types of lessons, I think are very important and big picture, have wide ranging implications for both the finances of the country and how we deal with them.

Senator BRAUN. Thank you.

The CHAIRMAN. Thank you, Ranking Member Braun. We will turn to our next Senator in a moment. I just want to mention, as many of you know, follow the work of this Committee and the schedule on Thursdays, we are going to have Senators in and out, some appearing and having to leave and come back, some appearing and being able to ask questions, so we have had Senator Kelly here and Senator Blumenthal, and we will now turn for questions to Senator Ricketts.

Senator RICKETTS. Great. Thank you very much, Mr. Chairman, and thank you to all of our witnesses for being here this morning.

I was the Governor of Nebraska from 2015 till just this year, and we dealt with a number of disasters, and including the COVID pandemic, but also tornadoes, wildfires, flooding, you name it, and appreciate all your comments, specifically with regard to older Americans and Americans with disabilities, because they are disproportionately impacted for all the reasons that you have just outlined, whether it is burden of paperwork or just people not thinking through how to be able to handle folks who have additional needs, and frankly, one of the things I also want to hit upon—well, two things I want to hit upon. One is, just making sure that we are doing the planning ahead of time and how important that can be, but also not having a one size fits all answer.

According to the Surgeon General Advisory, one of the things I also want to hit upon in that second part is with regard to loneliness, but I will talk about planning first. One of the things that we did in Nebraska is we got a CDC grant that allowed us to establish in 2015 the Infection Control Assessment and Promotion Program, and that was a training program, in conjunction with the University of Nebraska Medical Center, to be able to actually go to our skilled nursing facilities and assisted living facilities to train them in infection control, and this is one of the things that allowed us to be able to perform relatively better with regard to those congregate living situations where we knew for older adults in particular were so dangerous with the COVID pandemic. Now, how you actually get States to make those kinds of decisions ahead of time, I don't have a good answer for.

I would love to say, I was so smart and told people to do that. That was not the case. It was somebody in my Department of Health and Human Services who made the decision, working with the University Nebraska Medical Center, to establish that program well in advance of the COVID pandemic, to allow us to train our health care professionals in those facilities so that they had a leg up when the pandemic hit, and then, of course, we really ramped those programs up, so advanced planning can make a difference.

We have demonstrated it here in Nebraska, where some other States, which, for example, made some of the horrible decisions about sending people who had COVID back into those types of facilities that led to additional problems.

Another thing is just how we have to avoid having one size fits all answers coming from the Federal Government, because that is one of the things that really leads to bad outcomes and poor health outcomes for our senior citizens and so forth.

This is what I was going to—read this one, according to the Surgeon General Advisory, loneliness and isolation have detrimental effects on public health. The National Academies of Sciences, Engineering, and Medicine reports loneliness and isolation in older adults are strongly associated with greater incidences of morbidity, cognitive decline, depression, anxiety, and a decreased quality of life, and increased risk of early death of all causes.

I know that specifically, I have had a number of providers in Nebraska talking about this. One in particular is Papillion Manor, a skilled care nursing facility that has expressed strong dissatisfaction with CMS's COVID-19 regulations, and some facts on parents.

Residents report a loss of quality of life as a result of the isolation, which kept residents from events with other residents, and their families—Mr. Bydlak kind of gets to your point about having emergencies too long. Well after we didn't need to have the restrictions in Nebraska on, say, communal dining, CMS still had those regulations in place which really contributed to this loneliness, and of course, Mr. Bydlak, like you also mentioned, all the \$5 trillion in spending which has helped contribute to inflation, which also hurts our older Americans, but what I would like to do is just hit upon, Dr. Abir, what sort of things did you see, or what sort of experience did you have with regard to kind of a one size fits all answer coming from regulations that may give us an opportunity to look for some flexibility down the road in the future so we can have more of a flexible response to be able to help, whether it is the amount of paperwork for older Americans or Americans with disabilities, or other sorts of rules that we might be able to take a look at to be able to get better outcomes.

Dr. ABIR. Thank you so much for this question, so I think that one of the most important things is to understand the specific needs and vulnerabilities of these populations, and yes, planning in advance, and preparedness is one of the major paradigms of, again, preparedness, response, and recovery. The problem is that historically we have treated, whether it is older adults or people with disabilities, almost similar to everyone else. Whereas given all the vulnerabilities, the needs are going to be different. The intensity of both social services and health services is going to be quite different.

Advanced planning is the key. However, that is also extremely expensive, but it is an investment that is worthwhile, and comparisons with Denmark or Sweden or Switzerland, which are socialist countries that invest tremendously in their health system and social system infrastructures, have healthier populations as a result, and it's not the United States.

I think that we need to think differently because we have a significantly aging population. We have a population that in many instances does not have appropriate access or enough access to social services and health care, so I think that we need to think very hard and look back at the COVID-19 pandemic, which is, you know, not just the pandemic of 100 years, but is the worst case scenario.

Who would have planned for a three-year public health emergency that touched every corner of our Nation and cost us, who knows. For decades to come, we are going to be measuring the impact on lives, on health in general, on loss of workforce, on loss of income, on loss of education, and so many other aspects of society.

We need to take a nice, long look at this pandemic, and the way that we didn't prepare for it, and how we responded to it, and how are we going to recover from it, and step back and say, how can we do better, particularly for the most vulnerable populations, because if you do it right for those populations, you are going to get it right for everyone else as well.

Senator RICKETTS. Thank you, Dr. Abir. I would point out again, in Nebraska, we did take some steps ahead of time in preparing, like our ICAP program to do it. Again, that wasn't mandated, but that is just shows how we chose to do with our CDC grant. I am

sorry, Dr. Gayle, I was looking at you and I said Dr. Gayle—or Dr. Abir, but I wanted to ask you the same question, if I may. Mr. Chairman, can I have a few extra—a little bit extra time to give Dr. Gayle a chance?

The CHAIRMAN. Sure, sure.

Senator RICKETTS. Again, in your experience, were there things that we could do to provide more flexibility to help us address populations that are older or with disabilities?

Dr. Bennett GAYLE. Sure. I think we can't forget about the social context.

I think my fellow panelists here also mentioned it, but when we consider what happened in COVID, right, in the beginning, it wasn't pharmaceutical that we went in terms of response. It wasn't infrastructural, it was a social mandate, right. It was to self-isolate, physical distance, or increase our use of technology to kind of continue our tasks, but that caused some problems, and I don't think we really understood what that was going to cause, and the reason why is because we don't actually fund a lot of the studies to study that.

If we are going to increase spending around planning and preparedness, we actually need to know what we are planning and preparing for, and we actually need to know the individuals who are going to be impacted, and we need to invest in the research to do so.

That research can't be focused solely on pharmaceutical outcomes because that is not—that wasn't our first step. That wasn't our first response. The other thing is, I have lived in your State, and I lived in your State during the time that you were Governor, and having visited Nebraska Medical Center, a lot of the things they had in place for infectious disease were because they also were dealing with—I think they dealt with an Ebola outbreak at one point, and they already had a lot of stuff in place to deal with infectious disease where other States may not have, so that could be one of the things that made you guys a little bit, you know, better in terms of preparing for this, and that is you had some space in having to deal with it before, so that is also very unique.

When we were thinking about vulnerability, we have to be cautious when we are trying to compare against different societies, not just because the societies are different, but because vulnerability is different across different societies. What makes us more vulnerable in one than another can also be because of social context.

Our vulnerability as an older adult here could be very different in another country, and we have to take that into consideration as well.

Senator RICKETTS. Yes. Dr. Gayle, thank you very much. You are exactly right with regard to UNC. They are a leader in infectious disease control. We do have one of only three federally funded containment—isolation places and the only actually quarantine space that was federally funded, and we did handle the Ebola patients who were coming out of West Africa.

We did have the expertise on hand to be able to do things like the ICAP program, and I agree 100 percent that that was kind of my point is, it is not going to be a one size fits all answer. What

may work in New York, may not work in Nebraska and vice versa, so we do have to be flexible about it.

Thank you very much to our witnesses again, and Mr. Bydlak, I was just going to say one last thing. When we started our emergency response in Nebraska, we did use our rainy day fund to be able to start funding before the Federal Government actually got their, you know, program in place and start passing it, so anyway, thank you, Mr. Chairman, for being so patient with me as I take up all the time in your Committee.

The CHAIRMAN. Senator Ricketts, sometimes there is a reward for being at every hearing, I think so that is—you get extra time. I wanted to turn back to a question for Annie Lloyd. Annie, in your testimony, among—so much detail about those hours after the derailment and what your experience as a as a mom and as someone who was not the recipient of a lot of information, like so many in the community.

You made reference to Teddy's school and the accommodations and help he get to school. You made reference to the—his school's autism resource room, a special education teacher, a paraprofessional for his time in general education classes, speech therapy, occupational therapy, and special transportation, all of which are important to note, and then you also talked about his teacher.

I am just reading directly from your testimony. You said his special education teacher often responds to his anxiety with, "brilliance and expertise, and her precise, subtle explanation met Teddy's needs and was greatly appreciated by all of us."

I sometimes think as much as we are often frustrated of when there isn't planning and there isn't planning that includes people with disabilities or older adults, there are some real heroes out there that step up and not only do their job but go beyond their job, and I thought it was important that you share that insight into his teacher.

What we have got to do here, among other things, is to learn from good behavior and good practices, best practices. Her response is something that we should replicate or imitate and use as a foundation for good policy. I introduced another piece of legislation that is relevant here, the so-called PREP, P-R-E-P, For Students Act, that would ensure that schools have the tools they need to develop inclusive emergency preparedness protocols.

Annie, when there is an emergency or a disaster, what kind of information and resources do you think schools need? There is so many places that need good information, but just in the context of schools, and maybe ever more so in the context of schools that have a number of children in that have a disability of one kind or another, what information and resources do think schools need to ensure that children like Teddy are safe?

Ms. LLOYD. One thing I can't help thinking about of that day, once a week I go and I work downtown—in downtown Pittsburgh, an hour away.

I can't help but think if I happened to be in the office that day, an hour away, when all that was happening, I do think, especially in the needs, in terms of students with disabilities, there needs to be a way for the school to be able to communicate with each and every individual parent to make sure that when they are evacu-

ating kids in an emergency, that not only will someone be home, but someone capable, a capable caretaker will be home to continue the process of caring for that disabled person.

That is what stood out to me the most, and I would also add to that is, to this day, I actually have no idea why they were evacuated from school. I think a followup would have—it still is—would be appreciated. I have the feeling there is some—there might be some legal, you know, things that—reasons why they sent the kids home, but at one point, all the—you know, my son rides the small bus and the disabled kids right before this controlled explosion were driving toward the explosion to get these kids home, and it did not seem right to me.

The CHAIRMAN. Well, as you said, I am looking at page two of your testimony, that word navigated—navigate, jumped out of me where you said, when evacuating a child with a disability from school, and absent good policy, we are just hoping that they will, “navigate their way out of harm’s way.” Hoping for that is not the right approach. We have got to have—we have got to do a lot better than that. Senator Scott from Florida is here, and I will turn to him for his questions.

Senator Rick SCOTT. Thank you, Chairman. First, I thank you all for being here, so I come to the State that has hurricanes, as you probably know.

We unfortunately have lost in the last—we had a hurricane last year and we lost 150 people, and many of them elderly, so I have been traveling the State, I have been in seven cities in the last three weeks trying to get people ready for and prepare for hurricane season, which started June 1st.

The—as we know, many elderly don’t feel comfortable evacuating, whether it is because they like to be where they are, whether it is because they have pets, whether they are not comfortable they will have the right food or medicine, all the all these issues, so for each of you, what do you do—do you have any recommendations to make sure that our elderly citizens actually listen to evacuation orders and evacuate early enough?

Dr. ABIR. I think that leveraging the networks in the communities, for example, faith based community, health services, EMS, law enforcement, and ensuring that these networks are aware of these older adults’ locations and their needs in advance will be really important, and to communicate, and whoever is the trusted messenger in those communities to communicate in advance to those communities and populations the importance of being ready to leave with their medications.

Let’s say they have medical equipment or devices that they are dependent on, so that would make a big difference, but I think it is really important to leverage the right stakeholders and use the right messengers to get through.

Senator Rick SCOTT. Anybody else?

Dr. Bennett GAYLE. I would agree. I think additionally, beyond just the trust, it is also thinking about the other social connections that they have made, so it could be an official person, but it could be an informal person. It may be someone from their local house of worship, but it could also be, you know, their next door neighbor, and it is kind of hard to say. That is not some—we know this in

general, but we haven't done extensive research to think about all the different ways to make someone evacuate.

We have done research on how to get messages to people. We have done research on who is left behind. We have thought about, you know, all of these different things, but we do need to find out more information.

I think it is going to be unique to each individual, and I think that is where we—everything kind of gets lost. We look at things in large data sets and we kind of think about people, all is the same, but when we get down in the nitty gritty, you will figure out, oh, well, if we had some information about this or if we can answer specific questions.

I did last year a national hurricane conference, have a panelist who is from Florida, and they were emergency management personnel, and during COVID, they said some of the things that helped was their, as a local emergency management group, going out and talking to the older adults and people with disabilities, and then they found information for them. They can answer their specific questions and they made the relationships ahead of time because they were from fire department, and it was, you know, very nice and they were able to make those connections. You don't often hear, you know, that pivot to, okay, I am just going to go door to door now and try to figure out what is going on.

Sometimes it takes a little personal touch. The robocalls don't necessarily work for older adults, so we have to think about other ways, and I think there may be some other examples out there, but they are going to be localized, and so we definitely need to learn more about what emergency management personnel are doing so that we can learn from what they are doing well.

Senator Rick SCOTT. Yes, sir.

Mr. BYDLAK. I will just add one quick additional point, which is that I think that we do also need to take sort of a long term approach to this as well. I mean, we have plenty of Americans who are living in areas that are particularly vulnerable, and we know that we have huge problems with the National Flood Insurance Program, for example, and a number of my colleagues have done work on that topic. I think that we do also need to kind of think about some of the long term implications and sometimes some of the perverse incentives that have been created by poor Federal policy through the years.

Senator Rick SCOTT. Have you found—like what we do in Florida, we have shelters for people with disabilities, for pets, and we have all these different things. Have you found around the country that most of the States have shelters for specific purposes?

Dr. Bennett GAYLE. Yes. People—and you know, in general, there is a shelter that shows up, right. The concerns about the shelter situation is that often—well, now we are seeing more disasters frequently occurring. Shelters don't stay up long enough. You know, minimum time is about two weeks and then they are closing, and that is problematic for individuals who actually need that space. The other thing about sheltering is that everyone doesn't show up to the shelter, so you may have a shelter, but it is only for a specific percentage of your population. I don't have that information

offhand, but I know it's not nearing 50 percent, right, of those that are left behind.

When we are thinking about sheltering, we have to think that there are also individuals staying in place at their house instead of going to the shelter, and it could be for a number of different reasons. Maybe there is not enough information about the disability accommodations at the shelter, so they feel like it will be more comfortable or helpful if they stay at home.

There could be other things similar to that. You know, during Katrina, I know you mentioned pets, but we learned a big thing, oh, people won't leave without their pets, and then we started thinking about putting pets in shelters so that individuals will leave.

There are other things that we haven't learned, and we shouldn't be learning them after a disaster, we should be proactively doing it and learning beforehand so that we can make the right choices and decisions and spend our money wisely prior to a disaster.

Senator Rick SCOTT. Thank you. Thank you, Chair.

The CHAIRMAN. Thank you, Senator Scott, and we will turn next to Ranking Member Braun.

Senator BRAUN. Dr. Abir, you earlier were asked by Senator Ricketts about kind of one size fits all. You know, as we navigated through COVID, we could see that shutting schools down didn't make sense when we found out that it had very little impact on young people, shutting businesses down, we spent a fortune.

The transmission wasn't occurring there. Hospitals had to stop routine stuff, I think, which had a, you know, latent negative impact we still probably can't measure, but the one thing we did know, it ravaged the community 65 years and older, predisposed. I think we focused on such—so many other areas and we didn't relent there.

What could we have done better once the science was clear that this disease was aimed at a very small group that got disproportionately impacted and we didn't seem to do a very good job in preventing that?

Dr. ABIR. Yes. Thank you for this really important question, so a couple of things before I answer your question directly, so in hindsight, hindsight is 2020. I think that this pandemic, the virus was unknown to us, and we will be learning about the acute and long term impact of COVID-19 on the human body for decades to come, so at the time when those public health interventions were implemented, we were operating on the best available evidence, but you are absolutely right. When we learned that, for example, kids were not a major vector for transmission, then we should have pivoted from those policies and moved in a different direction—re-open schools, but again, this is hindsight, and I think the lesson for future pandemics, and there will be future pandemics, is to have a data driven approach so that you are measuring the outcomes and understanding in real time, and that real time understanding, and science is informing policy.

The willingness to say that this virus is unknown to us, we are learning as we are going, and I think that is really a big point and tell the public that we—this is what we know now. Based on what

we know now, this is what we think we should do, and it may change because this is a novel virus.

I think that we need to start, and now, and not waiting another decade until the next big one hits, and say, you know, how can we have systems in place that track data on outcomes in the key population in real time? Once we do that, really identify the highest risk communities and invest the majority of mitigation and resources to those communities.

Senator BRAUN. I think it is great advice and I think that data was coming in while we were contending with it, and we just were stubborn in not focusing on where we knew the problem was the worst with the elderly, and yes, we now know, and I think set the framework up in the future to do a better job with it. We will probably contend with it again. Thank you.

The CHAIRMAN. Thanks very much. I might have some more questions, but I will turn to Senator Vance.

Senator VANCE. Thank you, Mr. Chair. Appreciate you holding this hearing, and thanks, as well to the Ranking Member. I want to focus—obviously, you know, there are many different kinds of disasters that affect folks, and the one that I am most focused on is not a natural disaster, but a manmade disaster.

I know, Ms. Lloyd, you suffered from some pretty significant consequences from the East Palestine train derailment. I will rehash for those of us who have forgotten that on February 3rd, 2023, an Eastbound freight train derailed in East Palestine, Ohio, a town of around 5,000 people.

Now 11 tanker cars and the resulting pile up contained hazardous materials, some of which were released into the air, soil, and water of East Palestine in what was called a controlled burn, but it didn't feel like a controlled burn to a lot of people on the ground.

People were and still are afraid to let their kids play outside. They are afraid to drink the water. They are afraid of what has happened to their air, and they are afraid of what has happened to their long term health.

Ms. Lloyd, I am so sorry this happened. I am so sorry it is something that affected your life, and I maybe thought, just given that a lot of us in D.C.—I am an exception. I know the chairman is an exception as well, but a lot of us in D.C. don't know anybody personally affected by it.

Maybe you could walk us through what it was like when that happened, because am I correct that you were pretty—living pretty close and still live pretty close to where the train crash happened? Is that right, Ms. Lloyd?

Ms. LLOYD. I live five miles out.

Senator VANCE. Five miles out. Could you just maybe walk me through what happened? Did you see it? Did you hear it? What were the effects? How did it affect your family?

Ms. LLOYD. Yes, we definitely did see it, and you know my heart—I am constantly thinking about the people of East Palestine. I don't know if they will ever—you know, I worry that they will never feel resolved and at home there anymore.

Five miles out in the way of Pennsylvania, what we dealt with was our children being evacuated from school. My kids attend the

school district in Pennsylvania that was evacuated. I will also say that we have six to eight acre property that sits at a higher altitude than the train derailment site.

When there was the controlled explosion, which looked like a mushroom cloud to me, we got a clear view of it, and it was—it was mind blowing. It was very strange.

Senator VANCE. Yes, ma'am, and how many kids are at your kid's school? How many children? Do you know, approximate number?

Ms. LLOYD. I am going to guess about 400, but I can't say for sure.

Senator VANCE. That is a lot of scared kids, and that is a lot of scared parents, and I think it is just important to realize that behind these statistics and behind the news stories, there are real people who are affected by this. Ms. Lloyd, would you be surprised to learn there were more than 1,000 train derailments last year alone in this country?

Ms. LLOYD. I am not surprised, no.

Senator VANCE. I—well, it is, you are smarter than I am, because I was shocked when I saw that number, and if you think about East Palestine, that is effectively 1,000 potential East Palestines happening every single year in our country. Of course, most of them aren't that bad, thank God.

When you crash a train, you don't always control where it crashes. Just a couple of months after East Palestine, there was a train derailment about four or five miles outside of Cleveland that could have been incredibly catastrophic if it had crashed a little bit closer to the city of Cleveland.

Thank God that it didn't, but we can't just rely on luck, and we can't just rely on good circumstances to prevent these things from happening. You know, I am mindful, of course, that while our children are affected by these things in unique ways, because their little brains are still developing and they are still trying to understand what they see, a lot of our elderly folks are the ones who can't get out quickly, who can't move quickly, who maybe don't have any alternative when their homes become unlivable.

I encourage members of this body and members of this Committee, I know both of you are both working on this with me, and I appreciate that we could pass the Railway Safety Act out of this body and out of the house later this summer that would make these accidents much less common and expose you and your family, hopefully to a railway system that is a lot safer and doesn't allow this thing to happen again.

I am sorry, Ms. Lloyd, but I am glad that you are here. I appreciate all of you for being here, and I appreciate your testimony.

The CHAIRMAN. Thank you, Senator Vance. I am just having maybe one or two more. Dr. Abir, we know that older adults and people with disabilities suffer the most from the COVID-19 pandemic. That is so plain from the numbers. As I said before, just older adults aged 65 and over were 75 percent of the deaths.

The vast majority of deaths and serious illnesses from COVID-19 occurred among those two groups of Americans, both seniors and people with disabilities. We also know that in the context of a of a particular setting, congregate settings were often the place

where people with disabilities and older adults contracted the virus.

We know as well that home care is an alternative to congregate care and older adults, and people with disabilities who receive support at home often had better outcomes during the pandemic than those in congregate settings.

Unfortunately, we have a crisis in home care services in our country. Would you consider the development of a more substantial homecare workforce and a network part of the, both the preparation that is needed here, as well as the mitigation for circumstances if we are facing a pandemic?

Dr. ABIR. Absolutely, so I think that would be important for preparedness, response, and recovery, and the best thing about this idea is that it is relevant for routine care and routine circumstances, as well as in the setting of emergencies.

If a person is able to get discharged from the hospital sooner because they have a home to go to, and there is home care available and scheduled and planned so that the person can go home, a nurse can visit, give them their medications, check in on them, make sure they are eating, or whatever else that may be, that means that that person is spending fewer days in the hospital, accruing lower costs for a hospitalization, likely not picking up a hospital acquired infection or other complication in the hospital.

I think it is a win, win for everyone, and the current system of let's wait everyone—for everyone to get sick enough to go to the emergency department and get hospitalized is not sustainable, and you know, the population again, is aging, so we need to get creative about our solutions.

The home care and hospital at home solution is really something that is, I think should be at the forefront of strategies that we consider.

The CHAIRMAN. Well, thank you, and I think that is among the many—we have learned so many lessons from the pandemic. That is certainly one of them. Maybe just one more question for you, Dr. Abir.

You have been doing this work for a long time, and you have done it both from the point of view of a researcher as well as a physician. You have carefully studied the response to public health emergencies, all the way from COVID-19 to Puerto Rico after the devastating hurricanes. We are told that since Katrina, the Federal Government has made a concerted effort to include the needs of people with disabilities and older adults in this emergency planning and recovery processes.

Can you share with us some of the improvements you have seen? We are obviously focused on shortcomings and areas where we need to improve, but any improvements or progress we have seen—you have seen over the past decade when it comes to meeting the needs of those two groups of Americans?

Dr. ABIR. I think that there has been some progress, although it is a byproduct of thinking about and planning for other populations, not necessarily older adults or people with disabilities. I will give you an example, so one thing that was for the longest time not part of preparedness plans and response plans was planning for people with chronic kidney disease.

People who require hemodialysis, which as I am sure you know, is critical for a person, so if they miss enough days of hemodialysis, it is fatal, so planning for hemodialysis for individuals and where are they are going to get it if they are displaced or unable to go to their center because they just can't get to the place because of a tornado or hurricane, there are plans developed around that.

The vast majority of folks on dialysis are older adults, so that planning has been critical. Another example is that many emergency departments, I shouldn't say many—some emergency departments in the United States are now certified to specifically take care of older adults.

That just signals to you that how important and different it is, that there are certain needs, even during routine care, that we need to really consider differently and develop kind of practices around this particular population.

I think we have made some advancement and there are other examples, but I think that we really have kind of not explicitly focused on these populations, and we have not done it in a data driven way.

I think that the best opportunity now is the hindsight of looking at the pandemic, because it did affect these populations the most, and we now unfortunately have plenty of data to look back at.

The CHAIRMAN. Thank you very much, and I know that we have to conclude, so I want to move to my closing statement before I turn to Ranking Member Braun, but I do want to start by thanking our witnesses for bringing in each case a combination of expertise, experience, your personal experience, and your own your own perspective to these issues, because we have a couple of opportunities.

The Pandemics All Hazards Reauthorization is one of those moments where we can focus on making sure that people with disabilities and older adults are part of the planning and response, but we have to look for other pathways as well, and as we heard today, emergency preparation can only be truly inclusive when all stakeholders are invited to the table and are committed to meeting the needs of all groups of Americans.

We heard from Annie Lloyd about the importance of accessible and accurate information—how frightening it can be to not have up to the day accessible information, especially in her case, worrying about her son and her family. This is why it is so important that emergency planning explicitly protects the health, the safety, and the independence of older adults and people with disabilities.

The legislation that I have introduced, the REAADI For Disasters Act will ensure the voices of these individuals are included throughout the—throughout every phase of emergency preparation. I will continue to work with my Senate colleagues on the Committee and in the Senate to make sure that the Ready for Disasters Act is included in the reauthorization of the Pandemic All Hazards Preparation Act.

Together, we can protect the health, safety, and independence of older adults and people with disabilities, and help communities prepare and respond to disasters and emergencies in a truly inclusive manner. I will turn next to Ranking Member Braun.

Senator BRAUN. Thank you, Mr. Chairman. Today we heard from experts, practitioners, and those who lived experiences about the

importance of preparing for emergencies. Prudent budgeting and planning are integral for both emergency preparedness and response to be successful.

In planning, we should factor in the needs of older Americans and people with disabilities and set aside resources accordingly for current and future generations. We cannot continue to push our debt on to future generations. We have spent, as I said earlier, upwards of \$10 trillion on emergencies in just the last two decades.

We know they are inevitable. We need to plan accordingly for them. Interest payments on our debt are going to be the single most expensive thing we do in the Federal Government on an—compared to any discretionary spending, domestic and defense. That is a sad prospect.

We need to enact Article I, which would terminate disaster issues without having to do it in a special way. It can't linger on forever. Ensuring that emergencies terminate without the intervention of Congress, I think is important.

Finally, the COVID pandemic. Well, in submission, we have a golden opportunity. We discussed it to implement lessons learned and better prepare for the next inevitable occurrence, to some magnitude. We can do it better next time around. It just takes some backbone and some foresight.

Protecting older adults and people with disabilities in emergencies is a nonpartisan issue, and planning ahead to do so should be nonpartisan as well. I am Eager to work with my friends across the aisle to put these solutions into reality. I Appreciate all of you coming here today, and thanks, Mr. Chairman, for the hearing. I think it was a good one.

The CHAIRMAN. Ranking Member Braun, thank you very much for your time in working on this issue and working to plan this hearing. I want to once again thank all of our witnesses for their testimony and for being with us today, and for contributing both time and expertise.

If any Senators have additional questions for witnesses or statements to be added, the hearing record will be kept open for seven days until next Thursday, January—June not January, June 22nd. Thank you all for participating today. This concludes our hearing.

[Whereupon, at 10:57 a.m., the hearing was adjourned.]

APPENDIX

Prepared Witness Statements

United States Senate
Special Committee on Aging
June 15, 2023
9:30 am EST

Written Testimony

**Before Disaster Strikes: Planning for Older Americans and People with
Disabilities in All Phases of Emergencies**

Prepared By Dr. DeeDee Bennett Gayle
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Director of the Extreme Events, Social Equity, and Technology Laboratory
Emergency Management and Homeland Security Department
College of Emergency Preparedness, Homeland Security, and Cybersecurity
University at Albany, State University of New York



Introduction

Good morning and thank you, Chairman Casey and Ranking Member Braun for having me here today. Thank you to Senator Gillibrand, from my home state of New York, for the introduction. It is an honor to testify before the committee today. This is such an important issue; I am grateful for a hearing on this topic.

My research is focused on reducing disaster vulnerabilities for our most marginalized populations in the U.S. I also look for avenues where technology is appropriately leveraged to assist in resilience or where it presents barriers. The National Science Foundation, the Department of Homeland Security, the Federal Emergency Management Agency, the State University System of New York, among others have funded my work. In the last 15 years, my research has been published in various journals covering topics on disabilities, aging, disasters, and information science. I have contributed to a number of regulatory filings focused on improving emerging messaging for people with disabilities and for individuals with English language barriers.

Issue

The most marginalized members of our society are often negatively disproportionately impacted during disasters. These populations include older adults and people with disabilities, among others. Both populations have a higher potential of living in low-income households and have limited disaster resources.³ It should be noted that many older adults also live with at least one disability.⁴ According to recent AARP and Red Cross studies, older adults are more vulnerable than other age groups.¹⁻³ For

example, consider the AARP report that found older adults comprised over half of the fatalities in the following disasters:

- 50% in New Orleans following 2005 Hurricane Katrina
- 50% in the N.Y. area in Hurricane Sandy in 2012
- 60% following the Texas Winter Storm in 2021
- 70% in Florida following Hurricane Ian in 2022
- 84% in the 2018 California Camp Fire

Older adults often have situations that contribute to their vulnerability during emergencies and disasters such as living with the assistance of specialized devices, having an external caregiver, and living with a chronic health condition that needs continued treatment.⁴ Most of our studies focus on nursing homes and other congregate care facilities for older adults. We have little information about the needs or capacity of the many older adults living with a spouse or alone in the community.

Similarly, people with disabilities are also disproportionately impacted during disasters. In my own research, I have found the needs of people with disabilities absent from state-level emergency plans. Additionally, the way in which we define disaster and disability influences how people with disabilities are incorporated into disaster risk reduction efforts.

Some of the concerns for these populations are the lack of inclusion across the lifecycle of disasters, lack of understanding about social conditions that contribute to vulnerability, a focus on agent specific rather than all hazards approach, trying to change our culture of preparedness, and a dearth of sponsored research to addresses many of these concerns.

Considerations for Older Adults during Disasters

Demographics of Older Adults

The current status of many older adults is excellent. **We are aging healthier, longer, and living more independently.** Our older adult population is also more racially and ethnically diverse, overwhelmingly women, and is rapidly increasing.⁴ For example, my grandmother lived to be just over 96. Though her mobility slowed as she aged, her health was far superior to most in our family, without common physical ailments outside of arthritis. While this is great, we should be concerned that older adult populations are not actively included in disaster management.

In 1900, the older adult population (65 years of age or older) accounted for 4% of the U.S. population.⁵ In 2021, older adults account for nearly 17% of the U.S. population, and by 2040 they are estimated to be almost 22%.⁶ Nearly 60% of those older adults live with their spouse or partner, and 27% live alone.⁴ As of 2019, more than half of the U.S. older adult population lives in nine states: CA, FL, TX, NY, PA, OH, IL, MI, and NC. These states also have frequent natural hazards from wildfires, hurricanes, flooding, heat waves, and winter storms. There has been an increase in human-induced hazards, as well.¹

Culture of Preparedness

Our culture of disaster preparedness is more reactive than it is proactive. Legislation often lags an extreme event and is agent specific, meaning planned around specific types of disasters.⁷ However, we see similar disproportionate impacts across all hazards concerning our more vulnerable populations,

including older adults and people with disabilities. Attempts to increase preparedness among the U.S. population have largely been unsuccessful.⁸ A recent 2022 AARP study in Florida shows a reduction in preparedness levels among older adults.⁹

But this issue is broader than just one demographic; one-size fits all preparedness campaigns are unsuccessful. Many necessary changes for us to approach resiliency require that certain information and resources to meet the unique needs of different groups are available at the household level. These resources will help empower individuals to better mitigate and prepare for the hazards they may face. This will likely lead to more successful response and recovery efforts for these groups.

Social Impacts

The vulnerability of older adults is not merely the result of their pre-disaster health or direct injuries sustained. **Social factors often contribute to their increased vulnerability.** These factors include being left out of emergency planning, preparedness, response, recovery, and mitigation efforts.^{3,10,11} Their vulnerability also includes the increased isolation that many older adults and people with disabilities face in the aftermath of a disaster. The Surgeon General has recently issued an advisory about the indirect health impacts of loneliness and isolation.¹²

Research shows that neighbors and community members often serve as the initial first responders following disasters.¹³ Neighbors regularly check in with older adults and people with disabilities. These *social capital networks* provide resources unattained by wealth. Isolated people are less likely to seek, receive, or find appropriate resources. Without social networks, older adults and people with disabilities often face more difficulties during and after a disaster.

Sponsored Disaster Research

Federally sponsored research has underscored the importance of investments in infrastructure and, more recently, health-related medical concerns to tackle disaster preparedness. **Research should also proactively fund social, human behavioral factors, and workforce-related studies pertaining to disaster vulnerability.**¹³ Social-related research has been encouraged for some time; however, this research is often tacked onto larger projects primarily focused on engineered solutions and large secondary datasets.

The lack of human behavioral factor disaster research funding has resulted in very few academic research studies on the impacts of disasters on older adults and people with disabilities. Where these studies have occurred, **the populations are often investigated as a homogenous group of people or primarily as individuals in need of caregivers or living in congregate care.** With over half of the current older adult population living with a spouse or alone in the community, the true needs and capabilities of older adults remains largely understudied. To account for the social factors and change in the culture of preparedness, larger, more specific investments regarding the social impacts of disasters must be made.

The Real Emergency Access for Aging and Disability Inclusion for Disasters (READI for Disasters) Act (S. 1049) has the potential to focus our attention on fixing known challenges and ensuring the inclusion of older adults and people with disabilities. Furthermore, with potential investments in research centers, the READI for Disasters Act can fund necessary empirical studies related to the impacts of our marginalized populations during disasters.

Recommendations

We **need to change how our citizenry thinks about and understands disasters**. For one, disasters are not natural. The term natural disasters can be misleading – encouraging individuals to dismiss the notion that there is something they could do to reduce their risk. To empower individuals, we need to encourage people to be aware of their local hazards and to prepare for them appropriately. Given that we move around and readily visit different regions of our country, we must also encourage people to learn about the potential hazards in new areas they visit.

The whole community approach to disaster requires a **dedicated focus on building capacity**. However, we often focus on the deficiencies of our marginalized populations instead of understanding their strengths and capabilities. This leads to us talking *at people* instead of listening *to people*. This needs to change. When we do not have the appropriate trust or buy-in from community partners, we seek innovative solutions that do not adequately identify needs. For example, I have personally observed mock actors used to approximate probable concerns for people with disabilities during a large-scale hurricane shelter exercise. Having actual people with varied disabilities included in the training would be better for the workforce to improve sheltering considerations and simultaneously be enlightening for the person with a disability to better prepare for a disaster eventuality.

Our focus on deficiencies is likely related to our preconceived notions regarding aging and ability. **We must shed biases about aging and ability**. With older adults living longer, healthier, independent lives AND working well past our standard classification of ‘older adult’ – it is essential to consider their unique needs. Include them in developing preparedness plans, listen to their experiences, and learn from them. For example, people with disabilities have been largely ignored in disaster plans, and when they are included, it is often not because of their capabilities.

Consider the heterogeneity of these populations. Older adults are not a large group of individuals with the same need. Similarly, people with disabilities are often discussed as one homogenous group of people. However, they are of all ages and have differing abilities. Furthermore, these populations also vary in their racial, ethnic, and cultural background. This means that we must plan for and study populations factoring in that we are all not just members of one group. We need to incorporate disaster efforts that allow them to maintain their independence. Many older adults between 65 and 79 work and live independently. Not all older adults over 80 reside in nursing homes and may have informal caregivers who are their spouses of similar age or their family members. A young adult with a mobility disability will have a differing capability and need than an older adult with vision loss. For instance, in a recent study regarding the use of COVID-19 mobile applications in NY, my team found evidence that the privacy and mental health concerns surrounding the use of these apps varied by race and age, among other factors.¹⁴

We must make **investments before a disaster occurs**. We should proactively introduce legislation to increase preparedness and our individual understanding of hazards. Additionally, these investments should follow an all-hazards approach rather than an agent specific one. The issues and lessons learned across most of our major disasters are similar. After action reports tell a particular story. Communication, coordination, community engagement, and reaching vulnerable populations are among the most significant issues. This means that sponsored studies should also focus on remedying these challenges and encourage knowledge transfer between research and workforce.

Again, thank you for inviting me to be to speak before this committee, and I welcome your questions.

References

1. Red Cross. New Research: Older Adults More Vulnerable after Disasters. <https://www.redcross.org/about-us/news-and-events/news/2020/new-research-older-adults-more-vulnerable-after-disasters.html>.
2. AARP. The Impact of Disasters on Older Adults. AARP <https://www.aarp.org/livable-communities/tool-kits-resources/info-2022/disaster-risks-to-older-adults.html> (2022).
3. National Council on Disability. *The Impacts of Extreme Weather Events on People with Disabilities*. 171 https://ncd.gov/sites/default/files/NCD%20Extreme%20Weather_508.pdf (2023).
4. National Council on Aging. Get the Facts on Older Americans. @NCOAging <https://ncoa.org/article/get-the-facts-on-older-americans> (2022).
5. Taylor, P., Morin, R., Parker, K., Cohn, D. & Wang, W. Growing Old in America: Expectations vs. Reality. *Pew Research Center's Social & Demographic Trends Project* <https://www.pewresearch.org/social-trends/2009/06/29/growing-old-in-america-expectations-vs-reality/> (2009).
6. Administration on Aging. *2020 Profile of Older Americans*. 21 https://acl.gov/sites/default/files/aging%20and%20Disability%20In%20America/2020Profileolderamericans.final_.pdf (2021).
7. Birkland, T. A. *After disaster: Agenda setting, public policy, and focusing events*. (Georgetown University Press, 1997).
8. The US Federal Emergency Management Agency (FEMA). *Building Cultures of Preparedness: Report for the Emergency Management Higher Education Community*. https://training.fema.gov/hiedu/docs/latest/2019_cultures_of_preparedness_report_10.22.18%20final.pdf (2019).
9. AARP. Fewer Floridians 45+ Have a Disaster Plan in Place, AARP Survey Says. *Florida* <https://states.aarp.org/florida/fewer-floridians-45-have-a-disaster-plan-in-place-aarp-survey-says> (2022).
10. Bennett, D. State emergency plans: Assessing the inclusiveness of vulnerable populations. *International Journal of Emergency Management* **7**, 100 (2010).
11. Bennett, D. Five years later: Assessing the implementation of the four priorities of the Sendai framework for inclusion of people with disabilities. *International Journal of Disaster Risk Science* **11**, 155–166 (2020).
12. Murthy, V. *Our Epidemic of Loneliness and Isolation: The U.S. Surgeon General's Advisory on the Healing Effects of Social Connection and Community*. 82 <https://www.hhs.gov/sites/default/files/surgeon-general-social-connection-advisory.pdf> (2023).
13. Aldrich, D. P. & Meyer, M. A. Social Capital and Community Resilience. *American Behavioral Scientist* **59**, 254–269 (2015).
14. Bennett Gayle, D. M., Yuan, X. J., Dadson, Y. A. & Edwards, N. K. Contact Tracing Mobile Applications in New York: A Qualitative Study on the Use and Privacy Perceptions. *Proceedings of the 20th ISCRAM Conference* (2023).

**Annie Lloyd's Witness Testimony for United States Senate Special
Committee on Aging and Disability
"Before Disaster Strikes: Planning for Older Americans and People with Disabilities in All
Phases of Emergencies."**

June 15, 2023

Good morning, Chairman Casey, Ranking Member Braun, and Members of the Senate Special Committee on Aging. My name is Annie Lloyd, and I would like to tell you about my family and our experience with the East Palestine Train derailment.

We moved to Darlington, Pennsylvania after my husband served in Naval Special Forces as a Lieutenant with 11 years of service. His tour was chaotic, as I gave birth to both of my children during that time and we had moved twice. Darlington, Pennsylvania and Beaver County as a whole was the perfect place for us. My son Teddy, a toddler at the time, was showing signs of developmental delays, so we knew a quiet, private, and rural life would benefit him (and quite frankly, us.) We purchased a high-altitude, 6-acre property so my son can be free to be his active, rambunctious self.

He would later be diagnosed as being on the Autism Spectrum, with additional symptoms of anxiety and ADHD. Now 9-years-old, he is incredibly active, imaginative, and very funny. He can land a punchline like no one I've ever met. He is also dependent on special education services that include access to his school's Autism Resource Room, a special education teacher, a paraprofessional for his time in general education classes, speech therapy, occupational therapy, and special transportation.

Immediately after news broke that a train derailed in East Palestine, 5 miles away from our house, it became very clear to me that finding reliable information to keep our family out of harm's way would be difficult to secure. You see, I have a journalism degree and have worked at multiple media outlets throughout the country over the last 15 years. Living in a rural area, smack dab in between Youngstown, Ohio and Pittsburgh places us in a news/media barren desert. Beaver County newspapers are a shell of what they once were due to staffing cuts, so most of what they cover centers on the middle-to-southern part of the county, closer to Pittsburgh. Residents of my community often end up relying on social media "neighborhood watch groups" to try to figure out what's going on, and as you can guess, the posts and comments can be riddled with rumors and false information.

On the morning of the explosion, we received a message from Blackhawk School District that sending my kids to school was optional. I could surmise from the information I was gathering that the pressure building up in the derailed train cars was becoming increasingly concerning. At the time, I had concluded that the major concern was shrapnel from an anticipated explosion, so sending my kids to a school that was FURTHER away from the derailment than our home was the sensible thing to do.

Not long after, we got the call that our kids were being sent home from school early. Instantly I grew concerned. If officials didn't think my kids' school was safe, how was my home, even closer to the derailment, going to be safe?

I considered driving to my extended family's home in Youngstown, Ohio, but unfortunately the street our property is on was the furthest West anyone could drive. Officials blocked off all Westbound roads at my house, something I didn't realize until I saw barricades. If my street was the closest to the derailment site that anyone could get, was I now in the immediate evacuation zone? In all my panicked sifting of available information, I could not say for sure.

My son arrived home with a note from his Special Education teacher that she told him he was being sent home because a train was "stuck." She often responds to Teddy's anxiety and meltdowns with brilliance and expertise, and her precise, subtle explanation met Teddy's needs and was greatly appreciated by all of us.

My son came home totally stoked to be off school early and immediately took to running in the yard, as he often does after school to help him regulate his emotions, anxiety, and need for movement.

But today, I said, would not be a day he could get his running in.

"It's not raining, though," he said.

"I know, but we need to go inside to be safe because of the stuck train."

It wasn't long after that the black cloud erupted from the "controlled explosion." We had a clear view from our high-altitude property. The initial neighborhood sentiment of relief that we weren't hit with shrapnel quickly devolved into concern about our air, well-water and soil and the possibility of chemical contamination. Those concerns began immediately after the explosion and continue to this day. Even though we have taken all official steps to request testing of our well-water and soil, no testing has been available to us and no one has told us about the conditions of the air and soil around our property.

Senators, we desperately needed better, more reliable information. We needed clear communication from authorities with intimate knowledge of the train derailment of what the danger was and who needed to take active steps in protecting themselves. Evacuating disabled kids from their schools and hoping that they will navigate their way out of harm's way in an emergency is simply not enough. No disaster is ever truly expected, but everyone should be prepared for by our local and county emergency response authorities. And first in line in those preparations should be the needs of our most vulnerable.

At moments like these, I am reminded as my child's caretaker that I will not live forever. And that there will be a day where he will be navigating emergencies on his own. It's a perpetual feeling in the pit of my stomach, having struggled MYSELF, a non-disabled person, with figuring out what to do to stay safe during the explosion, to know that someday my son will be doing this without me.

Senators, I am asking you as a mother of a son with a disability and a friend of many disabled people, ALL of whom make unique remarkable contributions to our communities, to put forth a comprehensive accommodation plan for our disabled citizens for times of emergencies and disasters. There is nothing more fundamental to a dignified life than the capability of self-preservation. What is freedom if not an equal ability to survive?

Thank you for your time.



SUBMITTED STATEMENT OF
JONATHAN M. BYDLAK
DIRECTOR, GOVERNANCE PROGRAM
R STREET INSTITUTE

BEFORE THE
SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

HEARING ON
**BEFORE DISASTER STRIKES: PLANNING FOR OLDER AMERICANS AND PEOPLE WITH
DISABILITIES IN ALL PHASES OF EMERGENCIES**

JUNE 15, 2023

BEFORE DISASTER STRIKES: PLANNING FOR OLDER AMERICANS AND PEOPLE WITH DISABILITIES
IN ALL PHASES OF EMERGENCIES

Chairman Casey, Ranking Member Braun and members of the committee:

Thank you for holding today's hearing on "Before Disaster Strikes: Planning for Older Americans and People with Disabilities in All Phases of Emergencies," and for the opportunity to testify before you.

My name is Jonathan Bydlak, and I am the director of the Governance Program at the R Street Institute, a nonprofit, nonpartisan public policy research organization focused on limited, effective government and free markets. My professional specialty is in budget policy and identifying ways by which the federal government may operate more efficiently. Few policy areas exemplify these challenges and the urgency of solving them more than national emergencies.

As the members of this committee know, on May 11, the Biden administration allowed the COVID-19 national emergency to expire after a little more than three years.¹ The pandemic and its response imposed significant hardship on all Americans, but the experience was especially difficult for older and disabled Americans.²

As the nation begins to leave the emergency phase of the pandemic, now is the time to ensure that we are better prepared for the next emergency—whether public health or otherwise—and that no Americans are left behind.

Policymakers should approach this complex and multifaceted topic by keeping some key points in mind:

1. First, better planning helps to preserve resources and ensure more effective, targeted spending that helps those who need it most instead of furthering waste and abuse.
2. Second, there should be national attention and resources focused on true emergencies, rather than using such situations as *carte blanche* to enact favored policies or expand executive or administrative power.

¹ Sheryl Gay Stolberg and Noah Weiland, "As Covid Emergency Ends, U.S. Response Shifts to Peacetime Mode," *The New York Times*, May 10, 2023. <https://www.nytimes.com/2023/05/10/us/politics/covid-public-health-emergency.html>.

² Reginald D. Williams II et al., "The Impact of COVID-19 on Older Adults," The Commonwealth Fund, Sept. 15, 2021. <https://www.commonwealthfund.org/publications/surveys/2021/sep/impact-covid-19-older-adults>.

3. Finally, policymakers should consider a wide range of potential reforms, building on lessons from other countries and, when possible, leveraging comparative advantages of the private sector.

The Proper Understanding of an Emergency

At the core of many current issues with emergency planning is a persistent misunderstanding in how to define emergencies properly. Put simply, if everything is an emergency, then nothing is; and if resources are not directed appropriately, those most at risk will suffer when needs arise.

Emergencies are officially defined as “sudden,” “urgent,” “unforeseen” or “temporary” in nature.³ Practically, a great deal of emergency actions take place outside of this understanding or beyond initial, true emergencies. Here, it can be helpful to make a real-world comparison to help conceptualize this distinction.

In everyday life, car accidents are properly understood to be emergencies: they are sudden, unforeseen events that create a situation in need of rapid response. As a result, when a crash first happens, we recognize the importance of acting quickly, and bestow special powers in their immediate aftermath. For example, ambulances and first responders can ignore red traffic lights and exceed the speed limit on their way to treat victims and transport them to the hospital.

But the same is not true weeks later when injured parties are on their way to physical therapy. While this treatment may also be critically important and related to the initial emergency, we recognize that appropriate actions at this time are different than they may be during the initial incident. The same understanding ought to apply to national emergencies as well.

Furthermore, we should recognize that emergencies do not happen only as a result of natural events. Rather, some are manmade in nature, whether national defense emergencies or the recent derailment of Norfolk-Southern’s train in East Palestine, Ohio, and its subsequent cleanup. Recognizing the human element involved should underscore the need to identify ways to avoid these situations before they occur, as well.

The Budgetary Impact of Emergencies Is Much Larger Than Typically Understood

Since 2005, federal public health emergencies have been issued or renewed at least 132 times, ranging from the COVID-19 pandemic to hardships imposed by natural disasters.⁴ During that

³ Legal Information Institute, “2 U.S. Code § 900 - Statement of budget enforcement through sequestration; definitions,” Cornell Law School, last accessed June 7, 2023. https://www.law.cornell.edu/uscode/text/2/900#c_21.

⁴ Administration for Strategic Preparedness and Response, “Declarations of a Public Health Emergency,” U.S. Department of Health and Human Services, last accessed June 7, 2023. <https://aspr.hhs.gov/legal/PHE/Pages/default.aspx>.

time, the number of federally declared emergencies has increased dramatically. For context, the U.S. Department of Health and Human Services (HHS) reports there have been 89 declared or renewed public health emergencies since 2017, compared with just 14 from 2010-2017.⁵ Unsurprisingly, one recent analysis found that emergency spending has totaled \$3 trillion since 2000, but this estimate does not even come close to capturing the true impact of unforeseen events on the U.S. economy and the federal budget.⁶

Federal spending associated with the COVID-19 pandemic, for example, totaled more than \$5 trillion.⁷ Although much of this spending was not officially designated as being caused by the COVID-19 emergency, much—if not all—of these expenditures were unexpected prior to 2020. Likewise, national defense emergencies have had a significant impact on the federal budget. For example, an estimate from Brown University has put the total cost of the War on Terror at \$8 trillion, including costs associated with Afghanistan, Iraq and veterans' care.⁸ Policymakers, naturally, could not have expected or planned for these expenses prior to 2001.

But taken together, these events add up. Unforeseen spending on wars, natural disasters and public health crises have been regularly enacted without offsets and contributed significantly to the run-up in the public debt since the start of the century. There is a real need to begin to account for this large and growing area of federal spending, and to plan better for the future so that limited resources can be directed to those who need them most.

When emergencies arise, their impact is not felt equally. For instance, research by the Red Cross has noted that older adults are typically prone to increased psychological distress, lower levels of personal preparedness, and high levels of pre-existing medical conditions.⁹ As just one example, it is widely understood that the elderly—especially those living in nursing homes—were the most at risk during the COVID-19 pandemic, with death rates exceeding that of the general

⁵ Ibid.

⁶ Romina Boccia and Dominik Lett, "Emergency Spending Is on the Rise: Here's How Congress Can Stop It," Cato Institute, Dec. 20, 2022. <https://www.cato.org/blog/emergency-spending-rise-heres-how-congress-can-stop-it>.

⁷ Alicia Parlapiano et al., "Where \$5 Trillion in Pandemic Stimulus Money Went," *The New York Times*, March 11, 2022. <https://www.nytimes.com/interactive/2022/03/11/us/how-covid-stimulus-money-was-spent.html>.

⁸ Neta C. Crawford, "The U.S. Budgetary Costs of the Post-9/11 Wars," The Watson Institute for International and Public Affairs at Brown University, Sept. 1, 2021. https://watson.brown.edu/costsofwar/files/cow/imce/papers/2021/Costs%20of%20War_U.S.%20Budgetary%20Cost%20of%20Post-9%2011%20Wars_9.1.21.pdf.

⁹ "New Research: Older Adults More Vulnerable after Disasters," American Red Cross, February 17, 2020.

<https://www.redcross.org/about-us/news-and-events/news/2020/new-research-older-adults-more-vulnerable-after-disasters.html>.

population.¹⁰ Similarly, people with disabilities were disproportionately impacted across many metrics.¹¹ Unfortunately, helping vulnerable cohorts prepare ahead of time is often difficult.¹²

Emergency events tend to impact already vulnerable segments of the population the most, whether elderly Americans who live in flood and hurricane-prone areas, or recently, those citizens more prone to respiratory disease, or simply those more prone to social isolation.¹³ Likewise, governmental responses and their consequences will significantly impact vulnerable populations, too. The long-term results of poor planning, misguided responses and irresponsible budgeting are poised to impact those Americans who rely upon programs that are increasingly at existential risk.

The Total Costs of Emergencies Are Often Hidden and Increasingly Significant

Unchecked and unaccountable spending results in real costs to the American people, particularly those with lower income or a fixed income.

On a basic level, these decisions can result in proverbial waste, fraud and abuse. One recent exposé noted that pandemic aid to schools meant to address learning loss appears to have been mostly ineffective.¹⁴ Third-party watchdogs have documented other examples of waste, including money being used for golf courses and tourism campaigns.¹⁵ When money is misspent, the needs it was intended to address ultimately go unmet.

Not only does unaccountable spending leave urgent needs without solutions, it also creates other problems that harm those most at-risk. For instance, many economists have noted the recent relationship between generous pandemic-related spending and persistent inflation.¹⁶ As one

¹⁰ “COVID-19 Nursing Home Data,” Centers for Medicare & Medicaid Services, last accessed June 8, 2023.

<https://data.cms.gov/covid-19/covid-19-nursing-home-data>.

¹¹ “2021 Progress Report: The Impact of COVID-19 on People with Disabilities.” National Council on Disability, Oct. 29, 2021. <https://ncd.gov/progressreport/2021/2021-progress-report>

¹² “Reaching At-Risk Populations in an Emergency,” Centers for Disease Control and Prevention, last accessed June 8, 2023. <https://emergency.cdc.gov/workbook/index.asp>.

¹³ Lauren M. Webb and Christina Y. Chen, “The COVID-19 pandemic’s impact on older adults’ mental health: Contributing factors, coping strategies, and opportunities for improvement,” *International Journal of Geriatric Psychiatry* 37:1 (Nov. 15, 2021). <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8646312>.

¹⁴ Madeleine Ngo, “Schools Received Billions in Stimulus Funds. It May Not Be Doing Enough,” *The New York Times*, June 5, 2023. <https://www.nytimes.com/2023/06/05/us/politics/schools-stimulus-covid-pandemic-aid.html>.

¹⁵ Ryan Lanier, “States Wisely Increase Emergency Funds,” Citizens Against Government Waste, June 13, 2022. <https://www.cagw.org/thewastewatcher/states-wisely-increase-emergency-funds>.

¹⁶ François de Soyres et al., “Fiscal policy and excess inflation during Covid-19: a cross-country view,” Board of Governors of the Federal Reserve System, July 15, 2022. <https://www.federalreserve.gov/econres/notes/feds-notes/fiscal-policy-and-excess-inflation-during-covid-19-a-cross-country-view-20220715.html>.

recent investigative report noted, it is seniors and disabled Americans who disproportionately experience a substantial burden from this rising cost of living.¹⁷

The risks go beyond the immediate, however. With the national debt recently estimated to have exceeded \$25 trillion, there is an increasing risk that continuing to spend off-budget will jeopardize the very programs that elderly and disabled Americans rely on.¹⁸ With each additional unexpected expenditure, vulnerable populations are threatened by trust fund insolvency, crowding out of other budgetary priorities and potential benefit cuts if nothing is done.¹⁹

There Are Many Potential Reforms That Policymakers Should Pursue

One obvious way to improve emergency response is through better preparedness. Planning ahead, budgeting judiciously, and narrowing emergency response to true emergencies will allow these events to be addressed as efficiently and effectively as possible, minimizing the potential economic impact to all Americans—particularly seniors and Americans with disabilities. The following are some ideas that policymakers should consider.

Automatically Sunset Emergency Declarations to Limit Potential Abuses of Power

As recent history shows, it is easy for Congress to defer to executive power and allow emergencies to extend far beyond the initial event, and current rules encourage this situation. Changing these incentives is an important area of potential reform. The Assuring that Robust, Thorough, and Informed Congressional Leadership is Exercised Over National Emergencies Act (ARTICLE ONE Act), for example, would no longer require a resolution with supermajority support, and would instead automatically end any emergency declaration after 30 days unless Congress votes affirmatively to extend it.²⁰

As I noted in a report earlier this year, this change would allow the executive branch to respond immediately to emergencies while restoring the proper role of Congress after the initial crisis.²¹ This new power structure would place the onus on the executive branch to justify lengthy emergency declarations. Policymakers may want to consider requiring similar congressional

¹⁷ Aimee Picchi, “Inflation is slamming U.S. seniors. ‘It’s a scary time,’ one disabled widow said,” CBS News, Oct. 6, 2022, <https://www.cbsnews.com/news/social-security-2023-cola-increase-inflation>.

¹⁸ “Historical Debt Outstanding,” Treasury.gov, last accessed June 8, 2023.

¹⁹ <https://fiscaldata.treasury.gov/datasets/historical-debt-outstanding/historical-debt-outstanding>.

¹⁹ Tami Luhby, “Not touching Social Security could lead to 20% benefit cut within a decade,” CNN, March 8, 2023, <https://www.cnn.com/2023/03/08/politics/social-security-benefit-cut/index.html>.

²⁰ S. 241, ARTICLE ONE Act, (GPO, 2021), 117th Congress. <https://www.congress.gov/117/bills/s241/BILLS-117s241is.pdf>.

²¹ Jonathan Bydlak, “The Known Unknowns: Planning for the Next Emergencies,” *R Street Policy Study* No. 286, May 11, 2023, p.10. https://www.rstreet.org/wp-content/uploads/2023/05/FINAL_r-street-policy-study-no-286-1.pdf.

reauthorization under all emergency-related statutes, including the Defense Production and Stafford Acts.²²

Increase Spending Transparency to Ensure Limited Federal Funds Are Expended Effectively

Regardless of how long the response lasts, federal emergency actions should be as targeted as possible—which would help ensure that funds are spent appropriately, and that special benefits and cronyism do not undermine relief efforts. Preference should be given to temporary responses tied to the duration of the ongoing crisis, which would make it easier to ensure adequate spending transparency.

Congress should always prioritize oversight and transparency when providing aid in response to an emergency.²³ During the pandemic, for example, it could have required states to publish how they spent funds as a condition of aid, or otherwise directed states to provide such reporting directly to Congress.²⁴

Consistently tracking and evaluating aid, as well as identifying meaningful spending offsets, can minimize the long-term budgetary implications of relief while ensuring that the response is as effective as possible. As I noted during the pandemic, “the imperative to act quickly should not prevent us from guarding against unnecessary long-term costs.”²⁵

Establishing a Federal Rainy-Day Fund or Implementing Flexible Fiscal Rules Could Provide Budget Stability in Times of Unforeseen Events

There is much that federal policymakers can learn from the experience of states and other countries when it comes to emergency preparedness. One of the key reasons that states were able to respond more effectively than expected to the pandemic was the strength of their rainy-day funds.²⁶ Today, for many states, these funds are as well-stocked as they have ever been in their

²² Ibid.

²³ “Civil Society Urges the House to Prioritize Oversight over Emergency Funds,” POGO, May 13, 2020. <https://www.pogo.org/letter/2020/05/civil-society-urges-the-house-to-prioritize-oversight-over-emergency-funds>.

²⁴ Jonathan Bydlak, “Coalition Letter: federal response to state and local budget strain caused by COVID-19,” R Street Institute, July 6, 2020. <https://www.rstreet.org/outreach/coalition-letter-federal-response-to-state-and-local-budget-strain-caused-by-covid-19/>.

²⁵ Jonathan Bydlak, “Bipartisan groups lay out principles for transparency and oversight of coronavirus stimulus spending,” R Street Institute, April 6, 2020. <https://www.rstreet.org/outreach/bipartisan-groups-lay-out-principles-for-transparency-and-oversight-of-coronavirus-stimulus-spending>.

²⁶ Jared Walczak, “State Rainy Day Funds and the COVID-19 Crisis,” Tax Foundation, April 7, 2020. <https://taxfoundation.org/state-rainy-day-funds-covid-19>.

history.²⁷ The same is, of course, not true for the federal government. Creating a budget stabilization fund at the federal level could help alleviate fiscal strain in times of crisis.²⁸

When combined with other reforms, the addition of a rainy-day fund could be particularly impactful, especially as we re-enter a world where spending is subject to budget caps.²⁹ It is also important to limit the use of gimmicks and ensure that off-budget spending is constrained to what is necessary for crises, rather than used as a method of circumventing caps. This should be true both for emergency-designated spending and other supplemental spending packages. Existing institutions should be relied upon to ensure spending is managed appropriately, by utilizing agencies like the U.S. Government Accountability Office to better explore the relationship between emergency and pandemic spending, explore how best to implement a federal budget stabilization fund and so on.

More broadly, there is ample evidence from other countries demonstrating the effectiveness of well-designed fiscal rules. For example, Sweden's entitlement program guardrails have become a worldwide model, but these rules did not appear from nowhere.³⁰ In fact, much of the Swedish system is based on rules that were developed in the 1990s in response to a burgeoning entitlement crisis.³¹

Unlike its western neighbor, Sweden does not sit on substantial oil reserves and therefore did not have an obvious way to finance its pension system.³² Policymakers were forced not just to think about tradeoffs, but also to evaluate their fiscal position with rules that would encourage smarter budgeting. Their success should be a model to follow, ideally before such a crisis emerges in the United States. Fortunately, extensive evidence and multiple models of success exist should U.S. policymakers choose to seek better solutions.³³

Increase Flexible Savings to Allow Individuals to Respond Quickly to Emergencies

²⁷ "Record State Budget Reserves Buffer Against Mounting Fiscal Threats," Pew Charitable Trusts, last updated May 17, 2023, <https://www.pewtrusts.org/en/research-and-analysis/data-visualizations/2014/fiscal-50>.

²⁸ S. 718, A bill to establish the Federal Rainy Day Fund to control emergency spending, (GPO 2023), 118th Congress, <https://www.congress.gov/bills/118/congress/senate/bills/718>.

²⁹ H.R. 3746, Fiscal Responsibility Act of 2023, (GPO 2023), 118th Congress, <https://www.congress.gov/bills/118/congress/house/bills/3746>.

³⁰ "About the Swedish fiscal policy framework," Government Offices of Sweden, last accessed June 8, 2023, <https://www.government.se/government-of-sweden/ministry-of-finance/central-government-budget/the-fiscal-policy-framework>.

³¹ John Merrifield and Barry Poulson, "Swedish and Swiss Fiscal-Rule Outcomes Contain Key Lessons for the United States," *The Independent Review* 21:2 (2016), pp. 251-74, <http://www.jstor.org/stable/43999694>.

³² Johan Norberg, "How Sweden Saved Social Security," *The Wall Street Journal*, Feb. 22, 2023, <https://www.wsj.com/articles/how-sweden-saved-social-security-privatization-insolvency-market-brake-risk-contribution-biden-cf1583d3>.

³³ Ryan Bourne, "Budget Restraints That Work: Lessons from Chile, Switzerland, the United Kingdom, and the United States," Cato Institute, Feb. 21, 2018, <https://www.cato.org/tax-budget-bulletin/budget-restraints-work-lessons-chile-switzerland-united-kingdom-united-states>.

Finally, the federal government can and should incentivize individuals to take actions that will best prepare them for emergencies on a personal level. Allowing for more flexible personal savings can be a key component to responding effectively to emergencies. Existing health savings accounts (HSAs), for example, could be used for broader purposes during times when an emergency is declared, or entirely new vehicles could be created that allow people to save explicitly for emergency scenarios.³⁴

Last year's omnibus appropriations bill allowed for withdrawals from qualifying retirement plans during cases of federally declared disasters.³⁵ Some companies already have responded by creating emergency savings incentive programs for their employees.³⁶ Other longtime efforts like ABLE 2.0 have been key to ensuring savings opportunities are specifically available to Americans with disabilities.³⁷ Provisions similarly included in last year's omnibus opened up further savings opportunities for families in need.³⁸

Other potential tax changes could be helpful as well, such as waiving taxation of Social Security benefits or required IRA distributions when an emergency is declared, or allowing for penalty-free distributions for children or other family members who wish to financially help parents or grandparents dealing with a federally declared emergency.

Although it is too early to know the full impact of recent changes, the federal government would be wise to encourage private enterprise to assist with the goal of pandemic preparedness and explore opportunities to do so now instead of when the next crisis hits.

Conclusion

As the initial days of the COVID-19 pandemic draw further away, policymakers have a unique opportunity to be proactive and identify better solutions instead of continuing the status quo. Thank you again for holding today's hearing and for your consideration of these important issues. I look forward to any questions you may have.

³⁴ Bydlak, "The Known Unknowns," pp. 14-15. https://www.rstreet.org/wp-content/uploads/2023/05/FINAL_r-street-policy-study-no-286-1.pdf.

³⁵ Consolidated Appropriations Act, Pub. L. No. 117-328, (GPO, 2022), 117th Congress. <https://www.congress.gov/117/bills/hr2617/BILLS-117hr2617enr.pdf>, pp. 903-908.

³⁶ "Emergency savings program fuels employees' financial security and well-being," Delta, Jan. 23, 2023. <https://news.delta.com/emergency-savings-program-fuels-employees-financial-security-and-well-being>.

³⁷ Eli Lehrer, "Letter: ABLE 2.0 extends vital lifeline to families with special needs children," R Street Institute, May 30, 2017. <https://www.rstreet.org/commentary/letter-able-2-0-extends-vital-lifeline-to-families-with-special-needs-children>.

³⁸ Office of Senator Bob Casey, "Casey Bill to Expand Savings Accounts for People with Disabilities Passes Senate," Press Release, Dec. 22, 2022. <https://www.casey.senate.gov/news/releases/casey-bill-to-expand-savings-accounts-for-people-with-disabilities-passes-senate>.

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Mahshid Abir

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Tailoring Disaster and Public Health Emergency Preparedness, Response, and Recovery to the Needs of Older Adults and Disabled Americans

Testimony of Mahshid Abir¹
The RAND Corporation²

Before the Special Committee on Aging
United States Senate

June 15, 2023

Thank you Chairman Casey, Ranking Member Braun, and distinguished members of the committee for the opportunity today to testify on planning for older adult and disabled Americans in all phases of disasters and public health emergencies. I am a senior physician policy researcher at the RAND Corporation. In addition to being a researcher, I am a practicing emergency physician and have worked on the front line during the coronavirus disease 2019 (COVID-19) pandemic. The views I will share reflect my clinical experience in the emergency department for nearly two decades and my expertise as a health services and public health researcher with a focus on health system and community preparedness and response. This testimony will be informed by related work conducted by RAND.

I will make three points:

1. Disasters and public health emergencies disproportionately affect older adults and people with disabilities—especially those with complex medical needs.
2. There is a critical need to identify and benchmark population-specific best practices for local, state/territorial, and federal responders to ensure continuity of health and social services for older adult and disabled persons during and after disasters.

¹ The opinions and conclusions expressed in this testimony are the author's alone and should not be interpreted as representing those of the RAND Corporation or any of the sponsors of its research.

² The RAND Corporation is a research organization that develops solutions to public policy challenges to help make communities throughout the world safer and more secure, healthier and more prosperous. RAND is nonprofit, nonpartisan, and committed to the public interest. RAND's mission is enabled through its core values of quality and objectivity and its commitment to integrity and ethical behavior. RAND subjects its research publications to a robust and exacting quality-assurance process; avoids financial and other conflicts of interest through staff training, project screening, and a policy of mandatory disclosure; and pursues transparency through the open publication of research findings and recommendations, disclosure of the source of funding of published research, and policies to ensure intellectual independence. This testimony is not a research publication, but witnesses affiliated with RAND routinely draw on relevant research conducted in the organization.

3. There are many ways Congress could help address the specific needs of these populations in all phases of disasters and public health emergencies to protect their health and well-being.

Disasters and Public Health Emergencies Disproportionately Affect Older Adults and People with Disabilities—Especially Those with Complex Medical Needs

On a typical day in the emergency department, many older adults and individuals with chronic disabilities present for care. Many of these patients have multiple comorbidities and long lists of medications they take daily, and some are dependent on life-sustaining medical devices. The process of getting to the emergency department can be a massive feat for these individuals—often necessitating transfer via ambulance or dependence on family, friends, or transportation services to get there. Many will arrive with a packed bag of personal belongings anticipating potential admission to the hospital. Some will be sent from nursing homes with unclear medical problems and unable to communicate their medical complaints and health care needs.

During disasters and public health emergencies, these populations' challenges seeking health care services are compounded by the uncertainties presented by these events. Disruptions in access to food, shelter, transportation, electricity, health services and medications can put older adults and people with disabilities in an even more vulnerable position. Any *one* of these disruptions can lead to acute exacerbations of chronic illnesses and the need for acute care services in the emergency department and inpatient settings that at baseline disproportionately serve these populations. Furthermore, when older adults and people with disabilities have mental health diagnoses, such disruptions—along with the potential interruption of access to their psychiatric care or medicines—can create additional obstacles for these populations.

During the COVID-19 pandemic, fear of exposure to the virus in health care settings was another barrier to seeking care among these groups—especially since some may have been immunocompromised—resulting in delays in care or untreated (*otherwise treatable*) medical conditions that led to adverse outcomes, such as strokes and heart attacks, among other acute medical conditions, and even death. Because the abovementioned vulnerabilities are common among older adults and people with disabilities, mitigation of their needs before, during, and in the aftermath of disasters and public health emergencies requires special consideration distinct from the rest of the population. However, to date, much of disaster and public health emergency preparedness, response, and recovery has taken a one-size-fits-all approach. Best practices and policies are needed that consider the specific challenges to preparedness, response, and recovery related to older adults and people with disabilities to optimize their outcomes in emergency contexts. Given that preparedness, response, and recovery is likely most challenging in the context of older adults and people with disabilities because of the intensity of their health and social services needs, framing related policies and practices around these populations is likely to improve these processes for all Americans.

In addition to older adults and people with disabilities facing exacerbated challenges during disasters and public health emergencies, the routine challenges faced by the health systems and

social services in the United States are amplified during emergencies. For example, during periods of the COVID-19 pandemic, health care workforce shortages strained emergency department and hospital capacity, and *emergency department boarding* of hospitalized patients—where admitted patients may stay in the emergency department for days waiting for an inpatient bed—worsened. Since many older adults and people with disabilities are often in need of acute care services in the emergency department and inpatient settings, strained capacity and resultant barriers to accessing health care services can adversely affect their outcomes.

There Is a Critical Need to Identify and Benchmark Population-Specific Best Practices for Local, State/Territorial, and Federal Responders to Ensure Continuity of Health and Social Services

To optimally respond to the needs of older adults and people with disabilities when disasters and public health emergencies strike, much advance preparation is needed, including having policies and practices in place that will help both mitigate the threats posed from these events to these populations and support their recovery from such incidents once they are over.

The following steps can be taken to improve disaster preparedness for these specific populations

- Define the populations at risk and predict their specific health and social services needs under different emergency scenarios
 - A key step in preparing for addressing the needs of older adults and people with disabilities during public health emergencies and disasters is for all states, territories, and tribal governments to routinely define the size of these populations and the nature and magnitude of their health and social services needs.³ Such advance knowledge based on current data can help inform resource capacity and access planning for these populations by residence location and type of public health emergency or disaster.
- Build multi-sector, multi-stakeholder resiliency networks to support older adults and people with disabilities⁴
 - Previous RAND work has demonstrated the importance of community resilience to disaster preparedness, response, and recovery—especially for high-risk populations.⁵ Multi-sector resiliency networks can be developed in advance of disasters—including health and social services, faith-based, and community organizations—that are

³ Anita Chandra, Terry Marsh, Jaime Madrigano, Molly Simmons, Mahshid Abir, Edward W. Chan, Jamie Ryan, Nupur Nanda, Michelle D. Ziegler, and Christopher Nelson, *Health and Social Services in Puerto Rico Before and After Hurricane Maria: Predisaster Conditions, Hurricane Damage, and Themes for Recovery*, Homeland Security Operational Analysis Center operated by the RAND Corporation, RR-2603-DHS, 2020, https://www.rand.org/pubs/research_reports/RR2603.html.

⁴ Regina A. Shih, Joie D. Acosta, Emily K. Chen, Eric G. Carbone, Lea Xenakis, David M. Adamson, and Anita Chandra, “Improving Disaster Resilience Among Older Adults: Insights from Public Health Departments and Aging-in-Place Efforts,” *RAND Health Quarterly*, Vol. 8, No. 1, August 2018.

⁵ RAND Corporation, “Community Resilience,” webpage, undated, <https://www.rand.org/topics/community-resilience.html>.

educated and equipped with the needed information and resources to facilitate access to health and social services needs among older adult and disabled victims of disasters.

- Develop mechanisms for “smarter” federal funding to support the response and recovery needs of these populations⁶
 - During the COVID-19 pandemic, timely government funding was critical to ensuring continuity of medical operations in many hospitals and health care systems across the United States caring for the sickest and often older adult population. To collect the needed data to apply for federal relief funds, some facilities developed COVID-19–specific cost centers,⁷ while others developed COVID-19 care–specific time-entry codes to track and report pandemic-related care.⁸ These pandemic-related cost-tracking mechanisms helped facilitate providing the needed documentation in applications for relief funds. Implementing these and other cost-tracking strategies can be used for cost reporting both routinely and during emergency situations, which would make hospitals, health systems, and other relevant organizations more “application ready” and responsive to the needs of their patient populations.

Given finite resources, putting policies in place that facilitate the allocation of federal assistance among older adults and people with disabilities in the communities most affected by disasters and public health emergencies is critical. One way to do this is to ensure that relief funds are allocated proportional to the impact of disasters and public health emergencies on health care and social services organizations. To this end, systems may be developed to track the financial status of health and social services organizations using publicly available data. Furthermore, to ensure that relief funding across U.S. government agencies is not duplicated, interagency data-sharing and collaboration will be important. Such efforts could include the development of frequently updated systems that allow interagency data-sharing to help both the government and applicants avoid duplication of benefits. Ensuring that federal relief funds are allocated to the organizations and populations most affected by a disaster or public health emergency, and avoiding duplicate allocation of relief funds, can help decrease the likelihood of fraud and abuse while helping to direct relief funds in a fair and equitable way to individuals and communities in most need of them.

⁶ Mahshid Abir and Jessie Riposo, “There Are ‘Smarter’ Ways for U.S. to Fund Public Health Emergencies,” *Voices*, United Press International, December 20, 2022.

⁷ K. Michael Nichols, “Cost Reporting in the Time of COVID-19 Could Have an Impact on Hospital Payment,” *Healthcare Financial Management Association*, September 2, 2021.

⁸ NYC Health + Hospitals, “COVID-19 Timesheet Reimbursement Coding—Frequently Asked Questions,” ver. 1.0, April 24, 2020.

There Are Many Ways Congress Could Help Address the Specific Needs of These Populations in All Phases of Disasters and Public Health Emergencies to Protect Their Health and Well-Being

I'll conclude with several recommendations that Congress could consider to advance the health and safety of older adult and disabled Americans during disasters and public health emergencies as follows:

Require Medicaid payments to Be Made Out-of-State for Older Adults and People with Disabilities During Public Health Emergencies and Disasters

Past disasters, such as hurricanes and tornadoes, have resulted in the displacement of communities in affected areas. In many instances, such as in the aftermath of Hurricane Katrina, some affected individuals and families had to move out of state, losing access to their health care providers and insurance coverage. Inability to seek health care services and obtain needed medications due to loss of insurance coverage can have dire consequences for multiply co-morbid adults and disabled individuals. Requiring Medicaid to cover health care expenses for displaced older adults and people with disabilities is a step that could help ensure continuity of care for these populations when displaced in emergency contexts.

Extend the Medicare 20-Percent Increase for Inpatient COVID-19 Care to All Medicare-Eligible Older Adults and People with Disabilities During Future Public Health Emergencies and Disasters

During the COVID-19 public health emergency, the CARES Act provided for a 20-percent increase to the Inpatient Prospective Payment System Diagnosis Related Group rate for hospitalized COVID-19 patients. Congress could consider requiring a similar increase in Medicare payments for both emergency and inpatient care received by Medicare-eligible older adults and people with disabilities during future disasters and public health emergencies.

Require the Development of Resources and Capabilities Within Public Health Departments to Address the Needs of Older Adults and People with Disabilities

Many public health departments do not tailor any preparedness or community resilience activities to older adults, instead focusing on preparedness for those with functional limitations or those with chronic diseases, which disproportionately do include older adults but often do not fully address their needs. Many older adults live alone, and public health departments often are not aware of where these populations reside and often do not have a mechanism to communicate preparedness, response, or recovery information to older adults. Disasters not only disrupt health care but also disrupt the services that allow older adults to live alone and in their homes and communities (such as delivered meals and in-home care). Requiring the development (and providing the funding support) of resources and capabilities within public health departments to plan for addressing the public health and social services needs of older adults can be critical to more effective preparedness, response, and recovery for this population. Engaging key stakeholders and agencies that have contact with older adults, such as in-home care, dialysis

centers, nursing homes, and hospice care, could play a larger role in helping their users prepare for disasters.

Furthermore, the upcoming reauthorization of the Pandemic and All-Hazards Preparedness Act (PAHPA) offers an opportunity to modernize preparedness and response capabilities at all levels of government.⁹ Part of redefining our preparedness, response, and recovery framework is planning for worst-case scenarios that affect the most vulnerable in our communities—including older adults and people with disabilities.

Congress could also consider the following measures as part of the PAHPA reauthorization:

Conduct a National After-Action Analysis of the COVID-19 Pandemic as Part of PAHPA Reauthorization

With the end of the emergency phase of the COVID-19 pandemic, the national pandemic plan of the future can be informed by an after-action analysis of the pandemic response that is generated based on lessons learned,¹⁰ and best practices can be identified from individual after-action reports from each state, territory, and tribal government to help improve pandemic preparedness, response, and recovery for older adults and people with disabilities. This national pandemic plan would need to balance public health measures alongside other key factors, such as economic,¹¹ educational,¹² and other costs to society at large.¹³ It would also need to consider strategies for consistent and more effective public communication and education along with plans to combat misinformation.¹⁴ This after-action analysis could also include a careful consideration of knowledge, data, and technological gaps and evaluate the sufficiency (*and quality*) of collaboration among key response entities across the United States to inform future pandemic planning. For example, the need for collecting and analyzing a uniform set of outcome measures across all states—such as testing, hospitalizations, and mortality—in near real time to

⁹ Committee on Energy and Commerce, “Reps. Hudson and Eshoo Request Information in Preparation for Pandemic Bill Reauthorization,” press release, March 1, 2023; Administration for Strategic Preparedness and Response, “Pandemic and All Hazards Preparedness Act (PAHPA),” webpage, undated, <https://aspr.hhs.gov/legal/pahpa/Pages/default.aspx>.

¹⁰ Mahshid Abir, “An Opportunity to Learn from Our COVID Successes and Failures,” *Governing*, April 27, 2023.

¹¹ Raffaele Vardavas, Aaron Strong, Jennifer Bouey, Jonathan William Welburn, Pedro Nascimento de Lima, Lawrence Baker, Keren Zhu, Michelle Priest, Lynn Hu, and Jeanne S. Ringel, *The Health and Economic Impacts of Nonpharmaceutical Interventions to Address COVID-19: A Decision Support Tool for State and Local Policymakers*, RAND Corporation, TL-A173-1, 2020, <https://www.rand.org/pubs/tools/TLA173-1.html>.

¹² RAND Education and Labor, “COVID-19 Response Survey (CRS), Spring 2020,” webpage, undated, <https://www.rand.org/education-and-labor/projects/aep/surveys/items/covid-19-response-survey-crs-spring-2020.html>; RAND Education and Labor, “COVID-19 Response Survey (CRS), Fall 2020,” webpage, undated, <https://www.rand.org/education-and-labor/projects/aep/surveys/items/covid-19-response-survey-crs-fall-2020.html>.

¹³ “U.S. Gun Violence Increased 30% During COVID-19 Pandemic,” Penn State College of Medicine News, October 21, 2021.

¹⁴ Kate Cox, Theodora Ogden, Victoria Jordan, and Pauline Paillé, *COVID-19, Disinformation and Hateful Extremism*, Commission for Countering Extremism, 2021, <https://www.gov.uk/government/publications/covid-19-disinformation-and-hateful-extremism-literature-review-report>.

track the evolution of a pandemic and adjust mitigating strategies accordingly should be considered.¹⁵

Invest in Identifying Effective Strategies for Load-Balancing Among Public Health and Health Care Entities

The COVID-19 pandemic revealed the scope and scale of long-standing capacity and capabilities shortcomings in public health and health care in the United States. However, even though the pandemic affected every corner of our nation, at any given time during the declared public health emergency, there were outbreaks in some localities, while others were relatively less affected. This inconsistency in pandemic impact meant that some public health and health systems were strained for resources while others had capacity and excess resources. Evaluating policies—including incentives and disincentives—to encourage public health and health systems to collaborate and share resources during emergencies with their respective counterparts in more affected areas will be critical to ensuring the most vulnerable populations in communities across the United States—which commonly include older adults and people with disabilities—have access to needed health and social services during future public health emergencies and disasters.¹⁶

Invest in Developing a National All-Hazards Surveillance System

Early detection of emerging threats that may lead to mass casualty incidents, public health emergencies, or disasters can play an important role in prevention and timely mitigation of local, state, and national events. This will require the development of a near real-time surveillance system—similar to the Centers for Disease Control and Prevention’s Nationally Notifiable Infectious Diseases and Conditions database,¹⁷ which is updated weekly—with data input from every state across the country. Such a system could build on existing national databases, such as the National Emergency Medical Services Information System,¹⁸ to report and track incidents of gun violence, social unrest, and weather events, among other potential threats. Such a system can incorporate the identification of the proximity of communities with high proportions of high-risk individuals—including older adults and people with disabilities—to an incident to inform mitigation strategies. Furthermore, mechanisms for outreach and communication with older

¹⁵ Mahshid Abir, Megan K. Beckett, Wenjing Huang, Hamad Al Ibrahim, Joan Chang, Florian F. Schmitzberger, Kirstin W. Scott, and Peter S. Hussey, *A Comparison of National and International Approaches to COVID-19-Related Measures*, RAND Corporation, RR-A438-1, 2021, https://www.rand.org/pubs/research_reports/RR438-1.html.

¹⁶ Mahshid Abir, Christopher Nelson, Edward W. Chan, Hamad Al-Ibrahim, Christina Cutter, Karishma Patel, and Andy Bogart, *Critical Care Surge Response Strategies for the 2020 COVID-19 Outbreak in the United States*, RAND Corporation, RR-A164-1, 2020, https://www.rand.org/pubs/research_reports/RR4164-1.html.

¹⁷ Centers for Disease Control and Prevention, “Nationally Notifiable Diseases Surveillance System,” weekly tables of infectious disease data, Week 22, 2023, <https://www.cdc.gov/nndss/data-statistics/index.html>.

¹⁸ National Emergency Medical Services Information System, “What Is NEMSIS?” webpage, undated, <https://nemsis.org/what-is-nemsis/>.

adults and people with disabilities (who may be isolated or have limited means of communication) could be developed as part of this system.

Invest in Building Health Security into Broader National Security

Concurrent with the COVID-19 pandemic, the United States experienced wildfires in the west,¹⁹ hurricanes in the south,²⁰ social unrest,²¹ mass migration at its southern border, and many mass shootings²²—each event with its own public health and national security implications. These incidents indicate a need to build robust strategies for health security within broader national security.²³ In 2009, the U.S. Department of Health and Human Services released the nation’s first National Health Security Strategy “to help galvanize efforts to minimize the health consequences associated with significant health incidents.”²⁴ The 2019 Worldwide Threat Assessment of the U.S. intelligence community recognized infectious diseases and climate change as threats to national and global security.²⁵ Finally, in July 2022, the U.S. Department of Homeland Security established the Office of Health Security recognizing the importance of health security to national security.²⁶ With both climate change–related and man-made disasters on the rise,²⁷ a more whole-of-government approach may be needed to concurrently consider the public health and national security risks these incidents pose for an effective response.

Inclusion of measures in PAHPA reauthorization to facilitate building health security into national security, and to evaluate and leverage current and needed assets and capabilities in the Department of Health and Human Services, Department of Homeland Security, Department of Defense, and Food and Drug Administration, could inform synergistic efforts around developing inter-operable systems across these agencies and a comprehensive health security strategy to ensure health, safety and security in the face of future crises.

¹⁹ Harvard T.H. Chan School of Public Health, “Wildfire Smoke May Have Contributed to Thousands of Extra COVID-19 Cases and Deaths in Western U.S. in 2020,” news release, August 13, 2021.

²⁰ Michael Majchrowicz, “Hurricanes Were Active, Even During Peak COVID-19 Years,” PolitiFact, October 7, 2022.

²¹ Tim Campbell and Miha Hribernik, “A Dangerous New Era of Civil Unrest Is Dawning in the United States and Around the World,” Verisk Maplecroft, December 10, 2020.

²² Lauren Mascarenhas, “Mass Shootings in the US Increased During the Coronavirus Pandemic, Study Finds,” CNN, September 16, 2021.

²³ Mahshid Abir and Daniel M. Gerstein, “Healthy Nation, Safe Nation: Build Health Security into National Security,” *RAND Blog*, March 17, 2023, <https://www.rand.org/blog/2023/03/healthy-nation-safe-nation-build-health-security-into.html>.

²⁴ U.S. Department of Health and Human Services, *National Health Security Strategy 2009*, December 2009.

²⁵ Daniel R. Coats, “Worldwide Threat Assessment of the US Intelligence Community,” statement for the record presented to the U.S. Senate Select Committee on Intelligence, Office of the Director of National Intelligence, January 29, 2019.

²⁶ U.S. Department of Homeland Security, “DHS Establishes New Office of Health Security,” press release, July 19, 2022.

²⁷ Faizel Patel, “Natural Disasters Set to Increase by 37% Globally by 2025—Report,” *The Citizen*, March 14, 2022; “The Tragic Effects of Man Made Disasters,” *EKU Online blog*, Eastern Kentucky University, July 28, 2020.

Questions for the Record

U.S. Senate Special Committee on Aging
“Before Disaster Strikes: Planning for Older Americans and People with Disabilities in All Phases of Emergencies”
 June 15, 2023
 Questions for the Record
Dr. DeeDee Bennett Gayle

Senator Raphael Warnock

Question:

The Rosalynn Carter Institute for Caregivers, founded by First Lady Rosalynn Carter and based in Georgia, published important research in collaboration with Duke University that describes the experiences of family caregivers in finding community-based supports during natural disasters. This research is critical in capturing the diversity of needs and capabilities of older Americans and people with disabilities.

How can Congress support efforts to ensure that older Americans and people with disabilities who live within communities are included in conversations about disaster preparedness?

Response:

Senator Warnock, thank you for this question and the opportunity to provide more concrete recommendations. At its core, emergency management is “charged with creating the framework within which communities reduce vulnerability to hazards and cope with disasters.”¹ However, this only works if all community members are represented at the table when such frameworks are created. The whole community approach to emergency management was developed to engage the entire community capacity.² This approach requires emergency managers and related personnel to fully engage with the communities they serve before a disaster occurs. It is vital because the inequities or social context contributing to vulnerability in one location differ in another area, even within the United States.³ One size fits all approaches may not work.

The challenges of reaching older adults and people with disabilities before, during, and after disasters have been highlighted well in research and practitioner-led after-action reports.⁴ Similar suggestions can be found from academics and practitioners alike, including disproportionately impacted communities in the conversations around disaster preparedness. The study sponsored by the Rosalynn Carter Institute focused on caregivers acknowledges similar findings from previous literature around stress, challenges, and overall burden.⁵ I have similar recommendations as the authors, which could be enacted nationally. Congress should consider the following:

1) Prioritizing proactive legislation to support disaster preparedness and planning activities that will reduce our overall vulnerability in the face of hazards. Preparedness and planning activities would benefit from having a better understanding of the challenges and pitfalls faced

across our nation after a disaster regarding marginalized populations. Considerations should include streamline the assistance process for individuals and households following disasters,⁶ updating the application process for aid to be inclusive of the various family structures (such as informal caregivers and multigenerational households),⁵ ensuring compliance of disseminated information for accessibility (on paper, electronically, and online, etc.),^{6,7} encouraging mitigation efforts that acknowledges the needs of older adults and people with disabilities (inclusive, functional designs), incentivizing the inclusion of marginalized population in public sector disaster planning and exercises, and establishing an investigative board to reflect on lessons learned to promote resilience recommendations.

2) Funding for research addressing direct and indirect social and human behavioral impacts of disasters from all hazards (natural, human-induced, or technological) and appropriate interventions to increase resilience. For example, several interventions have been attempted, such as registries. However, the research on registries is limited and suggests significant problems in implementation among practitioners, adoption among the populations targeted, and maintenance of the registry.^{6,8} These challenges significantly reduce the efficacy of registries in any one location.

3) Encouragement and funding for local, state, and national emergency management agencies to actively engage and meaningfully include community organizations that service marginalized populations, including older adults, people with disabilities, and caregivers (formal or informal). Nearly every research study on various disproportionately impacted populations has suggested there is a significant lack of engagement and inclusion of the people most at risk during preparedness and planning for disasters.^{4,5,8}

Thank you for the opportunity to respond.

REFERENCES

1. FEMA. Principles of Emergency Management. [https://training.fema.gov/hiedu/docs/emprinciples/0907_176%20em%20principles12x18v2f%20johnson%20\(w-o%20draft\).pdf](https://training.fema.gov/hiedu/docs/emprinciples/0907_176%20em%20principles12x18v2f%20johnson%20(w-o%20draft).pdf)
2. FEMA. A Whole Community Approach to Emergency Management: Principles, Themes, and Pathways for Action. Published online December 2011. https://www.fema.gov/sites/default/files/2020-07/whole_community_dec2011__2.pdf
3. Cannon T, Twigg J, Rowell J. Social vulnerability, sustainable livelihoods and disasters. *Rep DFID Confl Humanit Assist Dep CHAD Sustain Livelihoods Support Off*. 2003;93.
4. Thomas DS, Phillips BD, Lovekamp WE, Fothergill A. *Social Vulnerability to Disasters*. CRC press; 2013.
5. Garcia-Rudolph A, Sauri J, Garcia-Molina A, et al. The impact of coronavirus disease 2019 on emotional and behavioral stress of informal family caregivers of individuals with stroke or

traumatic brain injury at chronic phase living in a Mediterranean setting. *Brain Behav.* 2022;12(1):1-13.

6. Roth M, Kailes J, Marshall M. *Getting It Wrong: An Indictment with a Blueprint for Getting It Right.*; 2018. https://disasterstrategies.org/wp-content/uploads/2018/08/5-23-18_After_Action_Report_-_May__2018.pdf

7. Bennett D, LaForce S, Touzet C, Chiodo K. American Sign Language & Emergency Alerts: The Relationship between Language, Disability, and Accessible Emergency Messaging. *Int J Mass Emergencies Disasters.* 2018;36(1).

8. National Council on Disability. *The Impacts of Extreme Weather Events on People with Disabilities.*; 2023:171. Accessed June 11, 2023. https://ncd.gov/sites/default/files/NCD%20Extreme%20Weather_508.pdf

U.S. Senate Special Committee on Aging
**“Before Disaster Strikes: Planning for Older Americans and People with Disabilities in All
 Phases of Emergencies”**
 June 15, 2023
 Questions for the Record
Ms. Annie Lloyd

Senator Raphael Warnock

Question:

Family caregivers are considered the primary and sometimes the only source of support for older Americans and people with disabilities, especially in rural communities. These caregivers provide a variety of supports for the clinical, transportation, nutritional, coordination, and other needs for the care recipient.

How can we be intentional in including these critical community members in communications and messaging during emergencies?

Response:

Thank you for your question, Senator Warnock. I think it first begins how our emergency response agencies and elected officials share information in times of emergencies. For example, during the East Palestine, OH train derailment, local officials, emergency response departments and affected town councils were sharing information that was not always consistent with each other. There were several different versions of the “evacuation” zone being shared, causing some confusion from those of us who lived nearby. While residents like my family, who were 5 miles out from the derailment, eventually became confident we were not in the evacuation zone, it was never clear that we were actually out of danger, especially with my children’s school, further away from the derailment site suddenly being evacuated without explanation.

There needs to be a systematic process of how this critical information is distributed. Local officials need to be taught about where to grab information from in a crisis. In terms of my disabled son, as he learns different life skills through us and his school, reacting to emergencies and understanding where he can get information from is a skill that should be in his curriculum. For my Autistic son to utilize and generalize that skill, it needs to be in a consistent place, like a Web site or phone number. How emergencies like this one are handled by his support team at school should be shared in full detail with caretakers and families.

Statements for the Record



Alzheimer's Association and Alzheimer's Impact Movement Statement for the Record

United States Senate Special Committee on Aging Hearing "Before Disaster Strikes: Planning for Older Americans and People with Disabilities in All Phases of Emergencies"

June 15, 2023

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the Senate Special Committee on Aging hearing "Before Disaster Strikes: Planning for Older Americans and People with Disabilities in All Phases of Emergencies." The Association and AIM thank the Committee for its continued leadership on issues important to the millions of people living with Alzheimer's and other dementia and their caregivers.

Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. Our mission is to eliminate Alzheimer's and other dementia through the advancement of research; to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. The Alzheimer's Impact Movement is the Association's advocacy affiliate, working in a strategic partnership to make Alzheimer's a national priority. Together, the Alzheimer's Association and AIM advocate for policies to fight Alzheimer's disease, including increased investment in research, improved care and support, and the development of approaches to reduce the risk of developing dementia.

An estimated 6.7 million Americans age 65 and older are living with Alzheimer's dementia in 2023. Total payments for all individuals with Alzheimer's or other dementias are estimated at \$345 billion (not including unpaid caregiving). Medicare and Medicaid are expected to cover \$222 billion – or 64 percent – while out-of-pocket spending is expected to be \$87 billion. Total payments for health care, long-term care, and hospice care for people living with dementia are projected to increase to nearly \$1 trillion in 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

When coordinating public health emergency preparedness and response activities, it is critical to take into account the unique needs of individuals living with Alzheimer's and other dementia. We encourage the Committee to consider the following recommendations to expand and better support the public health infrastructure providing care for individuals living with Alzheimer's and other dementia before, during, and after public health emergencies.

Improved Response Coordination

While there is a need for greater coordination between federal, state, and local officials, there must also be clear lines of responsibility between federal, state, and local offices during public health emergencies. Congress must clarify who is in charge and these roles and responsibilities must be clearly communicated to states and local governments so they can include this information in their own preparedness planning.

The Alzheimer's Association and AIM recommend that each state designate one specific point person on long-term care issues to liaise with the federal government in times of crisis. Oversight for separate long-term care settings falls to different federal and state agencies which can make it difficult to coordinate efficiently during a public health emergency. If states were to establish one long-term care point person in charge of communicating with the federal government during times of crises, it would lead to a more coordinated, tailored response in long-term care communities.

Improved federal and state response coordination would also help ensure sufficient stockpiling and equitable distribution chains of essential testing, personal protective equipment, and vaccines, when available. These supplies and distribution chains should also include caregivers and home- and community-based care providers.

Public Health Preparedness and Response

Public health professionals play a critical role in minimizing the negative impacts of public health emergencies. Public health officials are able to tailor the federal, state, and local response in order to address the special vulnerabilities of people living with Alzheimer's and their caregivers. During a pandemic, this not only saves lives but also protects the larger community and may reduce strain on health care systems.

The Alzheimer's Association and AIM recommend that each state public health department have an internal expert with deep knowledge of the unique needs of people living with Alzheimer's and other dementia. The lack of a senior career staff director with expertise in Alzheimer's and other dementia in many state public health departments has affected the ability of those departments to effectively tailor the COVID-19 emergency response for those with cognitive impairment.

To help ensure that local and state preparedness and response plans address the particular vulnerabilities of people living with dementia, public health agencies must elicit insights from people living with dementia, caregivers, and experts on cognitive impairment. Further, emergency responders and shelter staff benefit from specific training about the signs and symptoms of dementia and other cognitive impairments.

We also recommend that the Centers for Disease Control and Prevention ensure there is a full-time gerontologist or geriatrician within the Infectious Disease National Centers who is able to liaise on emergency preparedness and response. This will help ensure readiness in how to

respond to the unique needs of seniors and people with Alzheimer's and other dementia when a new threat arises.

Access to Telehealth

Emergencies, disasters, and crises can result in difficult care transitions — moving from one location of care to another — for people living with dementia, especially due to evacuations or hospitalizations. The Alzheimer's Association and AIM also support continued access to telehealth. As noted above, Medicare beneficiaries with Alzheimer's and other dementias are more likely than those without dementia to have other chronic conditions. While 26 percent of Medicare beneficiaries age 65 and older with Alzheimer's and other dementias have five or more chronic conditions, only 4 percent of Medicare beneficiaries without dementia have five or more chronic conditions.

Most people with dementia also develop at least one dementia-related behavior like hallucinations and aggression, and a significant percentage of these individuals have serious associated clinical implications. Improved access to virtual and telehealth services allow persons with dementia to avoid unnecessary visits or travel that could further compromise their physical health, and also provide strained caregivers help managing medical needs or behaviors in the home.

The Alzheimer's Association and AIM also supported the expansion of Medicare and Medicaid coverage for certain telehealth services in response to the COVID-19 pandemic. The Centers for Medicare & Medicaid Services (CMS) temporarily expanded coverage for numerous codes that are beneficial to people living with Alzheimer's and other dementia, and we appreciate the flexibilities CMS implemented to reduce the risk of beneficiaries' exposure to the virus and ensure regular access to quality care. We encourage CMS to evaluate the effectiveness of these temporary codes, to the extent possible, during future public health emergencies to determine whether some are appropriate for permanent telehealth eligibility.

In addition, the ability to receive care in the home decreases visits to unfamiliar places that may cause agitation in people with dementia and can ease some burden on caregivers. This increased flexibility can reduce interruptions in access to this kind of quality care. We also support and thank the Committee for its leadership in procuring CMS' permanent expansion of licensed practitioners, such as nurse practitioners and physician assistants, who can order Medicaid home health services. Twenty-seven percent of older individuals with Alzheimer's or other dementia who have Medicare also have Medicaid coverage, compared with 11 percent of individuals without dementia. We also encourage CMS to support innovative efforts to increase access to telehealth and telemedicine for Medicare beneficiaries for whom access to broadband or technology is problematic.

Addressing Down syndrome and Alzheimer's Disease

The Committee should continue to keep in mind the intersection of Alzheimer's in people living with Down syndrome when considering disaster preparedness policies for both older Americans as well as individuals with disabilities. Studies show that by age 40, the brains of almost all individuals with Down syndrome have significant levels of beta-amyloid plaques and tau tangles, abnormal protein deposits considered to be Alzheimer's hallmarks. Despite the presence of these brain changes, not everyone with Down syndrome develops Alzheimer's symptoms. According to the National Down Syndrome Society, about 30 percent of people with Down syndrome who are in their 50s have Alzheimer's dementia, and about 50 percent of people with Down syndrome in their 60s have Alzheimer's dementia. Most adults with Down syndrome will not self-report concerns about memory. Diagnosing dementia in a person with Down syndrome can be difficult because of the challenges involved in assessing thinking-skill changes in those with intellectual disabilities. By age 35, each individual's medical record should ideally include detailed information on baseline adult abilities and intellectual, behavioral, and social functions. There should be ongoing evaluations of these functions, which can better assist caregivers when preparing for emergencies.

Conclusion

The Alzheimer's Association and AIM appreciate the steadfast support of the Committee and its continued commitment to advancing issues important to the millions of older Americans and families affected by Alzheimer's and other dementia. We look forward to working with the Committee in a bipartisan way to ensure quality care for individuals living with Alzheimer's and other dementia before, during, and after public health emergencies.



June 26, 2023

The Honorable Bob Casey
Chair
Senate Special Committee on Aging
Washington, D.C. 20510

The Honorable Mike Braun
Ranking Member
Senate Special Committee on Aging
Washington, D.C. 20510

RE: June 15 “Before Disaster Strikes: Planning for Older Americans and People with Disabilities in All Phases of Emergencies” Hearing

Dear Chair Casey and Ranking Member Braun:

The Healthcare Leadership Council (HLC) thanks you for holding a hearing on, “Before Disaster Strikes: Planning for Older Americans and People with Disabilities in All Phases of Emergencies.”

HLC is a coalition of chief executives from all disciplines within American healthcare. It is the exclusive forum for the nation’s healthcare leaders to jointly develop policies, plans, and programs to achieve their vision of a 21st century healthcare system that makes affordable high-quality care accessible to all Americans. Members of HLC – hospitals, academic health centers, health plans, pharmaceutical companies, medical device manufacturers, laboratories, biotech firms, health product distributors, post-acute care providers, group purchasing organizations, home care providers, and information technology companies – advocate for measures to increase the quality and efficiency of healthcare through a patient-centered approach.

HLC took a leadership role even before the pandemic on disaster readiness, coordinating a meeting between its executive members and the Assistant Secretary for Strategic Preparedness and Response in 2019 and beginning work to develop recommendations on disaster readiness. Before this work could be completed, the pandemic began and highlighted additional disaster readiness vulnerabilities, particularly for the elderly. While social distancing was intended to protect this more susceptible population, the isolation negatively impacted their physical, mental and emotional health, as well as limited critical assistance with food and

medication.¹ HLC worked with the Duke-Margolis Health Policy Center and a broad group of organizations to develop recommendations to address these vulnerabilities, among others, and focused on three key areas: improving data and evidence generation, strengthening innovation and supply chain readiness, and innovating care delivery approaches. This initial [report](#) was released in February 2021. While many of these recommendations have been implemented through legislative or administrative action, as Congress considers reauthorization of the Pandemic and All Hazards Preparedness Act (PAHPA), we once again partnered with the Duke-Margolis Center for Health Policy and other organizations to release [updated recommendations](#) in May 2023 specific to PAHPA reauthorization. By implementing the recommendations in these two reports we will be better prepared to support all Americans, including older Americans.

HLC looks forward to working with you on steps to support disaster readiness for vulnerable communities. If you have any questions, please do not hesitate to contact Debbie Witcheby at (202) 449-3435 or dwitcheby@hlc.org.

Sincerely,



Mary R. Grealy
President

¹ Vulnerability and Fragility Expose Older Adults to the Potential Dangers of COVID-19 Pandemic (October 2020)
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8266024/>



May 3, 2023

Framework for Disaster Preparedness and Response: Updated

OVERVIEW

In February 2021, the Healthcare Leadership Council (HLC) and the Duke-Margolis Center for Health Policy published a [Framework for Private-Public Collaboration on Disaster Preparedness and Response](#). The report outlined key actions for private and public sector leaders to take in order to better prepare the U.S. for future public health emergencies. The report laid out three priority action areas:

- Improving data and evidence generation,
- Strengthening innovation and supply chain readiness, and
- Innovating care delivery approaches.

Since that time, private and public sector leaders have made some progress on those priorities. The Administration has prioritized supply chain readiness and resilience, and a series of reports in 2021 and 2022 by the [White House](#) and the [U.S. Department of Health and Human Services \(HHS\)](#) set forth concrete steps for continued progress. Private sector stakeholders, both independently and through private-public partnerships, have pioneered innovative approaches for care delivery during emergency circumstances, especially through digital modalities of care. HHS [elevated the Administration for Strategic Preparedness and Response](#) (ASPR, formerly known as the Assistant Secretary for Preparedness and Response) to an operating division of the Department, and Congress established a new, permanent [White House Office of Pandemic Preparedness and Response Policy](#).

Gaps in preparedness remain, however, as the U.S. still is not sufficiently ready for future disasters or to rapidly and effectively respond to emerging threats. Federal coordination for disaster response often lacks clarity and coordination, with no explicitly designated lead agency – particularly challenging for potential disasters that may require military and civilian response and care infrastructures to quickly integrate. Furthermore, real-time information is needed to guide disaster response – for example, using timely data on health system capacity, types of cases, and medical product inventories to inform responses, guide patient care, and direct supplies. And progress in health system resiliency is needed, with many facilities still encountering staffing

shortages and workforce burnout issues that hinder their capacity to handle the influx of patients that would accompany a future disaster.

Addressing these persistent issues will require further legislative action by Congress, policy and regulatory action from the Administration, and continued innovations by private sector stakeholders involved in disaster preparedness and response. It will also require more effective and sustained support for private-public partnerships, as health care organizations are an increasingly important part of disaster preparedness and response capabilities.

Given the need for further action and collaboration by private and public sector leaders, HLC and Duke-Margolis have updated recommendations from the 2021 report to identify the highest-priority areas for additional near-term action. This effort included two stakeholder workshops in October 2022 and February 2023, as well as expert interviews and focus group discussions. The result is a set of targeted, high-priority, broad-based recommendations to strengthen disaster response policy, with a specific focus on legislative and regulatory steps that can be achieved in 2023. Our recommendations leverage new medical and technological capabilities and insights from past emergency response efforts to enable:

- Coordinated, informed, scalable, and rapid national, state, and local responses by establishing a clear, collaborative, and coordinated leadership structure, with pre-specified divisions of responsibilities and information pipelines, for federal emergency response;
- Robust manufacturing and distribution practices, with better ability to anticipate and avoid shortages; and
- Greater health care resilience to respond to emergencies through improved rapid information-sharing capabilities to optimize deployment of health care resources and steps to enable more effective emergency care and reduce first-responder burnout.

Key recommendations are summarized in [Table 1](#).

TABLE 1 KEY RECOMMENDATIONS

Recommendations for Legislative Action	Recommendations for Regulatory and Executive Action
<ul style="list-style-type: none"> ASPR should serve as the operational lead for health-related components of disaster response to coordinate federal actions and integrate private and public health care capacity. ASPR should be granted expanded hiring and contracting authorities and sufficient funding to grow its expertise in health care delivery. ASPR should coordinate the disaster response activities of Centers for Medicare & Medicaid Services (CMS), Centers for Disease Control and Prevention (CDC), and other U.S. Department of Health and Human Services (HHS) agencies and sub-agencies. ASPR should create and maintain a two-way communications system with the private sector. Federal disaster preparedness should include pre-established mechanisms to rapidly support regional and state officials and private sector partners in areas affected by the emergency. <ul style="list-style-type: none"> Through the Regional Health Care Emergency Preparedness and Response Systems program (RHCEPRS), the federal government should provide guidance and funding to states and/or regions to support coordinated state, local and private sector response. Accountability for preparedness can occur through “stress test” exercises, key performance capabilities in Medicare Conditions of Participation (CoPs), and other mechanisms. ASPR should be granted the authority to require reporting of key information on drug and medical product supply and inventory in health-related emergencies to avoid shortages. <ul style="list-style-type: none"> Hospital Preparedness Program (HPP) health care coalitions and RHCEPRS partnership pilot sites should be used to enable collaboration with private stakeholders on expectations for reporting in public health emergencies and options for data aggregation that reduce the risks of sharing for individual health systems, while still keeping the federal and state governments informed of priority allocation needs. The Strategic National Stockpile (SNS) should be substantially and consistently funded and should engage manufacturers in longer-term committed contracts with frequent, scheduled ordering rather than occasional bulk purchases. The HPP should provide additional resources to health systems to support mental health care for their staff, and the federal government should revise policies to ensure that health care workers are encouraged to seek mental health care without punitive action. The federal government should continue to support research into workforce issues arising from health emergencies to build an evidence base for appropriate interventions. Federal and state governments should allow flexibility for all healthcare professionals to practice to the top of their licenses during public health emergencies. 	<ul style="list-style-type: none"> ASPR, Federal Emergency Management Agency (FEMA), and the U.S. Department of Defense (DoD) should work together before and during disaster response to leverage FEMA/DoD expertise in emergency command and align authorities and appropriations. ASPR should be organized to deliver “command-line” capabilities with rapid decision-making and response as the priority competency. CMS should reform existing hospital emergency preparedness CoPs to align with the enhanced private-public response capabilities proposed in this report. GAO should conduct a review of previous and ongoing work by RHCEPRS, HPP, National Disaster Medical System (NDMS), and other effective private-public partnerships to identify and scale best practices for health emergency response. CMS should serve as ASPR’s implementation entity within the federal government responsible for health care data collection in a public health emergency, which would allow for a single approach for standard data reporting for health systems. <ul style="list-style-type: none"> CMS should consider contracting a third-party entity to support data collection and real-time “heat maps” for local and regional situational awareness. ASPR and CMS should collaborate with other agencies, such as CDC’s Center for Forecasting and Outbreak Analytics, for data analysis. Relevant, de-identified, aggregate results should be shared with other federal partners, and state and local governments, and HPP coalitions or RHCEPRS sites, under existing or clarified authorities. CMS must ensure reporting is purposeful, with elements that can be extracted reliably and easily from existing hospital electronic data systems. CMS should develop a payment plan for additional provider payments for screening and counseling, “test to treat” capabilities for high-risk individuals, and timely electronic reporting for potential major public health threats (e.g., emerging infectious disease threat, radiation exposure, other hazards), in conjunction with the development of emergency data reporting and with consultation with health care providers. CMS should release a request for information to inform its proposed regulations related to how existing payment programs and its value-based payment approaches can support preparedness and how payment changes can support care innovations designed to prevent burnout and promote resiliency. CMS should develop timely processes for licensure flexibility during emergencies, such as the ability for qualified retired health care providers to support disaster response by boosting workforce capacity. CMS should work proactively with ASPR, state medical boards, and the Federation of State Medical Boards to create model waivers to allow for expanded telehealth, including across state lines, contingent on relevant performance measures. CMS should issue waivers for expanded home care services to improve access to care and reduce hospital stresses during a disaster contingent on appropriate quality safeguards. DoD should implement health emergency response training for National Guard members. ASPR should have the authority to call upon federal health care personnel to be brought in to increase the workforce during a surge.

Federal Coordination and Support for Local Response

There is general consensus among private and public sector experts on the need for a single point of contact and coordination within the federal government that is responsible for the health components of disaster response policy. Designating a lead federal agency would help establish a clear line of incident command, better delineate roles and responsibilities of federal agencies, and streamline private-public communication. The White House Office of Pandemic Preparedness and Response Policy, recently established by the [Consolidated Appropriations Act of 2023](#), will coordinate preparedness and response for future biological threats across departments, but has not yet received appropriations. Given its mission and resources, the ASPR should have its remit expanded to lead operations and serve as the point of coordination for the health components of any disaster response, not just biological threats. ASPR has a history of [partnering with key leaders](#) in private sector health care and public health as well as the capability to rapidly mobilize for emergency response.

This should include clarifying ASPR's disaster-based operational command where there are overlapping areas of responsibility among agencies. However, ASPR should continue to leverage other agencies' expertise through close collaboration to support effective public messaging, incident command structures, data sharing, and timeliness of decision-making and response. Additionally, critical to advancing preparedness and response is ensuring effective communication channels between the federal government and regional and state officials and their private sector partners before and during disaster response. ASPR should work with federal public health authorities, the Centers for Medicare and Medicaid Services (CMS), state and local public health and departments of health, and health systems to improve these channels of communication and strengthen and pressure-test regional and state abilities to quickly allocate needed supplies, coordinate emergency care, and communicate with private sector partners and the general public, among other key capabilities.

The following actionable recommendations could achieve a more organized and coordinated federal response reflecting these goals:

RECOMMENDATIONS FOR LEGISLATIVE ACTION

- ASPR should serve as the operational lead for health-related components of disaster response, including coordinating federal health agency actions, while the White House can amplify messaging and assure cross-department collaboration. ASPR should also serve as an organizing entity for seamless integration of private and public health care capacity in emergent disasters.
 - ASPR should be granted expanded hiring and contracting authorities and funding sufficient to enable the agency to grow its expertise in health care delivery in preparation for future emergencies and build connections to rapidly scale up its efforts as needed when an emergency occurs.
 - During a public health emergency, ASPR should be given clear authority to serve as lead coordinator of the disaster response activities of CMS, CDC, and other HHS agencies and sub-agencies as they become involved in broader health-related disaster response efforts.
 - ASPR should be accountable for creating and maintaining a two-way communications system with the private sector (building on its existing regional preparedness programs), to ensure that the expertise and engagement of the private sector is firmly incorporated in ASPR's work.
- Federal disaster preparedness should include an effective, pre-established mechanism to rapidly and reliably support key regional and state officials and private sector partners in each locality affected by the emergency, including area health systems, to identify critical pain points and ensure that disaster response policy works for those on the front lines.
- Through RHCEPRS, the federal government should provide accountable funding to states and/or regions to establish emergency response mechanisms that effectively coordinate state and local responses, including as appropriate governors' office or designate, departments of health, public health agencies, county and/or mayoral offices, working with regional private health care leaders.
- Accountability for preparedness can occur through "stress test" exercises for major types of health disaster response, key emergency performance capabilities in Medicare CoPs and other mechanisms as appropriate.

RECOMMENDATIONS FOR REGULATORY AND EXECUTIVE ACTION

- ASPR, FEMA, and DoD should work together more closely before and during disaster response to leverage FEMA/DoD expertise in emergency command, and authorities and appropriations must be aligned.
- ASPR should be organized and staffed to deliver “command-line” capabilities, with rapid and informed decision-making and response as the priority competency. Organizational culture should promote situational awareness, local support, and, critically, a communication team and strategy that is able to convey fast-moving guidance based on evolving information.

Avoiding Shortages and Promoting Supply Chain Resiliency

A disaster may cause an immediate spike in demand for certain medicines, and could also drastically reduce supply. As such, near real-time information on medical product inventories and supply chain capacity is needed – a clear and up-to-date understanding of potential shortages enables decisionmakers to allocate existing national inventory or surge manufacturing as needed. Data collection should be conducted as efficiently as possible to reduce burden on those asked to report it, and proprietary

data must be protected appropriately. Implementing a process that builds shared understanding of data uses and trust with health system leadership is also critical – for example, to address concerns about inventory being seized and reallocated, rather than coordinated steps to mitigate shortages and increase supply when needed. This likely requires continued collaboration, education, and tabletop exercises or other stress tests between emergencies.

The following recommendations can achieve these aims:

RECOMMENDATIONS FOR LEGISLATIVE ACTION

- ASPR should be granted the authority, with public comment and collaboration, to require reporting of some key information on drug and medical product supply and inventory in health-related emergencies. Greater transparency on these points – along with greater coordination as described in the preceding and following sections – will allow private sector entities (such as distributors, wholesalers, group purchasing organizations, and health systems) and public sector entities (such as ASPR's Strategic National Stockpile) to make more informed decisions and surge supplies to where they are needed most.
 - Existing Hospital Preparedness Program (HPP) health care coalitions and RHCEPRS partnership pilot sites should be used to enable collaboration with private stakeholders (group purchasing organizations, wholesalers, and distributors as well as hospitals and health systems) on expectations for reporting in potential public health emergencies (PHE), what conditions will trigger the start and end of such emergency reporting requirements, how the information they share will be used to provide local and national situational awareness and guide allocation of Strategic National Stockpile (SNS) supplies and federal procurement, and how proprietary information will be protected.
 - ASPR and other relevant HHS components should work with health system leaders through RHCEPRS and HPP to explore options for aggregation of data in ways that reduces the risks of sharing proprietary or confidential information for the individual health systems, while keeping government agencies informed regarding priority allocation needs. It also may be possible to have a tiered system, so as emergencies escalate more extensive data would be available.
- During emergencies, ASPR should require reporting of key information for avoiding shortages and maintaining supply such as inventory of commonly used products that may experience significant competition and supply chain constraints in major types of disasters, as well as prespecified disaster-specific supplies (e.g., PPE needed after a radiologic event, supplies and treatments required when there are widespread crushing injuries, etc.).
- The SNS should be more substantially and more consistently funded, and should engage manufacturers in longer-term committed contracts with frequent, scheduled ordering rather than occasional bulk purchases. This will ensure a fresh supply of products to the SNS and will maintain a “warm base” manufacturing capacity for certain essential medicines and supplies, allowing more rapid scale-up of production in case of a sustained surge in demand caused by an emergency.

Promoting Health System Resiliency, Improving Care Delivery, and Avoiding Burnout

Creating health system capacity responsive to an all-hazards approach for disaster preparedness is challenged by pressures to use resources efficiently and stresses on the health care workforce under nonemergent conditions. Experts agreed further policy action is necessary to develop more resilient health systems, especially policies that can strengthen care delivery pathways that mitigate overwhelming the health system during surges, but also noted eliminating the stresses of emergency surges is not realistic. To protect the workforce from burnout and reduce the stresses of emergency surges, federal and private sector efforts should focus on supporting a dynamic health system with relevant operational capabilities, such as care management for higher-risk patients, telehealth, and remote monitoring services, linked to readiness to surge, such as scalable staffing structures and cross training.

Timely and reliable sharing of key, limited data for situational awareness is also critical for the effectiveness of a comprehensive approach, with particular emphasis on guiding operational response. In times of crisis, it is critical to implement essential data-sharing without unnecessary diversion of vital resources or the creation of counterproductive administrative burdens. An effectively designed and implemented system can help optimize deployment of valuable health care resources when and where they are needed most. It would reduce, rather than exacerbate, administrative burdens – such as manual case reporting, searching for open beds, or combing sources for drugs and medical devices – that contribute to burnout and divert staff time and energy from patient care. Frontline staff and local response partners need to be well-informed and supported in their efforts through access to critical

data, but without being diverted from treating sick and injured patients to perform administrative tasks.

Such a system can be implemented by building on current standardized health care information-sharing mechanisms supported by CMS and the Office of the National Coordinator for Health Information Technology (ONC). This approach would reduce public health regulatory reporting burden while sharing only minimum necessary, anonymized information. Health care facilities would report only key information such as caseloads, staff, and bed capacity, along with disaster-specific information on patient information relevant to the response, using existing electronic data systems. Timely standardized laboratory reports of test results would inform responses to certain public health emergencies such as bioterrorism events and infectious disease outbreaks.¹ CMS or a third-party contractor would use the standardized data to produce anonymized, aggregated health care data to provide timely and accurate localized “heat maps” on the state of a disaster to those supporting response on the ground. That information would support better public health analytics and forecasting, and would enable federal, state, and local response coordinators to, for example, quickly identify where there is space to take in a new patient, or where providers or medical products are or will be most urgently needed. Clear, actionable updates and analyses from existing health care data systems are critical to optimizing the use of regional health systems’ capacity to treat those sick or injured for a variety of acute injuries related to the emergency, as well as other urgent health care needs if normal care has been disrupted.

¹ This reporting should occur through CMS and HHS regulatory authorities, with clarifications as needed, using standard procedures during public health emergencies to report relevant test results from high- and medium-complexity labs.

The following recommendations can achieve these aims:

RECOMMENDATIONS FOR LEGISLATIVE ACTION

Reduce health care workforce burnout

- The HPP should provide additional resources to hospitals and health systems to support mental health care for their staff, and, together with state medical boards, the federal government should revise policies to ensure that health care workers are encouraged to seek mental health care without facing unnecessary punitive action.
- The federal government should continue to support research into workforce issues arising from health emergencies and disasters to build an evidence base for appropriate interventions and identify opportunities to help address these issues in a more systematic way.

Workforce capacity

- Federal and state governments should allow flexibility for all health care professionals to practice to the top of their licenses during public health emergencies.

RECOMMENDATIONS FOR REGULATORY AND EXECUTIVE ACTION

Enhance health system capacity for disaster response

- CMS should reform existing hospital emergency preparedness CoPs to align with the enhanced private-public response capabilities proposed here, such as having action plans to implement a more flexible and scalable staffing structure with cross-training procedures, increase bed capacity and services to other settings, and coordinate with new and existing preparedness private-public partnerships noted above (similar to how existing CoPs require plans to coordinate with emergency officials).
- GAO should conduct a review of previous and ongoing work by RHCEPRS, HPP, National Disaster Medical System, and other effective private-public partnerships to identify best practices for health emergency response (including treatment guidelines and clinical cross-training guidance), opportunities to scale up or expand those best practices, and any significant remaining gaps in private-public response capabilities.

Support timely data sharing for local and regional awareness, to direct additional resources to where they are most needed, and help regional organizations, funded through RHCEPRS or HPP, optimize patients' care across sites

- In order to ease burden and confusion, CMS should serve as ASPR's implementation entity within the federal government responsible for critical health care data collection and sharing in a public health emergency. CMS should use its existing authorities, including HHS authorities under the PREVENT Act if needed, to enable a consistent data reporting approach through existing electronic health care data systems. Implementation should be guided by notice and comment rulemaking in collaboration with health care organizations, ONC, and public health agencies. This single approach for standard data reporting for health systems would improve the quality of reporting, and quicken the bi-directional flow of reliable information.
 - CMS should consider contracting a third-party entity to support data aggregation and production of real-time "heat maps" for local and regional situational awareness.²
 - ASPR and CMS should collaborate with other agencies, such as CDC's Center for Forecasting and Outbreak Analytics, for analysis and timely, actionable insights from the aggregated data reports to inform local responses.
 - Relevant, de-identified, aggregate results should be shared with other federal partners, and state and local governments, and HPP coalitions or RHCEPRS sites.
- To avoid unnecessary burdens on providers, CMS must ensure that reporting is purposeful, focusing on key emergency-relevant data that can be extracted reliably and easily from existing electronic data systems.

Support care delivery models that enable equitable early interventions to prevent surges from overwhelming health system capacity

- CMS should develop a payment plan for additional provider payments for screening and counseling, "test to treat" capabilities for high-risk individuals, and timely electronic reporting for potential major public health threats (e.g., emerging infectious disease threat, radiation exposure, other hazards), in conjunction with the development of emergency data reporting and with consultation from health care providers.
- CMS should release a request for information to inform its proposed regulations related to (1) how existing payment programs and its value-based payment approaches can support preparedness and (2) how payment changes can support care innovations designed to prevent and mitigate burnout and promote resiliency.
- CMS should develop timely processes for licensure flexibility during emergencies, for example through streamlined enrollment in billing, such as the ability for qualified retired health care providers to support disaster response by boosting workforce capacity.

² In conjunction with electronic reporting of deidentified data, a third-party entity could promote the use of such data for more advanced analysis. For example, the MITRE Corporation operates the Center for Aviation Safety Information Analysis and Sharing (ASIAS) initiative through a private-public partnership with the Federal Aviation Administration (FAA). The ASIAS initiative allows for confidential, anonymous reporting and analysis of potential safety incidents from airlines in order to improve safety systems and reduce the likelihood of future incidents. Alternatively, a third-party entity could facilitate analysis of deidentified data by expert groups to identify opportunities to improve threat analysis and response.

- CMS should work proactively with ASPR, state medical boards, and the Federation of State Medical Boards to create model waivers to allow for expanded telehealth, including across state lines. Waivers should be tied to data sharing and performance measures around continuity of care and, in the case of public health-related emergencies, to provide access to appropriate treatments.
- CMS should issue waivers for expanded home care services to improve access to care and reduce hospital stresses during a disaster.
 - Waivers should be contingent on adequate regional pre-disaster planning for how to prioritize home care patients based on medical need, risk levels, etc., as well as appropriate safeguards to ensure quality is not compromised.
- DoD should implement health emergency response training for National Guard members.
- ASPR should have the authority to call upon federal health care personnel to be brought in to increase the workforce during a surge.

Toward a Long-Term Vision for Coordinated Private-Public Health Emergency Response³

These legislative and regulatory actions to improve federal coordination, avoid shortages, and promote health system resiliency should be undertaken in the near term to shore up key vulnerabilities in U.S. emergency response capabilities. There is, however, more work to be done in the longer term to build a robust capacity to address both repetitive strains on health care and public health systems (such as seasonal Flu or RSV surges) and less predictable but serious emergency threats (such as radiological events or natural disasters). With concerted policy making and

sustained private-public collaboration, the United States has the opportunity to create a more robust and equitable preparedness and response strategy capable of handling the next health-related disaster or emergency. The Duke-Margolis Center and Healthcare Leadership Council stand ready to help stakeholders move these recommendations into reality and achieve that aim.

³ During our discussions many longer term recommendations were identified and we will continue our work to build out these recommendations.

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About

Duke Margolis Center for Health Policy

The mission of the Robert J. Margolis, MD, Center for Health Policy at Duke University is to improve health, health equity, and the value of health care through practical, innovative, and evidence-based policy solutions. The Duke-Margolis Center for Health Policy values academic freedom and research independence, and its policies on research independence and conflict of interest are [available here](#).

Healthcare Leadership Council

The Healthcare Leadership Council (HLC) is a coalition of chief executives from all disciplines within American healthcare, who care about a shared vision for the future. We provide the only forum of its kind, convening industry leaders to collaborate on policies, plans, and programs that will bring positive change to the healthcare system. Since HLC was founded in 1988, our purpose has been to bring together key stakeholders and decision makers from across the healthcare industry to create a healthcare system that is accessible, affordable, and patient-centered; that prizes innovation; and that delivers value to all. If you share this vision, please visit www.hlc.org to join us.



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STATEMENT FOR THE RECORD BY

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TO THE UNITED STATES SENATE SPECIAL COMMITTEE ON AGING

Hearing on

Before Disaster Strikes: Planning for Older Americans and People with Disabilities
 in all Phases of Emergencies

June 15, 2023

Chairman Casey, Ranking Member Braun, and members of the committee. Thank you for your invitation to present this statement for the record. My professional career has been committed to addressing disparities in educational, psychological, and social services provided to people with disabilities. My professional training was first as a special education teacher of students with significant disabilities. I later obtained my doctoral degree in Educational Psychology, with a focus on learning and cognition in individuals with intellectual disabilities. However, in August of 2005, just two days after beginning my sabbatical while an Associate Professor at Texas A&M University, Hurricane Katrina hit the Gulf of Mexico. Over 400,000 people evacuated from Louisiana into the state of Texas. During that first week, the U.S. Peace Corps contacted former Peace Corps Volunteers, of which I am one, to volunteer again as part of the national response to Hurricane Katrina. After consulting with my university, I reenlisted in the U.S. Peace Corps, was sent to Orlando for training with FEMA, then deployed several days later to a Disaster Recovery Center in Austin, Texas. There I assisted with the intake of disaster survivors and providing information about disaster resources, from 7 a.m. to 7 p.m., seven days a week. During that time, I encountered numerous people with disabilities and older adults who had been affected by the disaster. Although I had spent the better of 20 years in the disability field, I realized I had never considered how people with disabilities fare during disasters. Nor did I know much about research in the area. As I came to discover, this was because published research on disaster and disabilities was almost nonexistent in 2005. Once I returned to my position at the university, I remained deeply curious about how people with disabilities experienced disasters. Shortly after, I was awarded a grant to study disaster

case management services provided to Katrina survivors and, subsequently, changed my research trajectory to focus exclusively on the experiences of people with disabilities in the context of disability. My statement here thus primarily report on projects conducted by my colleagues and myself over the last 18 years at Project REDD: Research and Education on Disaster and Disability redd.tamu.edu at the Center on Disability and Development at Texas A&M University, as these findings are pertinent to your rationale for the proposed REAADI for Disasters Act.

Our reviews of the research literature confirm that people with disabilities are disproportionately affected by disasters.¹⁻³ Studies have found that people with disabilities, as well as older adults, have been found to die at higher rates when compared to the general population during disasters. Households of people with disabilities are often less likely to evacuate in advance of disasters and also often experience disproportionate property damage.

Much of the work we have done through Project REDD has examined disaster case management during the recovery phase of disaster.⁴⁻⁶ Together with colleagues at the National Disability Rights Network, we have interviewed both individuals with disabilities receiving case management and case managers themselves. Findings reveal that people with disabilities and older adults tend to have a higher number of support needs post-disaster, a longer time to recover, and require a higher level of disability-related expertise from their case managers. Such findings support REAADI's emphasis upon disability-related expertise as an important component in effective disaster service delivery.

Another area in which we have investigated is the impact of disasters on children.⁷⁻¹² Our studies have been based on children's experience during Hurricane Ike, the California wildfires, as well across various historical disasters that included tornados, floods, and landslides. Findings from these studies point to the particular struggles children with disabilities experience in evacuating during and recovering after disaster. Children with disabilities, as do other children, spend many of their waking hours in schools, however school emergency procedures often fail to include students with disabilities during evacuation or sheltering-in-place drills. In addition, findings pinpointed the essential role that special educators serve not only during, but following disasters, in supporting children with disabilities and their families—particularly with respect to finding disaster-related services and transitioning to new communities and schools. Our research also pointed out that teachers take considerable risks, sometimes fatal risks, in attempting to protect their students during disasters. These findings support REAADI's assertion that maintenance of and access to services and supports, as well as universal design of public building spaces, are essential for people with disabilities.

We have also examined disaster policy, including U.S. emergency preparedness policy, the international Sendai Framework for disaster risk reduction, and the United Nations Convention on the Rights of Persons with Disabilities.^{2, 13-14} Our analyses found that while disability-inclusive language and intentions have been increasingly incorporated into policies at the state, federal, and international levels, emergency procedures in civil society often does not fully include people with disabilities. The proposed REAADI Act asserts the importance of compliance with disability laws in the context of disaster.

We have also engaged in considerable amounts of translational research-to-practice outreach, training emergency managers, community members, and voluntary organizations active in disaster.¹⁵⁻²⁰ Within

each of these groups we found limited knowledge, training, and experience of how best to serve people with disabilities in disaster, including in public shelters. In addition, we have tracked how resources and services are delivered post-disaster, finding that services for people with disabilities are limited and often do not include resources, for example, durable medical equipment, which is often lost during disasters. At the same time, we find organizations hungry for the tools and knowledge that will make them better prepared to serve people with disabilities when the next disaster occurs. The REAADI Act aims to improve coordination among communities of individuals with disabilities and emergency management agencies, VOADS, and other related organizations.

To conclude, research clearly reveals that people with disabilities and older adults will be populations impacted disproportionately during and following disasters. The needs of these groups thus should be addressed proactively and appropriately design procedures and supports that can prevent such imbalances. Legislation such as the REAADI for Disasters Act will ultimately benefit all Americans as, when the disaster vulnerabilities of one segment of the population are addressed, the disaster resilience of the nation overall will be increased.

References

- ¹Stough, L. M., & Kelman, I. (2018). People with disabilities and disasters. In H. Rodriguez, J. Trainor, & W. Donner (Eds.), *Handbook of disaster research* (2nd ed., pp. 225-242). Springer.
https://dx.doi.org/10.1007/978-3-319-63254-4_12
- ²Kelman, I., & Stough, L. M. (Eds.). (2015). *Disability and disaster: Exchanges and explorations*. Palgrave/MacMillan Press. <https://link.springer.com/book/10.1057/9781137486004>
- ³Phillips, B. K., & Stough, L. M. (2016). Populations with functional or access needs. In K. Koenig, & C. Schultz, (Eds.), *Disaster medicine: Comprehensive principles and practices* (2nd ed., pp. 137-162). Cambridge University Press. <https://dx.doi.org/10.1017/CBO9781139629317.013>
- ⁴Stough, L. M., Sharp, A. N., Resch, J. A., Decker, C., & Wilker, N. (2016). Barriers to the long term recovery of individuals with disabilities following a disaster. *Disasters*, 40(3), 387-410. <https://doi.org/10.1111/disa.12161>
- ⁵Stough, L. M. (2011). Disaster case management: Disaster case management and individuals with disabilities following Hurricane Katrina. *Brain Injury Professional*, 6(4), 18-19. <https://oaktrust.library.tamu.edu/>
- ⁶Stough, L. M., Sharp, A. N., Decker, C., & Wilker, N. (2010). Disaster case management and individuals with disabilities. *Rehabilitation Psychology*, 55(3), 211-220. <https://doi.org/10.1037/a0020079>
- ⁷Peck, L., & Stough, L. M. (2010). Children with disabilities in the context of disaster: A social vulnerability perspective. *Child Development*, 81(4), 1260-1270. <https://doi.org/10.1111/j.1467-8624.2010.01466.x>
- ⁸McAdams Ducey, E., & Stough, L. M. (2011). Exploring the support role of special education teachers after Hurricane Ike: Children with significant disabilities. *Journal of Family Issues*, 32(10), 1325-1345.
<https://doi.org/10.1177/0192513X11412494>
- ⁹Stough, L. M., Ducey, E. M., & Kang, D. (2017). Addressing the needs of children with disabilities experiencing disaster or terrorism. *Current Psychiatry Reports*, 19(24), 1-10. [10.1007/s11920-017-0776-8](https://doi.org/10.1007/s11920-017-0776-8)
- ¹⁰Stough, L. M., Ducey, E. M., Kang, D., & Lee, S. (2020). Disasters, schools, and children: Disability at the intersection. *International Journal of Disaster Risk Reduction*, 45, 1-10. Article 101447.
<https://doi.org/10.1016/j.ijdrr.2019.101447>
- ¹¹Ducey, E. M., & Stough, L. M. (2021). Educational experiences of children and youth with disabilities impacted by wildfires. *Disaster Prevention and Management*, 30(3), 279-292. <https://doi.org/10.1108/DPM-10-2020-0310>
- ¹²Ducey, E. M., & Stough, L. M. (2021). Psychological effects of the 2017 California wildfires on children and youth with disabilities. *Research in Developmental Disabilities*, 114, Article 103981.
<https://doi.org/10.1016/j.ridd.2021.103981>
- ¹³Stough, L. M., & Kang, D. (2015). The Sendai Framework for disaster risk reduction and persons with disabilities. *International Journal of Disaster Risk Science*, 6(2), 140-149. <https://doi.org/10.1177/0261429416640332>

- ¹⁴Stough, L. M. (2015). World Report on Disability, intellectual disabilities, and disaster preparedness: Costa Rica as a case example. *Journal of Policy and Practice in Intellectual Disabilities*, 12(2), 138-146.
<https://doi.org/10.1111/jppi.12116>
- ¹⁵Montague, M. L., Sweet, K. S., Stough, L. M., Sharp, A. N., & Miracle, I. (2022). Designing and developing a disaster resource directory: A case example. *Journal of Emergency Management*, 20(1), 77-87.
<https://oaktrust.library.tamu.edu/handle/1969.1/196026>
- ¹⁶Stough, L. M., Sowers, M., & Tichá, R. (2021). The inequities of crisis. *Impact: Feature issue on crisis management for people with intellectual, developmental, and other disabilities*. 2-3.
<https://publications.ici.umn.edu/impact/34-1/cover>
- ¹⁷Stough, L. M. (2017, September). What comes after Hurricane Harvey for people with disabilities? Restoring, recovering, and rebuilding. *Research Counts*. Boulder, CO: Natural Hazards Center.
<https://hazards.colorado.edu/news/research-counts/what-comes-after-hurricane-harvey-for-people-with-disabilities-restoring-recovering-and-rebuilding>
- ¹⁸Stough, L. M. (2019, September). *Disability and disaster long-term recovery training in inclusion and support of individuals with disabilities*. Final report submitted to the American Red Cross.
- ¹⁹Stough, L. M. (2019, March). *Individuals with disabilities: Disaster recovery resources and training*. Final report submitted to Rebuild Texas and the Center for Disaster Philanthropy.
- ²⁰Stough, L. M. (2018, September). *Resources for Disaster and Disability (REDDy) Directory for individuals with disabilities and their families experiencing the effects of Hurricane Harvey*. Final report submitted to the Administration on Intellectual and Developmental Disabilities, Administration for Community Living.



U.S. Senate Special Committee on Aging
G16 Dirksen Senate Office Building
Washington, D.C. 20510

June 14, 2023

Dear Chairman Casey, Ranking Member Braun, and the members of the Special Committee on Aging,

Events of the past few years have made it all too clear that when public health emergencies, extreme weather events or other disasters arise, the heightened health risks and disruptions to basic physical and social infrastructure they bring pose particularly acute danger to older adults and people with disabilities. The National Partnership for Women & Families applauds the Committee for holding a hearing on this important topic, and urges the Committee to examine how the United States' lack of robust, national paid sick days or paid family and medical leave policies leaves older adults, disabled people and their caregivers less prepared to respond to emergencies.

The National Partnership is a nonprofit, nonpartisan advocacy organization based in Washington, D.C. We promote fairness in the workplace, reproductive health and rights, access to quality, affordable health care, and policies that help all people, especially women, meet the dual demands of work and family. Over the last five decades, we have focused specifically on tackling gender-based barriers, often rooted in longstanding stereotypes and biases, used to limit the opportunities available to women, men, gender minorities, and all those deemed to be out of step with assumptions about so-called proper gender norms or roles. We believe that it is essential to prioritize equity – in health care and health care systems, in our economy, in our workplaces – to create environments fully capable of responding to the diverse needs of patients, workers, and indeed all people regardless of their background or resources. Our goal is to create a society that is free, fair and just, where nobody has to experience discrimination, all workplaces are family friendly, and every family has access to quality, affordable health care and real economic security.

No working caregiver should have to choose between their job or paycheck and helping an aging parent evacuate from an encroaching wildfire or an immunocompromised loved one stay safe at home as a novel virus spreads. During the COVID-19 pandemic especially, those living in institutions have been at greater risk of infection and death: in 2020, nursing home and assisted living facilities made up 38 percent of COVID-19 fatalities.¹ And disabled workers – who are a growing part of the workforce² and who are more likely than average to be caregivers themselves³ – should not have to make impossible choices between their health and their jobs when emergencies occur.

Yet currently, nearly one-quarter of workers do not have paid sick days for urgent health and public safety needs, and three-quarters do not have paid family leave for extended serious family caregiving needs.⁴ Access is even lower among workers in part-time and low-paid jobs, which are disproportionately held by workers with disabilities, women, and workers of color.⁵ These workers have the fewest financial resources to fall back on in an emergency⁶ and can ill-afford to take unpaid time off work – or risk losing a job – to follow a quarantine or hurricane evacuation order.

In the attached brief, *Learning Our Lesson: COVID-19 Emergency Paid Sick and Family Leave Showed the Value of a Robust, Permanent Paid Leave Policy*, we analyze the policy design and impact on workers, public health and businesses of our nation's first-ever emergency paid sick days and paid family leave program, enacted as part of the Families First Coronavirus Response Act. We find that the emergency paid sick days and paid family leave program protected public health and enabled eligible workers to better manage their work and caregiving needs in the first year of the COVID-19 pandemic. But limits on eligibility blunted its potential reach, and the lack of a permanent paid leave program infrastructure to layer emergency benefits on top of led to challenges for employers, especially small businesses.

A national paid sick days policy, as proposed by the Healthy Families Act (S. 1664), would ensure all workers – including older adults, disabled workers, and working caregivers – can earn and use paid sick days outside of a public health emergency, and set a clear standard and provide predictability for employers. Similar laws are working well in 14 states (including the District of Columbia) and 22 other jurisdictions nationwide, many of which include provisions for use in public health and/or inclement weather emergencies.⁷ A national paid family and medical leave program, as proposed by the FAMILY Act (S. 1714), would ensure all workers can take leave with pay to address their own serious health conditions and family caregiving needs. Together, these policies would provide a clear and workable policy framework to layer on a permanent paid sick days policy, as proposed by the Public Health Emergency Response Act (H.R. 4009) that immediately goes into effect when a public health emergency is declared.

Thank you,

Sharita Gruberg
Vice President for Economic Justice
National Partnership for Women & Families

1 Girvan, G. (2020, May 7). *Nursing Homes & Assisted Living Facilities Account for 38% of COVID-19 Deaths*. Retrieved 13 June, 2023, from FROPP website: <https://freopp.org/the-covid-19-nursing-home-crisis-by-the-numbers-3a47433c3770>

2 Ditekowsky, M. (2023, February 23). *New Data on Disability Employment: Small Gains But Institutional Barriers Remain*. Retrieved 13 June 2023, from National Partnership for Women & Families website: <https://nationalpartnership.org/new-data-on-disability-employment-small-gains-but-institutional-barriers-remain/>

3 Boesch, D., & Cokley, R. (2020, October 27). *The Disability Community Needs Paid Family and Medical Leave*. Retrieved 13 June 2023, from Center for American Progress website: <https://www.americanprogress.org/article/disability-community-needs-paid-family-medical-leave/>

4 National Partnership for Women & Families. (2023, May). *The Healthy Families Act*. Retrieved 13 June 2023, from <https://nationalpartnership.org/wp-content/uploads/2023/02/the-healthy-families-act-fact-sheet.pdf>; National Partnership for Women & Families. (2023, May). *The Family And Medical Insurance Leave (FAMILY) Act*. Retrieved 13 June 2023, from <https://nationalpartnership.org/wp-content/uploads/2023/02/family-act-fact-sheet.pdf>

5 Mason, J., & Gallagher Robbins, K. (2023, March). *Women's Work is Undervalued, and It's Costing Us Billions*. Retrieved 13 June 2023, from National Partnership for Women & Families website: <https://nationalpartnership.org/wp-content/uploads/2023/04/womens-work-is-undervalued.pdf>

-
- 6 Mason, J., & Molina Acosta, P., (2021, March). *Called to Care: A Racially Just Recovery Demands Paid Family and Medical Leave*. Retrieved 13 June 2023, from National Partnership for Women & Families website: <https://nationalpartnership.org/report/called-to-care-a-racially-just-demands-paid-family-and-medical-leave/>
- 7 National Partnership for Women & Families. (2022, November). *Paid Sick Days Statutes*. Retrieved 13 June 2023, from <https://nationalpartnership.org/wp-content/uploads/2023/02/paid-sick-days-statutes.pdf>



Learning Our Lesson: COVID-19 Emergency Paid Sick and Family Leave Showed the Value of a Robust, Permanent Paid Leave Policy

By Jessica Mason

JUNE 2023

The end of the federal public health emergency for the COVID-19 pandemic on May 11, 2023 closes out an unprecedented period of innovation and action to advance public health and economic security in the United States – including the nation's first-ever national paid sick days and paid family leave policies. The experiments of the past three years offer policymakers a unique opportunity to learn from what worked so that we can be ready for the future, from the everyday demands of work, health and caregiving to the unpredictable needs of the next pandemic.

Lack of universal access to paid sick days for short-term illness increased the risk that COVID-19 would spread in workplaces. Lack of paid family and medical leave for serious, longer-term illness and family caregiving needs meant that widespread illness and school and child care closures would disrupt employment as well as economic security for millions. And without national policies in place, employers who wanted to support sick and caregiving employees would face administrative challenges and potentially high costs. Responding to this clear and urgent need, lawmakers created the United States' first-ever federal program for emergency paid sick days and paid family leave as part of the Families First Coronavirus Response Act (FFCRA), amended by the Coronavirus Aid, Relief, and Economic Security (CARES) Act.¹ This program was in effect from April 1, 2020 to September 30, 2021, with the employer mandate to provide leave expiring after December 31, 2020, and tax credits for voluntary coverage continuing into 2021.²

This brief reviews the research and evidence about workers' and employers' need for and use of emergency sick and family leave, implementation and enforcement, and the costs and benefits of the program. It also shares qualitative findings from 20 interviews with workers who met FFCRA eligibility criteria, to better understand experiences of workers who had expanded access to paid leave and those who had unmet needs for leave in 2020.

Summary of Findings

Because the United States did not have any national earned sick time guarantee or paid leave policy prior to the pandemic, policymakers had to choose an approach based on what could be implemented quickly, rather than what would work the most smoothly (in terms of ease of program use) or effectively (in terms of having the largest impact) for all stakeholders. That constraint led to a program design that worked relatively well for workers and public health in the short term, but would need significant improvements and changes to meet employers' and workers' long-term needs.

The emergency paid sick and family leave program was effective at protecting public health, initially reducing the spread of the coronavirus by an estimated 15,000 cases per day in states that had previously not had paid sick leave laws.³ This benefit would have been even greater if the program had not severely restricted eligibility – less than half of workers were covered – and a more substantial public education campaign had ensured workers and employers knew about the program.

For eligible workers, the program not only provided paid sick days and family leave to some workers who had not previously had access, but also supported workers' health needs as the pandemic extended through 2020, including by supplementing existing leave banks at a time of unprecedented need. By June of that year, an estimated one million eligible workers per month were still able to take paid sick days and family leave (primarily for illness or quarantine) thanks to the emergency program.⁴ Workers' economic security also benefited from the wage replacement and from the ability to keep their jobs, and workers who took leave reported greater peace of mind. But their use of paid family leave for child care purposes was limited, perhaps due to low wage replacement and little awareness.

“Taking a paid leave was for my family, thank God I was there for them.”

— “Amina”

In the absence of a pre-existing earned sick time mandate to clarify employer obligations or a federal paid leave agency to administer a universal paid leave program, employers were tasked with implementing these new laws on their own. Less than 7 percent of employers claimed the tax credit that was offered to them to offset the cost of providing leave, and uptake was especially low among small employers.⁵

In addition, even though tax credits continued to be available for employers who opted to provide emergency leave after the mandatory program ended, there is no evidence that tax credits without a mandate incentivized employers to maintain or increase paid

leave on a permanent basis. However, evidence from both workers and employers in states with already-existing paid leave programs – which manage applications for leave and payment of benefits – indicates that such programs worked well.

In conclusion, emergency paid sick days and paid family leave provided significant benefits to public health and workers, despite confusing and restrictive eligibility criteria and poor outreach and education. In the future, emergency paid sick days laws would be most effective if they are inclusive of all working people and layered on top of an existing permanent paid sick days policy and a publicly-administered paid family and medical leave program. These permanent policies would set a baseline to ensure that the United States is prepared for a crisis while meeting the everyday needs of workers and their families as well as small businesses.

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Emergency Leave Provisions of the Families First Coronavirus Response Act

The Need for Emergency Paid Sick and Family Leave

As of March 2020, one in four private sector workers – an estimated 30 million workers – did not have access to paid sick days at their job,⁶ posing a risk to public health: workplace contacts are a common vector of transmission for infectious disease, including for the novel coronavirus,⁷ and the United States' lack of adequate sick leave had previously been shown to worsen the spread of flu-like illness.⁸ Six in ten civilian workers did not have short-term disability insurance for longer-term illness. Nearly eight in ten civilian workers did not have paid family leave through their employer.⁹ Yet in more than 70 percent of households with children under 18 – some 48 million households – all parents were in the labor force,¹⁰ meaning that widespread school and child care closures had serious impacts on employment.

The absence of basic health and caregiving protections was, and three years later continues to be, especially concentrated among workers of color, with nearly half of Latinx workers and more than one-third of Black workers reporting no paid time away from work of any kind.¹¹ Workers with less than a high school education and those

without health insurance are also less likely to have paid sick leave.¹² Occupational exposure has been a driving factor in the heightened rates of coronavirus infections and death from COVID-19 in communities of color.¹³ Black, Latinx, Native, Asian and Pacific Islander people make up disproportionate shares of workers in essential jobs such as essential retail, transportation, building cleaning and maintenance, child care and health care support (including in long-term care and home health care).¹⁴

Emergency Sick and Family Leave

FFCRA (amended by the CARES Act) established a right for covered and eligible workers to take to up to 10 days of paid sick leave for their own pandemic-related illness or quarantine, for care for an ill or quarantined individual, or for child care due to school or child care closure, and up to 10 additional weeks of paid family leave for child care due to school or child care closure. The law covered state and local government agencies, most federal agencies and private sector employers with fewer than 500 employees. Workers taking paid family leave for child care were eligible for job protection rights under the Family and Medical Leave Act, which was amended by FFCRA. For workers taking paid sick leave, FFCRA included provisions for anti-retaliation, job protection and that workers could not be required to use up existing leave banks or find a shift replacement as a condition of taking leave.

All employees of covered employers were potentially eligible for 10 paid sick days, and those who had been employed for at least 30 days for 10 weeks of paid family leave.¹⁵ However, employers were permitted to exempt employees who were deemed to be health care providers or first responders from all forms of leave. Moreover, employers with fewer than 50 employees could exempt themselves from providing child care leave if it would jeopardize their viability.¹⁶ Additionally, in order to qualify for any form of emergency paid leave, a worker's worksite had to be open, and the worker had to be unable to telework, as well as have a qualifying reason for leave related to illness, quarantine or family care.¹⁷

Notably, an eligible worker could use emergency paid sick leave to care for any immediate family member, someone who regularly resided in their home, or someone whose relationship to the worker created an expectation of or dependence on the worker's care.¹⁸ This definition of family member was broader than that in the Family and Medical Leave Act, which limits "family" for the purposes of leave to only a worker's parent, spouse, minor son or daughter, or disabled adult son or daughter who is incapable of self-care.¹⁹

Leave was required to be paid directly by the employer. Sick leave for the worker's own health needs was paid at 100 percent of the worker's usual wages, up to a cap of \$511 per day (2020 dollars). Paid sick leave for the other purposes and paid family leave were paid at two-thirds of usual wages, up to a cap of \$200 per day. Private sector employers

were eligible for immediately refundable tax credits worth 100 percent of qualified wages, plus qualified health care plan expense and Medicare tax attributable to those wages paid for any form of emergency leave.²⁰

These provisions went into effect on April 1, 2020; the employer mandate sunset on December 31, 2020; and the tax credits sunset on September 30, 2021 after being expanded on April 1, 2021.

Extent of Coverage

As of March 2020, there were approximately 5.2 million private sector employers with fewer than 500 employees,²¹ as well as local, state and federal government employers, which would have been covered by the law. Due to a lack of data collection about employers' use of exemptions, as well as the Department of Labor's broad interpretation of exemptions in the statute,²² it is difficult to determine the precise number of workers covered. An estimated 22.2 to 60.6 million private sector workers²³ and 22 million public sector workers²⁴ should have been eligible for emergency paid sick and family leave.

"I know it was so bad, but I couldn't get time. I couldn't get any time to properly rest and recover. [...] Within the hospital I saw my residents who were employed still not take their sick days off, which is absolutely horrifying and deplorable because they look after people who could die because they contact illnesses.

— "Katie," an Asian American woman in her 20s who was a public health student working at a hospital in 2020

Approximately 68 million private sector workers were excluded from coverage because they were employed by large employers. An estimated nine million workers were subject to potential exemption from sick days or family leave by their employers as health care providers or first responders,²⁵ and up to 33.6 million employed by small employers could have been exempted from the paid family leave provision.²⁶

Particularly concerning in the context of a public health emergency in which health workers were especially vulnerable to exposure and illness, an estimated one in four workers in the health care sector were potentially excluded from eligibility.²⁷ By one estimate, just 30 percent of workers were likely eligible.²⁸

Emergency Leave's Impact as a Pandemic Response

In the context of a pandemic, the primary measure of success for an emergency policy is whether it helped protect public health, such as by limiting the spread of illness and/or by improving health outcomes of ill people. In addition, a successful pandemic policy might mitigate secondary effects of the pandemic, including mitigating negative economic impacts on workers and employers. The evidence is clear that emergency paid

sick and family leave achieved some success on both primary and secondary measures, despite its flaws.

Reduced COVID-19 Infections and Increased Leave-Taking

First and foremost, emergency paid sick leave did cut the number of coronavirus infections shortly after implementation, reducing spread by an estimated 400 cases per day in states where workers newly gained access to paid sick leave after the law went into effect, or approximately 15,000 cases per day nationally.²⁹ This finding reinforces a large body of research showing that paid sick leave reduces the spread of infectious disease, including flu-like illnesses.³⁰

Other research also indicates that emergency leave achieved this reduction in illness by enabling more workers to stay home while ill or quarantined. Analysis of Current Population Survey data suggests that workers primarily used emergency sick leave (not leave for child care).³¹ Men and women used emergency leave about equally, as did workers with and without minor children.³² Leave-taking patterns suggest that the additional bank of leave provided by FFCRA enabled eligible workers to better manage their leave-taking throughout a year that brought elevated health and caregiving demands, while workers who weren't covered exhausted their available leave early in the year. By June 2020, workers overall were 51 percent less likely to be on a paid leave than in previous years – but the workers most likely to be eligible for FFCRA leave were about 68 percent more likely to be on a paid leave in June 2020 compared to pre-pandemic baseline rates.³³ (Note that this increase is only large in relative terms: just 1.31 percent of employees were out on a paid leave in a given week in June 2020, compared to 0.89 percent previously.)³⁴ As of June 2020, an estimated one million workers per month took paid leave thanks to the FFCRA program.³⁵

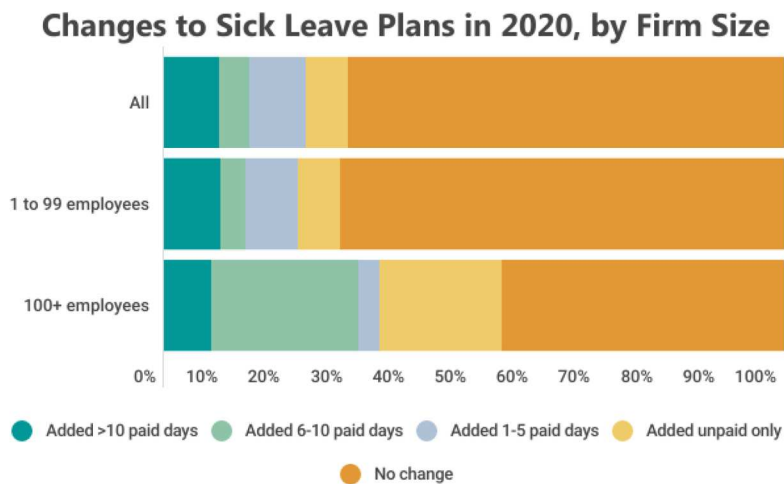
Limited, Temporary Expansion of Employer Leave Policies

Available evidence suggests that FFCRA did cause some employers to increase their paid sick leave benefits, whether to comply with the law (for employers under 500 employees) or because the law created some form of indirect pressure such as market competition over benefits or norm-setting (for larger non-covered employers). However, further research would be needed to confirm that it was FFCRA that caused these policy changes, rather than pressure from workers or the public, new state and local laws mandating leave, or other factors. Importantly, even though the tax credits continued to be available throughout 2020 and 2021 for employers who voluntarily provided paid sick and family leave, most of the increases in leave access seem to have been temporary.

As of March 2020, 25 percent of private sector workers had no paid sick leave, and among the other 75 percent, the median number of days available was just six³⁶ – far

short of the two weeks recommended for quarantine or recovery from even a mild case of COVID-19. The Bureau of Labor Statistics found that between March and May 2020, 25 percent of establishments made changes to their sick leave plans (see Chart 1). About 9 percent of establishments overall added more than ten paid sick days, exceeding FFCRA's requirement. Another 5 percent (4.1 percent of smaller employers and 27.5 percent of larger employers) added between six and ten days, potentially meeting FFCRA's standard.³⁷ However, the majority of employers reported not adding any additional paid sick leave.

Chart 1. Share of establishments reporting changes to paid and unpaid sick leave and number of paid sick days added.



Most employers that expanded sick leave benefits – 90 percent – reported that these changes would be temporary.³⁸ In fact, by March 2021, the National Compensation Survey found that 77 percent of private-sector workers had paid sick leave, up only two points from the previous year, and this increase was not concentrated among smaller employers.³⁹

These limited expansions may also have left behind some of the workers least likely to have had paid sick and family leave previously. A large-scale study of workers at large

service-sector employers, such as Walmart, Kroger and McDonald's, found that only 17 percent reported any increase in access to paid time off, and these increases were concentrated at firms that had already offered some paid sick leave. Women of color were least likely to report gaining access to paid time off (13 percent, compared to 14 percent of white women, 18 percent of men of color and 21 percent of white men).⁴⁰

Workers' Leave Experiences

Unfortunately, workers' leave claims under the FFCRA leave program could not be directly or precisely measured, unlike most states' paid family and medical leave programs, which create administrative data records thanks to their centralized application processes, allowing for tracking of leave-taking patterns during the pandemic.⁴¹ While some data is available regarding employer utilization of tax credits, it is not known how many leaves these tax credits represent, what share were for leaves of different types or purposes or other more detailed data about the leaves for which tax credits were claimed.⁴²

Keeping those caveats in mind, evidence indicates that a small but meaningful share of workers did take emergency leave. One survey-based estimate found that 5.4 percent of workers nationwide (approximately eight million) used emergency sick leave in 2020.⁴³

Workers Valued Emergency Leave

Interviews with workers who took paid leave for COVID-19 illness or caregiving revealed several themes.⁴⁴

Workers who were able to take paid leave strongly appreciated it not only for its direct financial benefits, such as being able to pay bills or not lose a job, but also for supporting their health and family relationships.

For "Amina,"⁴⁵ a Black woman in her late twenties who worked in an engineering firm, paid leave provided irreplaceable time to care for her mother-in-law, who had since passed away:

"I had to take some time off and to take care of my mother-in-law, and take care of my kids and be there for them. [My mother-in-law] was quarantined. So I was there like, it was not really that I was sitting with her, you know she was quarantined. I just had to be there [...] Like, she needs a family member to be around just to hear our voice [...] and do things for her. [...] Taking a paid leave was for my family, thank God I was there for them."

"Keith," a Black man in his early thirties who worked in business administration, recounted a harrowing experience of extended hospital isolation when he developed

COVID-19. Even so, without paid leave he would have needed to find work while in the hospital:

"I was isolated and also taken care of by the hospital I was isolated in. It was a very, very, very bad experience. Being away from my kids and my home, I [...] was praying not to die. [...] [Without paid leave,] I would have felt very bad. I would have felt like quitting my job. I would also look out for a job while I was in the hospital. Look out for ways, a way to provide for my family."

Workers who had been sick with COVID-19 generally reported needing more than two weeks of leave, particularly if they had more than one caregiving issue arise during the year.

"Ruben," a Latino man in his 30s who worked in IT, had to take about three weeks off in spring 2020 when he fell ill with COVID-19, including a short hospital stay. That leave was paid, and he said it had been enough time to recover. But later in the year, his father got COVID-19 and needed care during his isolation. This time, his manager denied his request for leave:

"I informed my manager, but he just told me that I cannot take time off, you know. [...] I think [my employer] could have done more, you know. It wasn't exactly as I expected. I can say that I expected more. There wasn't too much support in that period."

Workers who had family caregiving needs were more likely to report challenges accessing leave than those with their own medical needs.

"Nataasha," a Black woman in her mid-twenties, worked as a receptionist for a health care provider, and needed two months of leave to care for her grandmother while she was ill:

"I used to do like everything, from bathing, to feeding, to taking her to the hospital in, like, I did everything for her. [...] It was hard for me to explain to my supervisor that [...] my grandmother has got COVID. And [...] you find that most of the workplaces don't give paid leaves. So I had to convince them and tell them, you know, I'm the breadwinner. My grandmother depends on me. But after some time, we agreed and I got the paid leave. So at least I had some time to, some time with my grandmother, and at least I had some money to take care of her."

Limited Emergency Leave Left Significant Unmet Need

While emergency leave had significant value for workers who were able to take it, the estimated utilization rate is significantly smaller than the likely scale of need, and numerous sources point to a sizable amount of unmet need even while the program was in effect. Lack of systematic data makes it difficult to estimate how much unmet need was from workers who were simply ineligible for emergency leave, and how much

may have been due to lack of awareness, issues with employer compliance or exhausting the amount of leave provided.

In a survey of adults aged 18-64 about their behavior from March 2020 to late July 2020, 9 percent reported taking a leave from work for their own illness, 4 percent to care for an ill family member and 5 percent for child care. One-fifth to one-third of these leaves were not paid. 20 percent of respondents reported having needed leave but not taking it, most often because they could not afford to lose income or feared job loss or retaliation.⁴⁶ A survey of essential workers in late April to early May 2020 found that just one-third (34 percent) strongly agreed with the statement that they would receive some compensation if they took a day off of work because they had a fever, while just over one in ten (11 percent) strongly agreed that they would go to work with a fever.⁴⁷

A few workers interviewed reported losing their job due to COVID-19-related needs for which they were likely eligible for job-protected emergency leave. For example, "Tim," a Black man in his mid-20s who worked in IT, got sick with COVID-19 and also had to care for his grandfather.

"I had to take care of my grandfather. So you go on leave for only like two days, three days. And that persisted. Then I got COVID and you see, the hours you're working can't help them, the employer, no more. So he just told me that I needed to take the break so they can find someone better. Someone who can work. That's basically it. I lost my job."

The need for FFCRA-type leave persisted long after the program expired, particularly for low-paid workers and workers of color who are least likely to have employer-provided paid leave. For example, in mid-December 2020, 6.6 million adults were not working because they were sick with or caring for someone with COVID-19.⁴⁸ At the height of the Omicron wave in late 2021, this figure climbed to nearly 8.8 million, disproportionately Latinx and Black workers; less than half reported being able to use their regular income source to meet their spending needs.⁴⁹

Improving Agency Implementation and Enforcement

Stronger Enforcement Needed

One potential barrier to workers' utilization of leave is employers failing to follow the law. While WHD took some steps to enforce workers' rights to leave, more could have been done.

The Department of Labor (DOL) chose to stay enforcement immediately after the law went into effect, only beginning enforcement action on April 18, 2020. As of September 16, 2020, WHD reported having received 4,233 FFCRA paid leave complaints, 82 percent

of which resulted in a compliance action. WHD also appears to have initiated 4 compliance actions.⁵⁰ Of the 3,463 compliance actions WHD has undertaken, the enforcement action used in the vast majority (2,811) is conciliation, another 623 involve office audits, 12 limited investigations, and just 17 full investigations. As of September 16, 2020, 2,398 (69 percent) of all compliance actions had been concluded.⁵¹ A review of DOL press releases finds that through the end of 2021, WHD had identified FFCRA paid leave violations affecting 260 employees at approximately 63 employers and had restored just over \$250,000 in back wages to individuals who were wrongfully denied leave.⁵²

It is difficult to estimate a baseline for enforcement of a new law implemented during a pandemic, but comparing the number of complaints made to much longer-standing wage and hour laws with much broader public awareness suggests that workers have faced difficulty accessing leave. Over the decade before the pandemic, WHD had typically completed 10,000 to 12,000 cases with minimum wage violations each year, and a similar number of cases with overtime violations⁵³ and addressed approximately 1,200 to 2,000 FMLA complaints (although this number has declined in the past few years).⁵⁴ Compared to a typical year for FMLA, WHD fielded two to three times as many worker complaints about FFCRA leave. It seems likely that without the legally mandated right to leave established by FFCRA, and enforcement by WHD, few of these workers would have been granted their paid leave time or reinstatement to their job.

Evidence from legal services similarly points to employer compliance with leave laws being a significant issue. Litigation tracking by the firm Fisher Philips found that in 2020, issues related to remote working and leave were the most common type of employment litigation related to COVID-19.⁵⁵ In an analysis of calls to its legal helpline, A Better Balance reports receiving several hundred calls related to leave needs, with a disproportionate share coming from workers of color.⁵⁶

This evidence, while limited, suggests that the financial incentive of FFCRA tax credits was not enough on its own to encourage all covered employers to provide paid sick or family leave to workers in need during the pandemic. Workers' need for legal protections and support from WHD when seeking emergency sick and family leave appears comparable to the needs faced for other health and caregiving needs under FMLA. If the emergency paid sick and family program is extended, it will be critical to renew its anti-retaliation and job protection provisions as well as the employer tax credits. In addition, both workers and employers would likely benefit from additional outreach and compliance support.

Low Public Awareness Limits Program Benefits to Workers and Employers

Workers and employers also needed to know about FFCRA leave in order to fully benefit from it, but public awareness appears to have been generally low. In an April 2020 poll,

26 percent of U.S. adults reported hearing “not much” and 20 percent “nothing at all” about emergency paid sick and child care leave.⁵⁷ Another survey conducted between October and December 2020 found about 45 percent of workers had heard of federal emergency sick leave.⁵⁸ Public knowledge of other laws can be much higher: for example, about three-quarters of workers – and 85 percent of eligible employees – are aware of the Family and Medical Leave Act.⁵⁹

The Wage and Hour Division (WHD) of the Department of Labor reports having conducted 2,160 outreach events as of September 16, 2020, such as webinars, presentations and compliance consultations,⁶⁰ and that approximately 18,000 public service announcements had been aired on radio, on television and online as of October 12, 2020.⁶¹ Information was not provided on the numbers of employees or employers reached; whether particular regions, communities, industries or occupations were targeted; in which language outreach was conducted or other relevant information that would help determine potential gaps in outreach efforts.

Jessica: “Did you know that Congress had passed a law requiring employers to provide paid time off for Covid-19?”

“Tim”: “I think I just heard it from you. Maybe I should sue someone?”

Employer Experiences with Emergency Leave

Workers needing paid sick days and paid family and medical leave to manage pandemic-related health and caregiving needs was a common experience for employers, survey evidence shows. But while employers clearly needed policy support to address those needs, the evidence indicates that the design of the FFCRA emergency paid sick days and paid family leave program fell short for many employers, particularly smaller firms. In the absence of an existing federal program for paid leave or a permanent baseline standard for paid sick days, the FFCRA approach – requiring employers to create a new paid sick days benefit and administer paid family leave, and offering tax credits to cover their costs – did allow the new program to stand up quickly. But the data show that having an existing state paid leave program to build on top of in an emergency offers a model that responds faster and is more favorable for employers and workers.

A Significant Share of Employers Experienced Workers Needing Emergency Leave

Similar to data on workers' needs, there is little systematic data available about the number of employers that had employees take emergency leave. But surveys suggest that at a substantial share of employers, one or more employees took leave for FFCRA-

type purposes in 2020. A Morning Consult survey of small business owners conducted in April 2020 found that just over six in ten reported at least one employee had taken leave for personal illness because of COVID-19, and six in ten that at least one employee to care for a child or ill family member.⁶² Asking more specifically about FFCRA experiences, an NFIB survey of small employers found that as of August 2020, shortly after the expiration of the program, one in five (21 percent) reported having at least one employee take paid sick leave or paid family leave through the FFCRA.⁶³ GAO also found that one business community representative reported that the paid leave tax credits were helpful with employee retention as well as firms' finances.⁶⁴

Tax Credit Utilization Was Low, Especially by Small Employers

Given that workers' use of sick and family leave was common, employers' utilization of FFCRA tax credits for emergency leave was notably low. GAO reports that for the entire 2020 tax year – including both the period of mandated emergency leave from April to July and the remainder of the year, when employers could claim credits for voluntarily provided leave – 1.5 million employers claimed \$9.8 billion in tax credits.⁶⁵ This total is less than 10 percent of the \$105 billion CBO anticipated when the mandatory program was initially scored.⁶⁶ There were approximately 5.2 million private sector firms with fewer than 500 employees in 2020,⁶⁷ meaning only around one-quarter of employers covered by the law claimed a credit.

GAO could not determine an uptake rate due to a lack of data on employer eligibility. However, an analysis prepared for the Office of Tax Analysis estimates that between 3.7 and 6.8 percent of employers claimed a tax credit for emergency leave in 2020. This analysis also found that larger employers were more likely to claim a credit (up to the employer size threshold for eligibility), suggesting that a tax credit model for funding paid leave was particularly unhelpful for the smallest employers.⁶⁸ GAO also found that several of the industries most affected by the pandemic were not among the highest claimants of the tax credit.⁶⁹

It is important to note that low tax credit uptake by employers does not necessarily mean that their workers were not taking emergency paid sick days or family leave. Indeed, a survey by the National Federation of Independent Business (NFIB) found that as of mid-August, just three in ten small employers who had had an employee take leave (30 percent) reported having claimed a tax credit or advance refund.⁷⁰ Tax credit filings may thus undercount the number of employers that provided FFCRA leave. This gap suggests a mismatch between the intent of the policy – to provide paid leave necessary to workers and public health in a way that did not overburden employers – and the outcome.

Uptake of the paid leave tax credit could be depressed for a number of factors. One possibility is that emergency legislation established several programs simultaneously

that may have covered some overlapping purposes. For example, employers who used PPP funds to cover leave expenses would not have been eligible to claim paid sick and family leave tax credits for the same leave expenses.

Employers may also have experienced barriers to understanding and/or applying for the tax credits. GAO found some evidence of low awareness about the credits among employers as well as workers.⁷¹ Business groups also reported to GAO that businesses did not want to devote resources to filing for the paid leave tax credits.⁷² Employers (particularly those without professional tax assistance) may have found the tax paperwork confusing or onerous, or have had concerns about whether accessing this credit would affect their tax liability in unexpected ways or may not be fully aware of the program. However, the Office of Tax Analysis estimate did not find evidence that use of tax preparers increased likelihood of claiming a credit.⁷³

Other factors that could potentially have contributed to low tax credit use (compared to initial projections) relate to limitations on workers' ability to use emergency sick and family leave. For example, when the bill was initially scored, it was not yet known that DOL would interpret potential exemptions for health care providers and first responders so expansively in its regulations, meaning many more workers were exempted than initially contemplated. DOL regulations and guidance also limited eligibility in other ways, for example restricting parents from using child care leave for virtual school if in-person school was offered.⁷⁴

Finally, unanticipated factors related to the pandemic's course and its economic effects – in particular the depth and persistence of shocks to employment – may have meant that fewer workers than initially anticipated still held jobs from which they could take leave. In this case, many workers who would otherwise have taken sick or family leave might have been shifted onto the unemployment system, if eligible. The regulations may also have contributed to this interaction by specifying that workers were not eligible for emergency paid leave if their worksite was closed, even for a brief period, or if the employer did not have work available on a scheduled work day. In such a situation a sick worker with mounting medical expenses would have been incentivized to simply apply for unemployment insurance or other assistance.

State Paid Leave Insurance Programs: An Alternative Approach for Longer Leaves

As of early 2020, four states – California, New Jersey, New York and Rhode Island – already had statewide paid family and medical leave programs in place. These programs operate as social insurance programs covering most workers and employers, in which a small payroll tax (generally not experience-rated) supports an insurance fund that pays out benefits directly to eligible workers. In most states, a state agency reviews claims, relieving employers from most of the administrative burden of the program. Because the worker's leave benefit is paid out of the insurance fund, small employers do not

need to pay out of pocket, and may instead be able to use the amount saved to "top up" the employee's benefit, or to cover additional expenses incurred due to the employee's absence.

Evidence from state paid leave programs indicates that this model has potential to guide a more nimble national policy for future pandemics or public health emergencies. For example, claims data from Rhode Island and California shows that workers were able to begin claiming pandemic-related leaves soon after the public health emergency began, and workers received benefits more quickly than the federal program was implemented.⁷⁵ Research on small employers in New York and New Jersey found that support for state paid leave programs actually increased after the onset of the pandemic, particularly among employers who had had an employee use the state program.⁷⁶

"People are being stretched thin everywhere. We're all taking the hit. [Not providing benefits to workers] going to hurt your employment. It's going to hurt your care. It's going to hurt literally everything. Because, like, sick workers can only work so much, and they need to be taken seriously. And this is not a negotiable issue. This is a fundamental human right."

— "Katie"

Conclusion and Recommendations

Emergency paid sick and family leave had a measurable public health impact by meaningfully expanding access to paid sick days and paid family leave early in the pandemic despite limited eligibility, the lack of a major public awareness campaign and delayed enforcement of the law. Aspects of the policy design were also challenging for employers, in particular the reliance on tax credits to fund the longer paid leave benefits, rather than as a supplement to a permanent core paid leave program, similar to state policies.

The specific health and caregiving needs FFCRA leave intended to address are not entirely in the past – outbreak waves and future pandemics will continue to periodically impact schools and workplaces, and a growing population is experiencing ongoing needs related to long COVID. And workers, their families and their employers will continue to need help navigating myriad other health and caregiving challenges, from births and adoptions to serious illnesses to end-of-life care. The United States needs tailored solutions for all of these needs: paid sick days for short-term and routine health care needs; paid family and medical leave for more serious health and care demands; and an emergency paid sick leave program that can layer on to these baseline programs when public health emergencies arise. Lessons learned from the nation's first national paid sick and family leave program can point the way forward to strong, sustainable and permanent policy solutions.

Recommendations for Lawmakers

- Establish a permanent national paid sick days policy that ensures all workers, regardless of employer size, can earn and use paid sick days outside of a public health emergency.
- Establish a permanent national paid family and medical leave program that covers all workers, regardless of employer size. A publicly funded and administered model similar to state programs would provide coverage for workers' extended needs and shift some administrative burden from individual businesses to a public agency.
- Establish a permanent emergency paid sick days policy that covers all working people and immediately goes into effect when a public health emergency is declared. To make this policy easier to implement for small employers, it should offer tax credits that are immediately refundable, like in the CARES Act, and include funding for outreach, education, and technical assistance.

Recommendations for Administrators

- Ensure DOL conducts public education to ensure workers are aware of their rights in a broad range of languages, using a diversity of channels for outreach (including but not limited to community-based organizations), and targeting hard-to-reach communities.
- Ensure DOL and IRS conduct outreach and provide technical assistance to employers, particularly small employers, to ensure they understand their obligations to provide leave and can access tax credits in a timely way.
- Require DOL and IRS to collect and report data on employer uptake of tax credits, including analysis of use by employer size, industry and location, and about the number of employees, type of leave and amount of leave for which credits are claimed.

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¹ Families First Coronavirus Response Act, Pub. L. No. 116-127, 134 Stat. 178 (2020); Coronavirus Aid, Relief, and Economic Security (CARES) Act, Pub. L. No. 116-136, 134 Stat. 281 (2020).

² The American Rescue Plan (enacted January 2021) provided additional tax credits for small, midsize and some government employers who opted to to provide leave for the same purposes and adding a tax credit for sick leave for workers receiving or recovering from a vaccination, but the requirement to provide leave was not renewed. See I.R.S. (2022, March). Tax Credits for Paid Leave Under the American Rescue Plan Act of 2021 for Leave After March 31, 2021. Retrieved 10 May 2023 from: <https://www.irs.gov/newsroom/tax-credits-for-paid-leave-under-the-american-rescue-plan-act-of-2021-for-leave-after-march-31-2021>

³ Pichler, S., Wen, K., & Ziebarth, N. R. (2020, October). COVID-19 Emergency Sick Leave Has Helped Flatten The Curve In The United States. *Health Affairs*, online first. doi: 10.1377/hlthaff.2020.00863

- ⁴ Byker, T., Patel, E., & Smith, K. (2022, November 3). *Families First Coronavirus Response Act: Effect on Paid Leave Taking During the Early Pandemic*. Washington Center for Equitable Growth working paper. Retrieved 10 May 2023, from <https://equitablegrowth.org/working-papers/families-first-coronavirus-response-act-effect-on-paid-leave-taking-during-the-early-pandemic/>
- ⁵ Goodman, L. (2021, November). *Take-up of Payroll Tax-Based Subsidies During the COVID-19 Pandemic*. Working Paper 121. Office of Tax Analysis. Retrieved 10 May 2023 from U.S. Department of the Treasury website: <https://home.treasury.gov/system/files/131/WP-121.pdf>
- ⁶ U.S. Bureau of Labor Statistics. (2020, September). Employee Benefits in the United States: National Compensation Survey, March 2020 (Table 31, Private industry). Retrieved 10 May 2023, from <https://www.bls.gov/ebs/publications/pdf/employee-benefits-in-the-united-states-march-2020.pdf>
- ⁷ Lan, F., Wei, C., Hsu, Y., Christiani, D., & Kales, S. (2020, May). Work-related COVID-19 transmission in six Asian countries/areas: A follow-up study. *PLoS One*, 15(5): e0233588. doi: 10.1371/journal.pone.0233588; Fisher, K., A., Olson, S. M., Tenforde M. W., Feldstein L. R. et al. (2020, November). Telework Before Illness Onset Among Symptomatic Adults Aged ≥18 Years With and Without COVID-19 in 11 Outpatient Health Care Facilities — United States, July 2020. *Centers for Disease Control and Prevention Morbidity and Mortality Weekly Report*, 69(44): 1648-1653. doi: 10.15585/mmwr.mm6944a4
- ⁸ See National Partnership for Women & Families. (2022, November). *Paid Sick Days Improve Public Health*. Retrieved 10 May 2023, from <https://nationalpartnership.org/resource/paid-sick-days-improve-public-health/>
- ⁹ U.S. Bureau of Labor Statistics. (2020, September). Employee Benefits in the United States: National Compensation Survey, March 2020 (Tables 16 and 31, Civilian workers). Retrieved 10 May 2023, from <https://www.bls.gov/ebs/publications/pdf/employee-benefits-in-the-united-states-march-2020.pdf>
- ¹⁰ U.S. Census Bureau. (2020). *American Community Survey 1-Year Estimates 2019, Table DP03: Selected Economic Characteristics*. Retrieved 11 May 2023, from <https://data.census.gov/cedsci/table?q=dp03&tid=ACSDP1Y2019.DP03&hidePreview=false>
- ¹¹ Data is too limited to estimate access for Native American or Native Hawaiian and Pacific Islander workers, or subgroups of major racial/ethnic categories whose occupational segregation suggests they likely face inequities as well. U.S. Bureau of Labor Statistics. (2019, August). *Access to and Use of Leave: 2017-2018 Data from the American Time Use Survey (Table 1)*. Retrieved 11 May 2023, from <https://www.bls.gov/news.release/pdf/leave.pdf>
- ¹² Hawkins, D. (2023, January 9). Disparities in access to paid sick leave during the first year of the COVID-19 pandemic. *Journal of Occupational and Environmental Medicine*. Online first. doi: 10.1097/JOM.0000000000002784
- ¹³ Rogers, T., N., Rogers, C. R., VanSant-Webb, E., Gu, L. Y., et al. (2020, August). Racial Disparities in COVID-19 Mortality Among Essential Workers in the United States. *World Medical & Health Policy*, 12(3), 311-327. doi: 10.1002/wmh3.358; Zelnor, J., Trangucci, R., Narahariseti, R., Cao, A. et al. (2020, November). Racial Disparities in Coronavirus Disease 2019 (COVID-19) Mortality Are Driven by Unequal Infection Risks. *Clinical Infectious Diseases*, ciaa1723, doi: 10.1093/cid/ciaa1723; For more about racial inequities in the pandemic's effects, see [Called to Care: A Racially Just Recovery Demands Paid Family and Medical Leave](#).
- ¹⁴ Rho, H. J., Brown, H., & Fremstad, S. (2020, April 7). *A Basic Demographic Profile of Workers in Frontline Industries*. Center for Economic and Policy Research. Retrieved 4 April 2023, from <https://cepr.net/a-basic-demographic-profile-of-workers-in-frontline-industries/>
- ¹⁵ Part-time workers were eligible for prorated amounts of leave based on their recent work schedule. U.S. Department of Labor. (n.d.) *Families First Coronavirus Response Act: Employee Paid Leave Rights*. Retrieved 4 April 2023, from <https://www.dol.gov/agencies/whd/pandemic/ffcr-employee-paid-leave>
- ¹⁶ For further analysis of the bill's provisions, see [New Emergency Legislation Provides Paid Sick Days and Paid Leave for Child Care for Millions](#).
- ¹⁷ U.S. Department of Labor. (n.d.) *Families First Coronavirus Response Act: Employee Paid Leave Rights*. Retrieved 11 May 2023, from <https://www.dol.gov/agencies/whd/pandemic/ffcr-employee-paid-leave>
- ¹⁸ U.S. Department of Labor. (n.d.) *Families First Coronavirus Response act: Questions and Answers (Question #64)*. Retrieved 11 May 2023, from <https://www.dol.gov/agencies/whd/pandemic/ffcr-questions#64>
- ¹⁹ 29 U.S.C. § 2612(a)(1) (2022); 29 U.S.C. § 2611(7), (12), (13) (2022) (defining parent, spouse, and son or daughter).
- ²⁰ The IRS made provisions attempting to speed this reimbursement by allowing employers to defer payment of employment taxes up to the amount of qualified leave expenses, and by requesting advance payment of the tax credit, although only a minority of employers used these methods. See IRS. (2022, December 20). *COVID-19-Related Tax Credits for Paid Leave Provided by Small and Midsize Businesses FAQs*. Retrieved 11 May 2023, from <https://www.irs.gov/newsroom/covid-19-related-tax-credits-for-paid-leave-provided-by-small-and-midsize-businesses-faqs>
- ²¹ U.S. Bureau of Labor Statistics. (2023). *Quarterly Census of Employment and Wages, Table G. Distribution of private sector firms by size class: 1993/Q1 through 2022/Q1, not seasonally adjusted*. Retrieved 11 May 2023, from https://www.bls.gov/web/cewbd/table_g.txt
- ²² See for example ["Department of Labor revises FFCRA regulations to address New York court's challenge,"](#) DLA Piper, 30 September 2020.
- ²³ Glynn, S.J. (2020, April). *Coronavirus Paid Leave Exemptions Exclude Millions of Workers From Coverage*. Center for American Progress. Retrieved 11 May 2023, from <https://www.americanprogress.org/issues/economy/news/2020/04/17/483287/coronavirus-paid-leave-exemptions-exclude-millions-workers-coverage/>

- ²⁴ Federal Reserve Bank of St. Louis. (n.d.) *All Employees, Government*. Retrieved 11 May 2023, from <https://fred.stlouisfed.org/series/USGOVT>
- ²⁵ An August 2020 report by the DOL Office of Inspector General found that DOL's own estimate of 9 million was likely understated. See [COVID-19: WHD Needs to Closely Monitor the Pandemic Impact on Its Operations](#).
- ²⁶ See note 23.
- ²⁷ Long, M., & Rae, M. (2020, June 17). *Gaps in the Emergency Paid Sick Leave Law for Health Care Workers*. Retrieved 11 May 2023, from Kaiser Family Foundation website: <https://www.kff.org/coronavirus-covid-19/issue-brief/gaps-in-emergency-paid-sick-leave-law-for-health-care-workers/>
- ²⁸ Byker, T., Patel, E., & Smith, K. (2022, November 3). *Families First Coronavirus Response Act: Effect on Paid Leave Taking During the Early Pandemic*. Washington Center for Equitable Growth working paper. Retrieved 11 May 2023, from <https://equitablegrowth.org/working-papers/families-first-coronavirus-response-act-effect-on-paid-leave-taking-during-the-early-pandemic/>
- ²⁹ Pichler, S., Wen, K., & Ziebarth, N. R. (2020, October). *COVID-19 Emergency Sick Leave Has Helped Flatten The Curve In The United States*. *Health Affairs*, online first. doi: 10.1377/hlthaff.2020.00863
- ³⁰ See [Paid Sick Days Improve Public Health](#).
- ³¹ Byker, T., Patel, E., & Smith, K. (2022, November 3). *Families First Coronavirus Response Act: Effect on Paid Leave Taking During the Early Pandemic*. Washington Center for Equitable Growth working paper. Retrieved 11 May 2023, from <https://equitablegrowth.org/working-papers/families-first-coronavirus-response-act-effect-on-paid-leave-taking-during-the-early-pandemic/>; see also Goodman, L. (2021, November). *Take-up of Payroll Tax-Based Subsidies During the COVID-19 Pandemic*. Working Paper 121. Office of Tax Analysis. Retrieved 11 May 2023 from U.S. Department of the Treasury website: <https://home.treasury.gov/system/files/131/WP-121.pdf>
- ³² Byker, T., Patel, E., & Smith, K. (2022, November 3). *Families First Coronavirus Response Act: Effect on Paid Leave Taking During the Early Pandemic*. Washington Center for Equitable Growth working paper. Retrieved 11 May 2023, from <https://equitablegrowth.org/working-papers/families-first-coronavirus-response-act-effect-on-paid-leave-taking-during-the-early-pandemic/>
- ³³ Byker, T., Patel, E., & Smith, K. (2022, November 3). *Families First Coronavirus Response Act: Effect on Paid Leave Taking During the Early Pandemic*. Washington Center for Equitable Growth working paper. Retrieved 11 May 2023, from <https://equitablegrowth.org/working-papers/families-first-coronavirus-response-act-effect-on-paid-leave-taking-during-the-early-pandemic/>; see also Goodman, L. (2021, November). *Take-up of Payroll Tax-Based Subsidies During the COVID-19 Pandemic*. Working Paper 121. Office of Tax Analysis. Retrieved 11 May 2023 from U.S. Department of the Treasury website: <https://home.treasury.gov/system/files/131/WP-121.pdf>
- ³⁴ Byker, T., Patel, E., & Smith, K. (2022, November 3). *Families First Coronavirus Response Act: Effect on Paid Leave Taking During the Early Pandemic*. Washington Center for Equitable Growth working paper. Retrieved 11 May 2023, from <https://equitablegrowth.org/working-papers/families-first-coronavirus-response-act-effect-on-paid-leave-taking-during-the-early-pandemic/>
- ³⁵ Byker, T., Patel, E., & Smith, K. (2022, November 3). *Families First Coronavirus Response Act: Effect on Paid Leave Taking During the Early Pandemic*. Washington Center for Equitable Growth working paper. Retrieved 11 May 2023, from <https://equitablegrowth.org/working-papers/families-first-coronavirus-response-act-effect-on-paid-leave-taking-during-the-early-pandemic/>
- ³⁶ U.S. Bureau of Labor Statistics. (2020, September). *National Compensation Survey: Employee Benefits in the United States, March 2020 (Table 34)*. Retrieved 11 May 2023, from <https://www.bls.gov/ncs/ebs/benefits/2020/employee-benefits-in-the-united-states-march-2020.pdf>
- ³⁷ U.S. Bureau of Labor Statistics. (2020, October). *National Compensation Survey: Supplemental data measuring the effects of the coronavirus (COVID-19) pandemic on sick leave plans. Tables 1 and 2, unpublished calculation by the National Partnership*. Retrieved 11 May 2023, from <https://www.bls.gov/ebs/factsheets/effects-of-coronavirus-on-sick-leave-policies.htm>. Data was not reported separately for employers above and below the 500-employee threshold. Another BLS source, the Business Response Survey conducted from July to September 2020, found just under 14 percent of private sector establishments reported increasing the amount of paid sick leave offered as a result of the pandemic. U.S. Bureau of Labor Statistics. (2020, December). *Business Response Survey to the Coronavirus Pandemic: 2020 Results of the Business Response Survey*. Retrieved 11 May 2023, from <https://www.bls.gov/brs/2020-results.htm>
- ³⁸ Ibid. Table 3.
- ³⁹ Access increased 3 percentage points among employers with 500 or more employees, compared to 2 percentage points among those with 50 or fewer employees. U.S. Bureau of Labor Statistics. (2020, September). *Employee Benefits in the United States: National Compensation Survey, March 2020 (Table 31, Private industry)*. Retrieved 11 May 2023, from <https://www.bls.gov/ebs/publications/pdf/employee-benefits-in-the-united-states-march-2020.pdf>; U.S. Bureau of Labor Statistics. (2021, September). *Employee Benefits in the United States: National Compensation Survey, March 2021 (Table 33, Private industry)*. Retrieved 11 May 2023, from <https://www.bls.gov/ebs/publications/pdf/employee-benefits-in-the-united-states-march-2021.pdf>
- ⁴⁰ Schneider, D., & Harknett, K. (2022, April). *Good if you can get it: Benefits and inequalities in the expansion of paid sick leave during COVID-19*. Federal Reserve Bank of Boston Community Development Issue Brief. Retrieved 11 May 2023, from

<https://www.bostonfed.org/publications/community-development-issue-briefs/2022/good-if-you-can-get-it-benefits-and-inequalities-in-the-expansion-of-paid-sick-leave-during-covid-19.aspx>

⁴¹ For example, Rhode Island's Temporary Disability Insurance system publishes monthly reports on leave claims. See [Income Support Programs](#).

⁴² The tax forms employers provide to the IRS do not appear to collect such detailed information. See [IRS Form 7200](#) or [Form 941](#), lines 5a(i) and 5a(ii).

⁴³ This may understate usage of FFCRA leave because public awareness of the program was relatively low. Jelliffe, E., Pangburn, P., Pichler, S., & Ziebarth, N. R. (2021, July 20). Awareness and use of (emergency) sick leave: US employees' unaddressed sick leave needs in a global pandemic. *Proceedings of the National Academy of Sciences*. 118(29), e2107670118. doi: 10.1073/pnas.2107670118

⁴⁴ The author conducted 20 interviews with workers who were either sick with COVID-19 or caring for a family member with COVID-19 between March and July 2020, about half of whom had taken paid leave and half of whom had not been able to take paid leave. Because worker awareness of the program was low, participants were selected whose employer at that time had fewer than 500 employees, and who reported that their employer had expanded leave during the program period, whether or not they were able to name FFCRA as the policy providing their leave.

⁴⁵ All participant names are pseudonyms.

⁴⁶ The survey did not collect data on the size of respondents' employers. NORC/University of Chicago survey of 3,518 working-age adults (age 18-64) conducted from July 23 to August 7, 2020. Rachidi, A. (2020, December). *Employment and Safety Net Survey, Wave I: Paid Leave and Childcare During the Pandemic*. American Enterprise Institute publication. Retrieved 11 May 2023, from <https://www.aei.org/wp-content/uploads/2020/12/Paid-Leave-and-Childcare-During-the-Pandemic.pdf>

⁴⁷ Essential workers included those working in social services, health care, protective services, food service, custodial/building maintenance, personal care, sales, installation and repair, and transportation. Hertel-Fernandez, A., Naidu, S., Riech, A., & Youngblood, P. (2020, June). *Understanding the COVID-19 Workplace: Evidence From a Survey of Essential Workers*. Roosevelt Institute publication. Retrieved 11 May 2023, from <https://rooseveltinstitute.org/publications/understanding-the-covid-19-workplace-evidence-from-a-survey-of-essential-workers/>

⁴⁸ U.S. Census Bureau. (2020). *Household Pulse Survey, Week 21, Employment Table 3. Educational Attainment for Adults Not Working at Time of Survey, by Main Reason for Not Working and Paycheck Status While Not Working: United States*. Retrieved 11 May 2023, from <https://www.census.gov/data/tables/2020/demo/hhp/hhp21.html>

⁴⁹ Analysis of U.S. Census Bureau Household Pulse Survey, in Mason, J. (2022, January). *Lack of Paid Leave Stifles Economic Recovery and Blocks Women's Return to Work*. Retrieved 11 May 2023, from National Partnership for Women & Families website: <https://live-national-partnership-for-women-dev.panteonsite.io/wp-content/uploads/2023/02/lack-of-paid-leave-stifles.pdf?wpld=71067>

⁵⁰ U.S. Government Accountability Office. (2020, November). *COVID-19: Urgent Actions Needed to Better Ensure an Effective Federal Response*, p. 199. Retrieved 11 May 2023, from <https://www.gao.gov/assets/720/710891.pdf>

⁵¹ U.S. Government Accountability Office. (2020, November). *COVID-19: Urgent Actions Needed to Better Ensure an Effective Federal Response*, p. 201. Retrieved 11 May 2023, from <https://www.gao.gov/assets/720/710891.pdf>

⁵² Author's review of U.S. Department of Labor Wage and Hour Division press releases related to leave benefits for 2020 and 2021, accessed at <https://www.dol.gov/newsroom/releases>. Contact the National Partnership for more information.

⁵³ U.S. Department of Labor, Wage and Hour Division. (n.d.). *Fiscal Year Data for WHD: Fair Labor Standards Act*. Retrieved 11 May 2023, from <https://www.dol.gov/agencies/whd/data/charts/fair-labor-standards-act>

⁵⁴ U.S. Department of Labor, Wage and Hour Division. (n.d.). *Fiscal Year Data for WHD: Family and Medical Leave Act*. Retrieved 11 May 2023, from <https://www.dol.gov/agencies/whd/data/charts/fmla>

⁵⁵ Fisher Phillips. (n.d.) COVID-19 Employment Litigation Tracker and Insights. Retrieved 11 May 2023, from <https://www.fisherphillips.com/innovations-center/covid-19-employment-litigation-tracker-and-insights/index.html>

⁵⁶ A Better Balance. (2020, December). *Save Families First: Workers' Voices & the Need for Action*. Retrieved 11 May 2023, from <https://www.abetterbalance.org/ffcr-worke-voices/>

⁵⁷ Morning Consult/New York Times survey of 2,200 adults conducted from April 9 to April 10, 2020. Retrieved 11 May 2023, from https://assets.morningconsult.com/wp-uploads/2020/05/19175645/200424_crosstabs_NYT_Adults_v5_JB.pdf

⁵⁸ Jelliffe, E., Pangburn, P., Pichler, S., & Ziebarth, N. R. (2021, July 20). Awareness and use of (emergency) sick leave: US employees' unaddressed sick leave needs in a global pandemic. *Proceedings of the National Academy of Sciences*. 118(29), e2107670118. doi: 10.1073/pnas.2107670118

⁵⁹ Brown, S., Herr, J., Roy, R., & Klerman, J. A. (2020, July). *Employee and Worksite Perspectives of the Family and Medical Leave Act: Results from the 2018 Surveys*. Retrieved 11 May 2023, from https://www.dol.gov/sites/dolgov/files/OASP/evaluation/pdf/WHDFMLA2018SurveyResults_FinalReport_Aug2020.pdf

⁶⁰ U.S. Government Accountability Office. (2020, November). *COVID-19: Urgent Actions Needed to Better Ensure an Effective Federal Response*, p. 198. Retrieved 11 May 2023, from <https://www.gao.gov/assets/720/710891.pdf>

⁶¹ Chapin, A. (2020, November). "The Paid Leave Trump Doesn't Want You to Know About." *The Cut*. Retrieved 11 May 2023, from <https://www.thecut.com/2020/11/covid-aid-package-qualify-paid-leave-12-weeks.html>

⁶² Morning Consult/Bipartisan Policy Center survey of 502 small business owners conducted from April 8 to April 12, 2020. Retrieved 11 May 2023, from https://bipartisanpolicy.org/wp-content/uploads/2020/04/Topline_BPC_Small_Business_Owners_Executives_v1_LM.pdf

- ⁶³ 95 percent of employers surveyed had fewer than 50 employees. National Federation of Independent Business. (2020, August). *Covid-19 Small Business Survey (11): PPP, EIDL, Unemployment Insurance, the Economy*. Retrieved 11 May 2023, from <https://assets.nfib.com/nfibcom/Covid-19-11-Questionnaire-and-Write-up-FINAL.pdf>
- ⁶⁴ U.S. Government Accountability Office. (2022, May). *COVID-19: IRS Implemented Tax Relief for Employers Quickly, but Could Strengthen Its Compliance Efforts*. GAO-22-104280. Retrieved 11 May 2023, from <https://www.gao.gov/products/gao-22-104280>
- ⁶⁵ U.S. Government Accountability Office. (2022, May). *COVID-19: IRS Implemented Tax Relief for Employers Quickly, but Could Strengthen Its Compliance Efforts*. GAO-22-104280. Retrieved 11 May 2023, from <https://www.gao.gov/products/gao-22-104280>
- ⁶⁶ Joint Committee on Taxation. (2020, March 16). *Estimated Revenue Effects of the Revenue Provisions Contained in Division G of H.R. 6201, the "Families First Coronavirus Response Act" (JCX-9-20)*. Retrieved 11 May 2023, from <https://www.jct.gov/publications/2020/jcx-9-20/>. See also Congressional Budget Office. (2020, April 2). *Re: Preliminary Estimate of the Effects of H.R. 6201, the Families First Coronavirus Response Act*. Letter to the Chairwoman of the Committee on Appropriations. Retrieved 8 December 2020, from <https://www.cbo.gov/system/files/2020-04/HR6201.pdf>.
- ⁶⁷ U.S. Bureau of Labor Statistics. (2023). Quarterly Census of Employment and Wages, Table G. Distribution of private sector firms by size class: 1993/Q1 through 2022/Q1, not seasonally adjusted. Retrieved 11 May 2023, from https://www.bls.gov/web/cewbd/table_g.txt
- ⁶⁸ Goodman, L. (2021, November). *Take-up of Payroll Tax-Based Subsidies During the COVID-19 Pandemic*. Working Paper 121. Office of Tax Analysis. Retrieved 11 May 2023 from U.S. Department of the Treasury website: <https://home.treasury.gov/system/files/131/WP-121.pdf>
- ⁶⁹ U.S. Government Accountability Office. (2022, May). *COVID-19: IRS Implemented Tax Relief for Employers Quickly, but Could Strengthen Its Compliance Efforts*. GAO-22-104280. Retrieved 11 May 2023, from <https://www.gao.gov/products/gao-22-104280>
- ⁷⁰ National Federation of Independent Business. (2020, August). *Covid-19 Small Business Survey (11): PPP, EIDL, Unemployment Insurance, the Economy*. Retrieved 11 May 2023, from <https://assets.nfib.com/nfibcom/Covid-19-11-Questionnaire-and-Write-up-FINAL.pdf>
- ⁷¹ U.S. Government Accountability Office. (2022, May). *COVID-19: IRS Implemented Tax Relief for Employers Quickly, but Could Strengthen Its Compliance Efforts*. GAO-22-104280. Retrieved 11 May 2023, from <https://www.gao.gov/products/gao-22-104280>
- ⁷² U.S. Government Accountability Office. (2022, May). *COVID-19: IRS Implemented Tax Relief for Employers Quickly, but Could Strengthen Its Compliance Efforts*. GAO-22-104280. Retrieved 11 May 2023, from <https://www.gao.gov/products/gao-22-104280>
- ⁷³ Goodman, L. (2021, November). *Take-up of Payroll Tax-Based Subsidies During the COVID-19 Pandemic*. Working Paper 121. Office of Tax Analysis. Retrieved 11 May 2023 from U.S. Department of the Treasury website: <https://home.treasury.gov/system/files/131/WP-121.pdf>
- ⁷⁴ U.S. Department of Labor, Wage and Hour Division. (n.d.) *Families First Coronavirus Response Act: Questions and Answers (#99)*. Retrieved 11 May 2023, from <https://www.dol.gov/agencies/whd/pandemic/ffcra-questions#99> This was a common circumstance for parents in many parts of the country in 2020, including in large school districts such as New York City, Los Angeles, and Chicago.
- ⁷⁵ Boyens, C. (2020, June). *State Paid Family and Medical Leave Programs Helped a Surge of Workers Affected by the COVID-19 Pandemic*. Retrieved 11 May 2023, from Urban Institute website: <https://www.urban.org/research/publication/state-paid-family-and-medical-leave-programs-helped-surge-workers-affected-covid-19-pandemic>
- ⁷⁶ Having an employee use state paid leave was associated with a 9.7 percentage point increase in support, from a pre-pandemic baseline of 61.6 percent. Bartel, A. P., Rossin-Slater, M., Ruhm, C. J., Slopen, M., & Waldfogel, J. (2021, December 9). Support for Paid Family Leave among Small Employers Increases during the COVID-19 Pandemic. *Socius: Sociological Research for a Dynamic World*. Online first. DOI: 10.1177/23780231211061959

Statement for the Record for the Senate Special Committee on Aging

Hearing: Before Disaster Strikes - Planning for Older Americans and People with Disabilities in All Phases of Emergencies

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Dear Chairman Casey, Ranking Member Braun, and members of the Senate Special Committee on Aging,

Thank you for holding the hearing “Before Disaster Strikes: Planning for Older Americans and People with Disabilities in All Phases of Emergencies” on the importance of inclusive disaster management for older adults and people with disabilities. I appreciate your respect for, and dedication to, the health and safety of community members who are elderly, medically frail, and/or living with a disability. Morbidity and mortality outcomes for these community members are disproportionate to the rest of the population residing in the same disaster-affected area. Not addressing their disaster-related vulnerabilities has been shown to have negative effects on both the response and recovery phases of the disaster, and on the community as a whole.¹⁻³

However, the elderly, medically frail, and community members with disabilities can also be assets in disasters. These individuals serve as trusted messengers who disseminate risk communication messages to their social networks. They can teach younger generations about traditional survival skills. They instill hope for the future by sharing their experiences with recovery from past disasters. They can provide local environmental knowledge to assist emergency managers in selecting optimal shelter or supply distribution centers. They have also been known to look after supplies, the sick and injured, orphans, children, and other dependents during the disaster recovery phase.⁴⁻¹¹ Protecting these community members, as well as utilizing them in disaster preparation, response, and recovery, will enhance community resilience overall.²

These individuals are the experts on what is needed for them to endure disasters without increased risk of injury or illness, a decrease in their baseline functional status, exacerbation of a chronic illness, or need for outside assistance. These community members should be included in the planning of all phases of disaster management, but

especially in disaster preparedness. In the aftermath of disasters, emergency medical services and hospitals experience an influx of patients related to exacerbations of chronic illnesses. If emergency managers and healthcare providers understand the needs of these community members and educate them on how best to prepare for disaster conditions, many of these hospitalizations can be avoided. We can think of disaster preparedness activities as primary prevention for disaster-related morbidity and mortality.

I will briefly describe my background as a content expert. I will then further elaborate on what makes individuals who are elderly, medically frail, or living with a disability vulnerable during disasters. I will conclude with evidence-based interventions supported by the REAADI for Disasters Act that can help these community members endure disasters safely.

Background of the Author

I am an Assistant Professor at the Hunter-Bellevue School of Nursing at Hunter College of the City University of New York. I have clinical nursing experience in telemetry, emergency department, critical care transport, and post-anesthesia care unit nursing. As a member of my local Medical Reserve Corps, I volunteer my nursing expertise to my community during extreme weather events, public health emergencies, and disasters. I hold several certifications in disaster preparedness, response, and recovery and have presented my research at the American Academy of Nursing, the Sigma Theta Tau / National League for Nursing, and the World Association of Disaster and Emergency Medicine conferences. I teach nursing and I conduct research on disaster preparedness intervention effectiveness and disaster-related health disparities. I have been interviewed about my research by the [Future of Nursing Campaign for Action](#) and [Forbes](#).

I had the experience of living through several extreme weather events as a child living at the New Jersey shore. The most memorable event for me was the nor'easter of 1992. This nor'easter created a storm surge that completely flooded my street. As a 10-year-old child, I witnessed neighbors using boats to row to the main road. A house nearby caught on fire and burned to the ground because fire trucks could not get to it due to the flooding. I watched a woman jump out of her second story window to escape the flames. My mother still lived in this home during Hurricane Sandy. The house flooded to a depth of two feet with my mother still inside.

At 14-years-old, I joined the local ambulance squad as a junior volunteer and then as an Emergency Medical Technician (EMT) at 16. Instead of being just a community member living through severe weather events, I was now also a responder. I witnessed life-threatening events related to medically frail community members being unprepared for disaster conditions. Two events were especially memorable.

The first event happened during a severe thunderstorm that caused power outages to much of the city. A patient with kidney failure was receiving a dialysis

treatment at home when the power went out. There was no backup battery for her equipment and no generator in the house. Her machine shut off mid-treatment. It took us longer than usual to get to the patient's house in the ambulance due to a backlog of emergency calls related to the severe storm and downed trees preventing access to her street. Fortunately, the patient was eventually successfully transported to the city hospital without incident.

I was also on duty when a severe thunderstorm knocked out power to a long-term care facility one summer night. The nursing home's generators did not turn on and the staff did not know how to troubleshoot them, or even where they were located. The facility was completely dark and had no air conditioning. The patients were extremely frightened. I and other EMTs had to assess each patient via flashlight and obtain enough portable oxygen tanks to evacuate the patients with no operable elevators. I was astounded that a healthcare facility that assumed care and responsibility for medically frail patients was so completely unprepared.

Hurricane Katrina in 2005 also made an impression on me. Living in New Jersey, I was not physically affected by the hurricane. However, I had just graduated from nursing school. I obsessively watched the news and felt overwhelming empathy for the community members, the hospitalized patients, and the healthcare providers working through the disaster. I was heartbroken that such devastation could take place in this country - not the damage to the physical infrastructure, but the massive loss of lives. I followed news coverage about the alleged euthanasia that took place in a flooded hospital in New Orleans. As a brand-new nurse, I hoped to never have to be in a situation where I would have to make the decisions that those healthcare providers made. I hoped that no healthcare providers would ever have to make those decisions again.

I have worked as an EMT and a nurse in New Jersey since 1999 and have either volunteered or worked throughout every local disaster during that time. I have shouldered the burden of unprepared community members during disasters. I and my coworkers have been put at risk when rescuing people during dangerous storm conditions. I have cared for scores of patients who arrived at the hospital because of acute exacerbations of chronic conditions related to not being adequately prepared for a disaster. They came for an oxygen source, to have prescription medications refilled, to charge their electronic medical devices, to receive dialysis treatments, and to escape temperature extremes in their homes. Many patients came for the simple reason that they did not want to be alone during the disaster. The surge of patients placed a burden on the ambulance and hospital staff who were working in less-than-optimal conditions, such as short-staffed or on generator power, or worrying about their own families and homes located in the same affected community.

As a result of my personal and professional experiences, I began my program of research with a feeling of frustration with my unprepared community members. However, from the very start of my research journey, I quickly transitioned from frustration to understanding. There are several physical and social circumstances that

render elderly, medically frail, and community members with disabilities less prepared than they could be. I hope that my research will help policy makers, emergency managers, and other healthcare providers understand and become passionate about their role in the household emergency preparedness of fellow community members. Many of the mandates in the REAAD for Disasters Acts will provide disaster responders and healthcare providers with guidance needed to keep our most vulnerable community members safe during disasters.

I started my program of research by exploring household emergency preparedness of elderly and medically frail community members qualitatively with the hope of better understanding the reasons why people do or do not prepare for disasters to inform policy.¹² Needing an evidence-based household emergency preparedness questionnaire to continue my research, I led a team of disaster nurse researchers and disaster experts representing 36 countries to develop the first global, empirical, all-hazards, valid, and reliable Household Emergency Preparedness Instrument (HEPI).¹³⁻
¹⁴ The HEPI is easy to administer, accurately captures the various indicators of preparedness, explains an acceptable amount of variance, and demonstrates strong reliability. The team agreed to make the HEPI free to use for research purposes to encourage widespread application in disaster preparedness assessment and intervention studies. We are now developing nurse-led household emergency preparedness interventions and evaluating the outcomes of adequate preparedness on disaster-related morbidity, mortality, and resources utilized.¹⁵⁻¹⁶ I am also engaging in climate change research, measuring the biological effects of air pollution and heat stress on humans to determine the resulting health risks from these exposures. I will then educate the community about these hazards and how to best prepare for or mitigate the risks related to the hazards.

Disaster-Related Challenges for Individuals who are Elderly, Medically Frail, or Living with a Disability

My experiences and research have allowed me to identify several physical and social pathways to vulnerability during disasters for community members who are elderly, medically frail, and living with a disability.

The *physical* pathways to vulnerability include the following² (pp. 52-54):

- 1) Advanced age: As individuals age, they become less tolerant of temperature extremes due to circulatory problems, loss of subcutaneous tissue and sweat glands, reduced ability to perceive heat, delayed thirst and perspiration mechanisms, and possible exposure to medications that influence body temperature regulation.
- 2) Chronic illnesses: Diabetes, cardiovascular disease, chronic lung conditions, hereditary blood disorders, end-stage renal disease, high blood pressure, arthritis and dementia are frequently identified as chronic illnesses exacerbated by disaster conditions. Stress related to the disaster have considerable effects on glycemic control resulting in negative health outcomes among individuals with

diabetes. Individuals living with chronic illnesses are also at risk due to disruptions in their routine medical care because of difficulty in accessing their care providers and healthcare facilities.

- 3) Mobility deficits: Mobility deficits impede an individual's ability to quickly evacuate or take cover in sudden-onset disasters. Individuals with mobility deficits may be forced to leave behind their mobility aids (e.g. wheelchair, walker or cane) during evacuation, rendering them incapable of being self-sufficient even after a successful evacuation.
- 4) Cognitive deficits: Cognitive deficits, such as memory disorders, dementia, delayed reaction times and psychological distress, are frequently cited as predictors of disaster vulnerability.
- 5) Sensory deficits: Sensory deficits hinder one's ability to see, hear, taste or smell, which can impair an individual's ability to see warning signs, hear emergency instructions and alerts, and navigate in unfamiliar environments. Individuals with sensory impairments are also more likely to eat contaminated or spoiled food during the disaster.

The *social* pathways to vulnerability include the following² (pp. 52-54):

- 1) Low socioeconomic status: Many elderly, medically frail, and/or individuals with disabilities live on fixed incomes and have poor credit-worthiness, limiting their ability to afford disaster-related expenses such as fuel, food, and lodging. They are also less able to afford post-disaster expenses, including home repairs, protective home improvements, and purchasing a generator or supplies for a household emergency preparedness supply kit. Elders are also less likely to recover economically from the expenses related to the disaster, making them at high-risk for poverty.
- 2) Low education level: Individuals who have a low education level are vulnerable in disasters due to their difficulty or inability to access quality disaster information resources.
- 3) Native language speaking ability: Individuals with language barriers experience the same lack of access to quality information resources as those with low education level.
- 4) Lack of social support: Individuals with adequate social support receive assistance from family, friends, and the community to obtain disaster information, evacuate, find shelter and food, access health care and rebuild after disaster situations. House-bound and socially isolated individuals are less likely to receive disaster information or ask for assistance, which can render them invisible to responders.
- 5) Reliance on others or objects: Reliance refers to the need for assistance with activities of daily living (e.g. bathing, dressing, grooming, using the toilet); meals or medical care; electricity for medical devices, supplemental oxygen or refrigeration for medications (e.g. insulin). Individuals who rely on others or devices are at risk due to disruptions in their routine care because of difficulty in accessing their home care and social services providers and disruptions to their basic utility services.

- 6) Emergency shelter conditions: Shelters may lack ramps, railings, health services, medications, medical equipment, accessible toilets, adequate lighting, decent beds, and appropriate food. Shelters may be excessively noisy and create separation of the individual from family support. Individuals may choose to stay home instead of enduring the shelter conditions.
- 7) Condition of home: Older people tend to live in older homes of low structural quality because they lack means to make storm-resilient improvements.
- 8) Experience with disasters: Individuals who have survived a previous disaster with minimal negative effects may underestimate the consequences of future disasters and not take appropriate protective actions. Additionally, failure to recover from a recent disaster compounds the vulnerabilities for subsequent disasters.

Policies and Programs Needed to Support Individuals who are Elderly, Medically Frail, or Living with a Disability

Responsibility for home disaster preparedness should be shared by households, family/friends/neighbors, community- and faith-based organizations, and the local, state, and federal government. During my experience as a disaster responder and via my research, I have seen several successful community interventions that assist households to overcome physical and social barriers to preparedness.

Effective preparedness and mitigation interventions include locating vulnerable community members; assessing their resources and capabilities for household emergency preparedness; educating them about household emergency preparedness; including them in emergency planning; and assuring them that evacuation assistance, medications, health care and appropriate shelters will be accessible to them in a disaster. Response interventions include evacuation of vulnerable community members in advance of predicted extreme weather events with their necessary assistive devices and pets or service animals. They should be provided with free transportation and an Americans with Disabilities Act compliant host site. Recovery interventions include ensuring equitable distribution of supplies, providing psychological care, and aiding individuals in obtaining governmental assistance. Central to both pre- and post-disaster periods is the need to maintain effective communication with community members and other agencies in formats that will equitably reach all community members. Additional information on these interventions can be found in the referenced report.²

All disaster-related community interventions should be developed with input from the individuals who will utilize them. Elderly and medically frail people and individuals with disabilities should be queried about preferred venues for risk communication and evacuation messages, optimal shelter locations and accessibility needs within the shelters, food preferences that meet unique dietary requirements from the meal distribution centers, and crisis standards of care. These individuals should be included in the After Action Reports post-disaster to evaluate and improve their experiences. Research should be conducted on intervention effectiveness with the goal of improving disaster-related outcomes for all community members.

These evidence-based recommendations are all supported in the proposed REAAADI for Disasters Act (S. 1049). Specifically, the directives that state and local disaster plans and crisis standards of care will be developed with the input of an advisory council of individuals with disabilities and older adults will be most helpful. Adherence and accountability to the mandates outlined in this bill will conceivably lead to improved morbidity and mortality outcomes for our community members with disabilities and for those who are elderly or medically frail and improve disaster-related community resilience.

References

1. Bell, S.A., Singer, D., Solway, E., Kirch, M., Kullgren, J., & Malani, P. (2021). Predictors of emergency preparedness among older adults in the United States. *Disaster Medicine and Public Health Preparedness*, 15(5), 624–630. <https://doi.org/10.1017/dmp.2020.80>
2. Heagele, T.N. & Pacquiao, D. (2018). Disaster vulnerability of elderly and medically populations. *Health Emergency and Disaster Nursing*, 6, 50-61. <https://doi.org/10.24298/hedn.2016-0009>
3. Veenema, T.G. (2019). Disaster nursing and emergency preparedness for chemical, biological, and radiological terrorism and other hazards (4th ed.). Springer Publishing Company
4. HelpAge International. (1999). Older people in disasters and humanitarian crises: guidelines for best practice [Press release]. [Cited 13 May 2016.] Available from URL: <http://www.helpage.org/silo/files/older-people-in-disasters-and-humanitarian-crises-guidelines-for-best-practice.pdf>
5. Powell, S., Plouffe, L., & Gorr, P. (2009). When ageing and disasters collide: lessons from 16 international case studies. *Radiation Protection Dosimetry*, 134(3–4), 202–206. doi: 10.1093/rpd/ncp082
6. Ardalan, A., Naieni, K. H., Rezaie, M., Mazaheri, M., Teimoori, F., & Pourmalek, F. (2010). Older people's needs following major disasters: a qualitative study of Iranian elders' experiences of the Bam earthquake. *Ageing and Society*, 30(1), 11–23. doi:10.1017/S0144686X09990122
7. Benson, W. F. (2007). *CDC's disaster planning goal: protect vulnerable older adults*. http://www.cdc.gov/aging/pdf/disaster_planning_goal.pdf
8. Henderson, T. L., Roberto, K. A., & Kamo, Y. (2010). Older adults' responses to Hurricane Katrina: daily hassles and coping strategies. *Journal of Applied Gerontology*, 29(1), 48–69.
9. Tuohy, R., Johnston, D., & Stephens, C. (2015). Disaster preparedness: older adults' perspectives. *International Journal of Emergency Management*, 11(1), 46–61. doi:10.1504/IJEM. 2015.069516
10. Mayhorn, C. B. (2005). Cognitive aging and the processing of hazard information and disaster warnings. *Natural Hazards Review*, 6(4), 165–170. doi:10.1061/(ASCE)1527- 6988(2005)6:4(165)

11. Roberto, K. A., Henderson, T. L., Kamo, Y., & McCann, B. R. (2010). Challenges to older women's sense of self in the aftermath of Hurricane Katrina. *Health Care Women for Women International*, 31(11), 981–986. doi:10.1080/07399332.2010.500754
12. Heagele, T.N. (2021). A qualitative survey of household emergency preparedness for the elderly and the medically frail living in coastal urban communities. *Journal of Emergency Management*, 19(2), 143-163. <https://doi.org/10.5055/jem.2020.0493>
13. Heagele, T.N., McNeill, C.C., Adams, L.M., & Alfred, D.M. (2022). Household emergency preparedness instrument development: A Delphi study. *Disaster Medicine and Public Health Preparedness* 16(2), 570-582. <https://doi.org/10.1017/dmp.2020.292>
14. Heagele, T.N., Adams, L.M., McNeill, C.C., & Alfred, D.M. (2022). Validation and revision of the Household Emergency Preparedness Instrument (HEPI) by a pilot study in the City of New York. *Disaster Medicine and Public Health Preparedness*, 17(e126), 1-9. <https://doi.org/10.1017/dmp.2022.35>
15. Heagele, T.N. & Nurse-Clarke, N.J. (2022). A nurse-led home disaster preparedness intervention for new parents. *Neonatal Network: The Journal of Neonatal Nursing*, 41(1), 5-10. <http://doi.org/10.1891/11-T-714>
16. Heagele, T., Samuels, W.E., Wholeben, M., Nurse-Clarke, N., Adams, L.M., & McNeill, C. (accepted for publication May 9, 2023). Nurses Taking on Readiness Measures (N-TORM): A nurse-facilitated household emergency preparedness intervention feasibility study. *Health Emergency and Disaster Nursing*.