



## **The Forgotten Faces of Winter Storm URI**

The Impact on Texans with Disabilities When We Fail to Conduct Inclusive Disaster Planning and Preparedness

A Report By:

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for Texans with Disabilities

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## **Section 1: Introduction**

During a disaster, people with disabilities are more vulnerable when infrastructure and community lifelines fail because they often rely on technology, transportation, or in-home care to live safely in the community. Between hurricanes, fires, freezes, tornados, and floods, Texas has experienced its fair share of disasters in recent years. The State has had ample opportunity to fulfill its obligation to strategize for such events and to include the disability community in the process of planning and preparedness. Sadly, Winter Storm Uri is yet another example of the consequences when state and local governments do not plan or prepare to effectively provide inclusive disaster and emergency services for all of its citizens.

To better understand the impacts of Winter Storm Uri on Texans with disabilities, Disability Rights Texas (DRTx) conducted a survey of people impacted by the storm. The survey was accessible to the disability community and was publicized online by DRTx, as well as by some of our community partners. Questions attempted to gauge the unmet needs of persons with disabilities before, during, and after the storm, as well as assess public awareness and accessibility of disaster-related services. We also included a number of open-ended questions so that respondents could describe their unique experiences. We received a total of 597 responses from individuals across Texas.

The majority of the respondents (56%) were people with disabilities. Thirty-five percent were people who support a person with a disability. The remaining 9% of respondents either worked at an organization in Texas that provides services to persons with disabilities or none of the above – those people were thanked for their interest but did not answer the survey questions. Additionally, approximately 87% of respondents were willing to share their stories publicly, indicating their commitment to putting a spotlight on these issues.

The purpose of this report is to share respondents' answers to our questions and inform the public of the true cost to people with disabilities when they are treated as an afterthought for purposes of disaster planning and preparedness. To that end, we have highlighted some of the most illuminating responses to our survey to put a face on the suffering of those Texans who are too often overlooked and forgotten.

## Section 2: What the Survey Revealed

### Issue 1: Power and Water

#### ***Survey Question: Did you lose power during the Winter Storm?***

The most significant impact of Winter Storm Uri was the failure of much of the state's critical infrastructure, including power and water. **More than 75%** of those who responded to this question indicated that they lost power. Individuals with disabilities are often more reliant on these services, especially electricity, to maintain their independence and power life sustaining equipment. For example, access to power is necessary to charge batteries for durable medical equipment such as oxygen concentrators, ventilators, wheelchairs, and nutrition delivery systems.

Power is important for all people to keep their homes at a safe temperature. For people with disabilities, it also enables the use of communication devices as well as allows for refrigeration of perishable items such as food and medication. An extended loss of power can be deadly for those who are medically fragile.

*"We were [forced] to made difficult choices about which machines were most important to help keep our son alive knowing full well he needs all of them. It was a really hard three days that were extremely stressful that didn't need to be that way, and we're still shocked and recovering."*

*"I have three autistic children, one of whom also has an intellectual disability. We were completely stranded in our homes, unable to leave because of the snow and ice. We had no power and no water. I have no [fireplace]. My children were terrified, and one would not stop crying from fear and cold. I could not help him. I felt powerless and like a failure as a mother because there was not a thing I could do to help."*

#### ***Survey Question: What was the longest period of time you went without power?***

Close to two thirds of those surveyed stated that they experienced an outage for more than 24 hours, over 22% of which reported being without power for more than four days.

*"I planned for a mini storm issue, not a LONG one. Without power I cannot use my assisted breathing, [communicate] with outside world, no power to keep my bed or wheelchair working, no water to flush fecal material, pet alerts too. Food and water."*

*"Our house was extremely cold - I would bundle up our child with blankets and had our small dogs in her bed to help keep her warm - she suffers from*

*seizures [through] out the day and night so [I] could not put [too] many heavy blankets on her so during her seizures she wouldn't be contained during her body jerks - she is tube fed but had no place to warm up her food nor milk so [I] gave her cold liquids and food."*

**Survey Question: Were you in danger because of a loss of power?**

*For example, you use medical equipment that requires power, you have medication that spoiled because of lack of refrigeration, etc.*

Due to issues like a lack of refrigeration of medication and an inability to charge durable medical equipment (DME), nearly 45% of the respondents to the question felt they were in danger due to the power loss.

*"It was dangerous and painful. I'm disabled and have 3 children living with me with disabilities. It was 12 degrees with no way to warm up. Food got spoiled, my insulin was not good. Power got restored around me but my power was out for 6 days. Why?? It was not fair the way they restored service. Some neighborhoods did not [lose] power at all."*

*"It was hell. I could not bathe or anything for 2 weeks. And the only thing our apartment provided was porta-potties which are not friendly for someone in a motorized chair. I have never felt so gross, disgusting, and humiliated. And also terrified with lack of power having a motorized chair."*

**Survey Question: Did you lose water?**

Nearly 60% of people who responded to this question lost access to water during the storm. In a follow up question, more than 80% stated they lost water for more than 24 hours with 32% losing water for four or more days. Access to clean drinkable water is a necessity for everyone but can be of even more importance for persons with disabilities. A lack of proper hydration can lead to skin conditions that can become infected.

Moreover, water helps flush toxins, waste, and bacteria from the body to fight disease and infection as well as strengthens the immune system. This is especially important for those who are immunocompromised. Additionally, some medications have to be taken or mixed with water. A lack of water causes persons to be less likely to take their medications.

Water is also essential to maintaining hygiene, toileting and food preparation. **The lack of power and water exacerbated the food insecurity issues of a fragile population already impacted by the ongoing COVID -19 pandemic.**

*“We were trapped. My attendant had to carry snow in to melt for us to have water. Couldn't flush the toilets. We had only dry cold food to eat ...crackers, breakfast bars, peanuts. It was freezing cold at 40 degrees in the house. My wheelchair was perilously low on power and I couldn't charge it without electricity. We had no way to charge our phones so we didn't know what was going on nor could we call out. It was the worst experience of my life. My attendant had a panic attack from all the stress and fear.”*

*“[My] child with a disability is also medically complex, fighting among other things, staph infections on the skin. The lack of water hampered our ability to follow treatment guidelines given to us by her infectious disease specialist. The staph infections got worse. She ended up on oral Bactrim the week after the storm to get things back under control.”*

## **Issue 2: Help from Local or State Government Programs**

The State of Texas says it has a viable working disaster plan to meet the needs of people with disabilities. Unfortunately, systems such as STEAR (State of Texas Emergency Assistance Registry), 211 Texas, and public utility critical care lists were either ineffectual or overwhelmed before, during and after Winter Storm Uri. Our survey received some truly alarming responses that emphasize more than ever the need to reevaluate disaster planning and preparedness in the light of climate change.

### ***Survey Question: Were you signed up and receiving emergency notifications and/or safety alerts?***

While nearly 43% of those surveyed responded yes, the vast majority, over 57%, responded no. The more disturbing statistic however is that more than **70% responded that the notifications/safety alerts that they did manage to receive were inaccessible.** This again points to a lack of planning, preparation, and consideration of the needs of persons with disabilities.

*“.. since I am totally blind, I found the Messages on TV to be totally inaccessible since they were nonverbal.”*

*“During the outage we received no alerts or updates re: what was going on with electricity. [Without] electricity we were not able to obtain info via TV or internet thus making decisions re: what we should be doing i.e. evacuate impossible. My autistic daughter has been traumatized and regressed due to freezing temperatures [without] heat.”*

***Survey Question: Are you registered on the State of Texas Emergency Assistance Registry known as STEAR?***

STEAR is a free registry operated by the Texas Department of Emergency Management (TDEM) that claims to provide local emergency planners and emergency responders with additional information on the needs in their community. Texas communities use the information in different ways. As stated on the TDEM website, registering for STEAR does not guarantee that a person will receive a specific service during an emergency. Accordingly, services vary by community. There are no mechanisms to ensure that the registry is being used as intended by local governments and emergency responders, nor has there been any consistent commitment to adequately publicize its existence or purpose. Of the people surveyed, **only 6% were registered with the State of Texas Emergency Assistance Registry (STEAR).**

*“I cannot express the stress this placed on me & my family. What is the point of registering for programs like STEAR if it's still going to take a week to get power & longer to get clean, safe water[?] My children had medical complications because of a lack of safe water.”*

*“The STEAR program was absolutely useless since no one took into consideration to [ensure] that vulnerable population was considered during the black outs.”*

***Survey Question: Are you signed up for the Critical Care Registry with your Electric Provider which may provide benefits to people with certain medical conditions related to notifications or interruptions in power?***

A Texas resident who has a medical condition that can become life-threatening if their home were to lose power can qualify for critical care or chronic condition status with their electric provider. Electric customers with critical care or chronic condition status can receive certain benefits related to notification or interruptions or suspensions of service, and certain protections related to the disconnection of service.

**Only 6% of those surveyed were registered with a “Critical Care Registry” managed by their local electric provider. Like the STEAR registry, a majority of the respondents (more than 53%) simply did not know that these registries even existed.** Also, because many cell towers were inoperable due to a lack of power, many people could not even call their local power company or receive electronic updates.

*“They need to do better. They need to put the disabled and senior communities first. What’s the point of being signed up for assistance or for alerts when our phones didn’t work? I couldn’t make a phone call at all! I was scared for my son’s*

*life. At one point I was sure I would have to take him to the hospital. And I haven't taken him out of our home since the COVID pandemic! Thank God we are ok."*

### **Issue 3: Medical Impact**

Through our survey, DRTx received tragic stories from people with disabilities regarding the storm's impact on medication utilization. As stated previously, many medications require refrigeration, so when the power went out for an extended period, people could no longer take their medications. Additionally, a lack of service coordination and proper information meant many people with disabilities could not access an advance supply of medications from pharmacies, be transported to a medical facility if an emergent condition occurred, or even contact their medical provider, which further threatened their health and safety.

*"My son takes a medication that has to be prescribed and handed to me. We had to ration my son's medication because I could not get the medication during this emergency."*

*"I receive home health services because I need assistance getting out of bed, toileting, eating. My agency called me two days before the storm to ask if I had help because they could not guarantee that my provider would make it in. Thankfully, I'm really good friends with my provider and she made it through to me. But not once did anyone call to see if they could help or assist me in any way. And if it had not been for her, I would have been stuck in bed without help for four days."*

### **Issue 4: Mental Health Impact**

The impact Winter Storm Uri had on people's mental health has been largely ignored. Due to the COVID-19 pandemic many people with disabilities are already struggling with their mental health because of isolation and fear of contracting the virus. When the power went out and the water stopped, people with disabilities, some who were diagnosed with mental illness, experienced unnecessary trauma. As the survey revealed, the storm has continued to negatively impact mental health long after the ice had melted.

*"The night before the storm my 14-year-old daughter with Autism, [Attention Deficit Hyperactivity Disorder] (ADHD), [Obsessive Compulsive Disorder (OCD)], [Sacroiliac Joint Dysfunction] (SI), and unspecified mood disorder, attempted suicide and had to be admitted to a facility where she was unable to shower for several days. I called the facility and [explained] that she has a skin condition that gets infected really quick without being cleaned regularly and that*

*she needed to be washed, and that she was telling me she stunk and the other residents stunk really bad. The Head of Nursing was very apologetic and quick to fix the problem. Water was restored and the residents were given showers and their clothes were washed. Upon discharge her skin was sure enough infected and she's back on Minocycline which is constantly out of stock with the pharmacies. She doesn't do well with change and she always gets violent and destructive when things get too scary and she doesn't understand them."*

*"My daughter had just returned home from inpatient psychiatric care the day prior to the storm's impact. Severe weather, in addition to what she'd just experienced was traumatic on [its] own. As an only child, having to be secluded and away from school even longer due to our community's lack of access to clean (or any) water, electricity, or safe roads to travel complicated her already fragile mental health. Further traumatizing was the fear of the unknown we all faced. Not knowing if we, our loved ones, and our community would be safe. Furthermore, we were unable to re-engage her in a much-needed return to regular routines, as is recommended after care, due to a lack of basic needs being met across the state."*

## **Issue 5: Financial Impact and Food Insecurity**

While our survey questions did not specifically touch on these subjects, we received many responses in the open ended comments about the financial impact and the food insecurity issues caused by Winter Storm Uri. To provide some perspective, a 2019 study conducted by the Institute on Disability noted that in 2018, the poverty rate (percentage of individuals living in families with incomes below the poverty line) was 26.9 % for individuals with disabilities. In contrast, in 2018 the poverty rate of people without disabilities was estimated at 12.2%. This means that the poverty gap between people with and without disabilities was 14.7 percentage points in 2018.<sup>1</sup> This data shows many people with disabilities are already economically marginalized, and the cost of replacing lost food and medications because of a lack of refrigeration has placed increased pressure on their already difficult financial situations.

Unfortunately, food insecurity has been a consistent issue for people with disabilities. According to 2010 U.S. Census Data, nearly one-third (31.8%) of all U.S. households with food insecurity included a working-age adult with a disability and nearly 38% of households with very low food security included a working-age adult with a disability. By comparison, 12% of households with no working-age adults with disabilities were food

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<sup>1</sup> [2019 ANNUAL REPORT ON PEOPLE WITH DISABILITIES IN AMERICA. University of New Hampshire – Institute on Disability /UCED](#)

insecure. The census also demonstrated that food insecurity is an issue even when people with disabilities were employed: over 20% of households with an adult with a disability who was working full-time were food insecure. It is safe to assume that these issues have been further worsened by the double blow of an ongoing COVID-19 pandemic and Winter Storm Uri.

Complicating matters further, our survey showed that people with disabilities experienced a loss of expensive medical equipment and extensive property damage due to flooding which occurred from broken pipes. Some homes were so damaged that people were displaced and have to now bear the increased cost of obtaining new housing.

Finally, there is the unforeseen economic cost of extremely high utility bills, either due to electric utility providers having consumers on plans that allow for price gouging, having to run water for an extended period to avoid broken pipes, or excessive water usage due to a broken pipe.

*“[Need money]. Gridity charged us starting the exact day our electricity went out and continued until the following week. It was like a slap in the face. We lost all our perishable food and had to buy more. We didn’t have water so we had to buy bottled water that was sparse. When the water returned, we had a boil notice, so we just kept using the bottled water to brush our teeth and stuff. The boiled water looked disgusting. It had a film on top and I was not going to use that for anything. I accidentally brushed my teeth one morning without bottled water and I had diarrhea all day. My migraine medication is worthless. It is very expensive and my [insurance] company pays for it, thankfully, but I feel sorry for them.”*

*“I need my food stamps replaced as all our food was spoiled and 311 told me I did not live in San Antonio even though SAHA pays part of my rent. So we never got the hot meals, and water. So I was unable to care for myself and my elderly mother who just had cancer. There were not blind resources given to me when I called.”*

## **Section 3: Recommendations**

All of the previous stories describe terrible consequences from Winter Storm Uri that never should have occurred. These situations could have been prevented with improved infrastructure and emergency planning for extreme weather events. Many of our survey respondents included personal stories about their experiences during the storm as a person with a disability - some of those additional responses are included at the end of this report.

Additionally, to prevent putting people with disabilities at risk in the future, we have provided the following recommended steps that Texas can take as governmental entities engage in weather disaster planning going forward.

### **Ensure all disaster planning is inclusive of people with disabilities.**

Emergency plans of public entities must adhere to the standards of the Americans with Disabilities Act (ADA). People with disabilities are extremely vulnerable during a disaster, and it is imperative that the state account for their unique needs when planning for disaster response. These efforts must include seeking input from the disability community to identify specific needs during the planning process. Operational infrastructure can be a life-or-death matter for people with disabilities, and not including disability services in disaster planning is irresponsible and unacceptable. To ensure that the needs of people with disabilities are considered, the state should:

1. Encourage state and local agencies responsible for disaster planning to involve the disability community in the decision-making process by including community members with disabilities on committees and other governing bodies;
2. Increase public awareness of State of Texas Emergency Assistance Registry (STEAR) for the purpose of getting more high-risk individuals with disabilities registered. Additionally, mandate state and local governments to use STEAR data to conduct proper emergency planning to provide a timely and appropriate response;
3. Require that all emergency planning consider the impacts that weather events including the resulting isolation that comes with power outages, have on individuals experiencing mental illness. Emergency planners should work with the medical community, social workers, advocacy groups, and most importantly, persons experiencing mental illness, for key recommendations of how to incorporate emergency planning that addresses the accessibility issues persons experiencing mental health face during a crisis such as Winter Storm Uri;
4. Increase funding to community-based Medicaid waivers or other state funded health services to allow for the purchase of generators if deemed medically necessary for high-risk individuals with disabilities;

5. Increase public awareness of Texas Occupations Code Sec. 562.054 (a.k.a. the Texas Pharmacy Act). When a disaster is declared, this law allows a pharmacist to dispense an advance 30-day supply of a prescription drug other than a Schedule II controlled substance. Additionally, public awareness should be increased of the Texas Health and Human Services Emergency Prescription Assistance Program (EPAP). EPAP allows enrolled pharmacies to process claims for prescription medications, certain medical supplies, vaccinations, and some forms of medical equipment for persons without health insurance who live a federally identified disaster area;
6. Ensure that appropriate medical supplies are stocked at multiple sites such as warming centers and shelters, not just hospitals and health centers, to allow for wide distribution and prevent shortages. Additionally, ensure that medical personnel are on site to administer medications; monitor and assess medically fragile individuals; and provide appropriate medical interventions as needed; and
7. Require all public entities covered under Title II of the ADA implement in their emergency plans ways for addressing food insecurity during a disaster.

### **Improve notification systems ahead of disasters.**

While Texas has some disaster policies in place to address the needs of people with disabilities, due to a lack of enforcement and coordination between state agencies and local entities, these policies are not having an impact. The state's voluntary registries are a perfect example of efforts that proved ineffective, and, unfortunately, have resulted in more harm than good. Because these registries have not been publicized, we have heard from members of the disability community that they thought they were registered when they were not, and therefore expected services they never received, including exemptions from blackouts. To be certain that people with disabilities are aware of important information pertaining to disasters and emergencies, the state should:

1. Ensure that public utility Critical Care registry lists are accurate and used for their intended purpose of alerting localities to people at elevated risk of complications during a power outage. Individuals on these registries should be notified of any power outage ahead of time, or exempted from any "rolling blackouts" due the power grid overflow;
2. Require that all notification and alert systems be accessible and provide effective communication for all persons with disabilities, including, but not limited to, persons with visual impairments, who are deaf or hard of hearing, or who have neurological conditions. These systems should be routinely tested to make certain that messaging can be sent out timely during a disaster; and

3. Require that all alert notification systems be publicized, including using local stakeholders and advocacy organizations for persons with disabilities to help with outreach.

### **Disaster planning for cold weather events, including weatherization, should be treated as a priority for the State of Texas.**

Climate change is only going to increase the frequency and severity of cold weather events, and Texas must make a greater effort to plan for them. To keep Texans safe during cold weather events, Texas should:

1. Provide direction and oversight of public entities to make certain that preparation for winter weather is sufficient to avoid a repeat of Winter Storm Uri;
2. Require that public and private entities adopt the recommendations of the “Report on Outages and Curtailments During the Southwest Cold Weather Event of February 1-5, 2011”;
3. Adopt minimum, uniform standards for weatherization of natural gas production and processing facilities;
4. Require that public entity properties receiving federal funding, such as public housing authorities and tax credit properties, modify their properties to include alternate energy sources, such as generators or solar panels; and
5. Require that transportation vehicles be weatherized and accessible for persons with disabilities to help facilitate transport to critical care facilities, such as hospitals, warming centers, heated temporary housing, and any other shelters.

## **Section 4: Additional Responses to the Winter Storm Survey**

We have included quotes from people with disabilities who took the survey throughout this report. We would also like to include the following words from others that continue to express how our state’s lack of preparedness endangered the lives of Texans with disabilities.

### **Issue 1: Power and Water**

“I have been unable to sign up for the electric priority list with Entergy due to very poor management at Entergy (broken website links, 45 minutes+ wait time on the phone, and when I emailed the priority list request to the email address that the Entergy phone rep instructed me to email, I simply got a reply telling me to call the Entergy number again), and I have no other choice of electric providers in my area. We need to be on the priority list as my daughter requires [electric] medical equipment to maintain her airway ([Durable Medical Equipment] (DME) for tracheostomy).”

“The way the blackouts were handled was racist. Lakeway didn't lose power, downtown Austin was lit up like a Christmas tree but East Austin was blacked out for four days.”

“My 3-year-old daughter has Down Syndrome. After freezing all night in a house without power...temps below zero...she was shivering in the morning and vomited. We drove to Oklahoma and stayed in a hotel to keep our children warm.”

“No electricity, [full] outage. I could not use a videophone to call my family [and tell them] that I am okay. I could not call a hotel. I could not call Houston Mayor's Office [for] People with Disabilities. Nothing I could call because videophone, modem, internet access require electricity.”

## **Issue 2: Help from Local and State Government Programs**

“I am blind and without the assistance of my [sighted] brother, I would have been stuck in my apartment with no power for 78 hours. I also would have been without water for a week. Luckily he is staying with me currently, but generally I live by myself. I did research to determine what services Dallas county or the city of Dallas was offering to people with disabilities as far as assisting [to] warming centers, or assisting in getting water, but found nothing. I know the city of Austin had para transit services delivering water if needed to residence, but I did not find that type of assistance in Dallas if it was provided. The city talked a lot about offering warming centers, but there was no assistance offered for people who did not have the ability to drive to go to those warming centers, that’s leaving us in the cold with no way to recharge or warm up for a short period of time. I am very disappointed in the lack of services, or at least lack of information, to Dallas citizens. If services were available, Dallas city and county needs to do a better job of advertising those services. I work for Texas Health and Human Services and have the ability to do that type of research and still found nothing. That concerns me for the families that I work with who don’t have as much ability as I do to access services. Calling 211 was not helpful at all. I spent an hour on the phone at one point and still didn’t get through to anybody for services.”

“All emergencies and alerts MUST be in ASL and no interruptions like covering the screen for ASL.”

## **Issue 3: Medical Impact**

“There is one medication my son takes that has to be prescribed and handed to me that could not be done during this emergency so we had to ration my son’s medication.”

“I did not have enough medical supplies. Because I had no water, I got skin infections at injection sites.”

"I did not have transportation to the warming [centers]. We had no way to leave. My daughter called 911 because I became ill. They made an expectation and took us to a friend's. Then I became ill and had to go to the hospital and had no way to come back home except ambulance. I was told I didn't qualify because I could sit in a wheelchair. I did not have my wheelchair. There was talk we might have to sit in the atrium on a stretcher. The only way I could go home with all para transport closed and I cannot sit or stand independently. My daughter had to hire an ambulance for close to a \$1000 that was a great burden to pay."

#### **Issue 4: Mental Health Impact**

"Being a child with special needs made it hard for me to have to leave my home so quickly and to have to be [away] for so long. I did not understand what was happening which [caused lots] of anxiety that [lasted] for over a week and I am just now feeling safe again in my home."

"I had no heat and or electricity and no water. [With the] frigid temperatures I thought that I would freeze to death and be found months later dead. I still suffer from agonizing anxiety and depression and panic attacks that I was having during the winter storm and feeling isolated and miserable in my apartment."

"I thought I was going to die."

"Winter Storm Uri created a terrifying situation where I did not know if my family would have a functioning place to live. Not having a safe place to live kept me up at night because I'm at serious risk of severe disease or death should I get COVID and one of my children has disabilities that [impacts] her ability to process change. The fear that this will happen again and we will not have a functioning home and the impacts that would have on my family has continually produced sleepless nights, fear, anxiety, and worsening depression."

#### **Issue 5: Financial Impact and Food Insecurity**

"My light bill is very, very high. I need help with paying for it. Better heat to heat my house. I was very, very cold."

"Need assistance with medical costs related to my hospital stay and for my home to be inspected for any winter damage. Plus [replacement] of a wheelchair I borrowed to try and get to bus line but it froze in the snow and had to have my son come carry me home. Of course it wasn't there when the snow melted. Worried about my electricity bill even though we didn't have power for almost five days."

## **Section 5: Concluding Remarks**

Disability Rights Texas would like to thank all of those who responded to our survey and to our community partners who helped to distribute the survey. As stated before, our purpose in conducting the survey and publishing this report is to highlight the severity of the impact of this weather disaster on Texans with disabilities that will continue to occur until state disaster planning is inclusive of the needs of millions of Texans with disabilities.