Disabled During Disaster

Experiences of a disabled survivor of Hurricane Sandy in the disaster system

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The Calm Before the Storm

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Afterword
The Calm Before the Storm

It would be a busy weekend. My son and his wife were traveling to Long Island for a two-day Bar Mitzvah and planned to sleep at my home on Saturday night. I made spaghetti sauce, roast chicken and two pounds of honey roasted shrimp, just in case we had dinner. There were two pints of Ben and Jerry’s Chocolate Chip Cookie Dough in the freezer, my son’s favorite, and a lemon meringue pie. Since my sons moved from Long Island several years ago, visits were a treat.

As others, I was casually watching reports of the hurricane coming up the east coast. All day pretty women in red dresses made cutesy quips to weathermen about this and other storms. But the bottom line was always that it would hit us with winds of 75 miles an hour. I and others reacted with the knowledge that we had been through storms like that before. There were not predictions, like last year, that this was “the storm of the Century,” when I had gone to my son’s house in Albany. And then I couldn’t get back for a week because the upstate inland streams and rivers swelled and destroyed roads and whole towns. There were no ominous reports on this one, until late that last evening, when they finally dubbed it a “Monster Storm,”. and officials belatedly warned, “Don’t underestimate this one.” I never received an evacuation call, like I did last year.

The night before the storm surge, I sat content, making 48 meatballs for our Christmas Eve feast, a difficult task with intractable pain. But, my disability had always been my challenge, not my master, certainly making life more difficult, but more productive and satisfying; because the more difficult my life became, the harder I tried, the more I accomplished.
Christmas was looming in my mind’s eye, and by making one dish every two weeks, I had a feast in my commercial freezer by Christmas Eve, and the pain of the cooking was behind me. The meatballs turned out yummy, evenly browned and fragrant. I lined them 1/4 inch apart into a sparkling white Corningware roasting pan and placed it covered with foil in the freezer next to two casseroles of buttery-tender pot roast, a white meat chicken and broth entree, two spaghetti meat sauces, a lasagna, and four pounds of shrimp waiting to be honey roasted. Sweet satisfaction!

I had finished phase one of Christmas. Prior planning was crucial for me for successful implementation of a holiday, if I wanted to join in. I was a master of organized living, not by choice, but by necessity. And nobody ever knew how deliberate my decisions, my actions were, because I was o.k. That’s the way I wanted it.

Morning came, and I felt like I was being crushed and torn apart at once. I knew it was the change in barometric pressure. It was eerily calm, warm and humid. I spent the time washing my hair, washing my dog and washing all the floors. How ironic, to wash floors not dirty, when 24 hours later a storm surge would splatter sewage across my nest, lacerating tomorrow. Oh the violation: the disrespect!

About two o’clock my son’s wife called, saying they had finished early and were on their way. I was ready. I was prepared for any turn of events, except Sandy.

They arrived at the house stressed, because my daughter-in-law’s cousin had been rushed from the Bar Mitzvah to the hospital for complications of Ovarian Cancer. We spent the next two hours sad, agitated, frustrated, and bewildered. Finally they decided to go to her sister’s in-laws house in a neighboring town in the hope of learning information about her cousin’s condition,
only to learn that she had emergency colon surgery. There was dinner with her family, and a late
evening return to a warm soft bed. We promised we would eat my dinner the next time they
came. None of us suspected there would never be a next time.

Morning was hectic, as my son’s wife wondered if she should visit her cousin in the
hospital or attend the son’s Bar Mitzvah. They decided to stop at the same in-laws and take it
from there. She came into the living room in a black and white halter dress, smiling, “Take our
picture.” Those were the very last pictures ever taken in my sweet home, of two lovers, all
dressed up, acting silly, anticipating showing off new dances they learned in Manhattan.

The weather reports had gotten more specific this morning. They were now saying it was
going to be a big storm, a strange storm because of the tides and the moon, and an unprecedented
loop that it was going to make at about the level of Long Island. The storm, they predicted, was
going to hook to the west, pick up a cold front, and loop back to Long Island with the cold front
inside of it. But they always prefaced the reports with the fact that the winds were only 75 miles
an hour, hardly a hurricane.

I suggested that my son and his wife should either stay overnight at my house or leave the
party early, because it was predicted that the storm was going to make landfall in Northern New
Jersey. My son assured me that he was watching the weather forecast, and if they needed, they
would leave the party early. “We are going to be in Long Beach, right on the ocean, so we will
be able to see if it gets bad.” Who imagined big chunks of Long Beach would be gone tomorrow.
Certainly not two innocents dreaming of dancing in party clothes. My son’s wife repeated that
this party was just really important to her. I just wanted them home safe before the storm hit. It
was 11 a.m. when they left the house, pretty and unafraid. I was uneasy at their optimism. I
feared them crossing the Bridges in a high wind, or driving into a blinding storm on I-95. That
was the last I heard from them until about 4:30pm, when I looked on Google Latitude on my computer and saw that they were almost home. I was relieved, but thought they had cut it close.

I crawled into my hospital bed, unawares that I would never be that comfortable again. As my throbbing body settled into memory foam and my service dog snuggled under my arm, I whispered one last time, “Thank you God.” I was at peace.

Sunday was the 29th, the day my world went away. The wind was picking up. The air was moist and claustrophobic. Watching my favorite classic movies, I was cozy and content in my sweet bed all day. Every once in a while I would tune into the weather. Until evening, there was really not much new. But evening hours brought news conferences with officials warning us, “Don’t underestimate this storm. It is going to be an extremely dangerous storm.” They explained the moon and the tides, and the turn west to pick up the cold front. Their voices were stressed. Suddenly there was no time to prepare. No time to be afraid.

I wondered why officials waited so long to warn us? If my two sons had not pushed me to evacuate, I would have chosen to be comfortable and warm in my own bed. I would have been in my hospital bed, plugged into the wall, as 6 feet of turbulent water sheared off my front door, gulping chunks of my past, spewing unsanitary slime across my treasures. My bed, my comfort, my sanctuary, went on fire.

I went to my ex-husband’s house: uninvited, calling up favors, close-by and north of Sunrise Highway. He slept in his bed with his cat, snoring. I slept on the floor, with my service dog, moaning softly with spinal pain, wishing I was at home in my own bed. All through that last
dark night, in that unwelcoming place, the wind and rain outside seemed no worse than a Nor’easter. Not so bad.
I opened my eyes to an overcast murky world that would not lift, foreshadowing reality: a world that would become too stark, too awful, too present, to bear or to escape. A light rain fell, winds gusting with deceptive lack of force, lulling one into false optimism, soon to be shattered.

I woke crumpled against the wall of a cold, overcrowded room smelling of cat, on the floor, wrapped in soft blankets I brought here, with my service dog clinging to my lap. There was pain, much pain, and I just wanted my own bed. My only goal was to get home and uncrumple myself in my sweet nest. The storm was over. There was no heat or electric. But I had lots of warm blankets at home and we would be just fine. So, I expressed my gratitude for the shelter, and headed happily away.

The rain was no intrusion to driving and the wind was a relief from stuffiness. I thought of strawberry ice cream in my freezer and decided to make it a special breakfast treat, rather than watch it melt away with the power outage. Whack! In front of me across the road, a tree: a wall of branches, now blocked the road. Looming fast, it was reality, right smack in front of me, looming fast. Something powerful happened to make this giant fall in such an undignified manner. I was jolted.

I could not turn right nor left, but turned around and found a street around the giant, broken and defeated. Suddenly the winds seemed stronger and the rain was more in my face. I squinted watchfully as I made my way along side streets strewn with branches. Driving south, trees across the road increased in frequency. They were like footprints to the deconstruction of my life.

Coming down Willoughby Avenue, Merrick Road was the line of demarcation. Below Merrick Road the path of the water was devastating. Above Merrick Road, homes were untouched. I did not know. Most of us had no electric or television since yesterday, so we saw nothing that happened during the storm. I continued across Merrick Road, down Willoughby. At the postman’s house, the prettiest house in the neighborhood, just renovated last year, with 4
little girls sleeping inside, there was a huge tree across the road: fallen away from the house, not touching those on the other side. Around the corner a large curbside tree had torn through the living room roof and wall of the yellow cape cod with violets along the fence. White curtains, tangled in the branches in the wind, were tattered and filthy. I became aware of violence, and worried for little children. My car moved faster, past people I did not see. I pulled slowly in front of my modest green ranch house: all seemed intact, oddly silent. Neighbors were uncharacteristically standing clustered together, but I paid no attention. I was looking at the dark boggy earth that had become my front yard.

I backed into my driveway as I always did. The ground felt soft and slippery beneath me. I snuggled my car by the side door and sighed, secure. I was home! The storm was gone. How quickly we make assumptions based on what we want to believe. I did not notice the leaves and branches strewn across my yard. The cinder block wall that I built so many years ago was smashed against the north side of the house, in pieces. I was overwhelmed by the fury: I filled with fear. I picked up my cell phone to call my children, but realized they no longer lived close by. I sent an email describing what I saw, ending with, “I am afraid to go in,” not realizing how understated those words would become.

The ground had become spongy, a soggy black bog. There was a foul stench about the yard. Putrid black silt covered the back stoop, broken wall, and back door. I put the key into the lock and turned it gently. It was as if I was a stranger, the door was blocked against me. I pushed, but it did not budge. Puzzled, unable to enter my own home, I approached the front door. The metal storm door was bashed in, hanging in shards that tore the coat off my back. I pushed the metal inner door: it opened barely a few inches.

Furniture was piled against the door, placed there by a vile intruder, pernicious. I had to break into my own home, like a sneak thief in the night. Both entries were rudely barricaded by furniture. Nothing could have prepared me for the violence inside. It was like a tornado hit, but left the walls standing. My home, my sanctuary was shattered, disrespected, violated: my belongings torn, twisted, fractured, muddy, smeared, stinking, filthy, clotted, polluted, defiled, clumped into one horrific collage. I was appalled! I was horrified! I was afraid.
Black silt, brown residue, leaves, seaweed, muck, covered everything. My life welled up in my throat and poured from my eyes, gulping, gasping. It was my worst nightmare. The 48 inch cabinet television was thrown to the floor on top of the cable box, VCR/DVD player and Roku, all gifts from people who love me. My movies! I gasped. “Oh my God. Oh my God”. Everything in the room was somewhere else. My double memory foam hospital bed that took three men to carry into the house, was thrown across the room like a toy. A gallon jug of vinegar that was by the back door was thrown against the north living room wall. The couch, the love-seat, hassock and my bed were soaked with slimy seawater and stinking sewage. Fifteen tanks full of oxygen were flung about the rooms and propelled down the hall amid macerated sea plants. A thick brown trail of sewage wiped across my bed, the couch, through the electronic equipment, and grossly down the hallway to the bedrooms and bathroom. There was the acrid smell of fire. I was choking, wheezing, smothering from the oppressive air.

My fluffy white service dog jumped from my arms onto our precious bed, strewn with pillow pets she loved. I gasped and grabbed her from the vile polluted mess that had been my comfort, my solace from the pain, yesterday. Baby pictures, birthday cards, reference books I used in my writing every day, scores of classic movies, vital papers, vitamin bottles, leather folders, jewelry, unused check books, paper clips, lemon drops, fleece blankets and shirts, teddy bears, antiques, brass lamps, houseplants, Florida sea shells, couch pillows with pictures of bunnies and teddy bears, were smeared with sewage and strewn about the room. My honey oak desk drawers were dashed, broken: filled with water, filled with tiny treasures, special papers and poop. My emotions ruptured across the fetid mess before me. I sobbed uncontrollably, mumbling to myself over and over, “It’s gone. All gone. I lost everything. It’s all gone.” Over and over throughout the rooms I heard my voice. The violence in that room was terrifying. My cell phone rang. All I could say was, “It’s gone. All gone. I lost everything.” I don’t know who was listening.

The floor was slimy and gritty all at once. I was devastated. I was destroyed. I was appalled. The house smelled pungent, acrid. I was nauseous. My eyes were flaming coals ignited by the stench. I was numb, operating in slow motion. I screamed, but no sound came from me. I
was in someone else’s nightmare, not my own. I was alone. I was not there at all. The smell was smothering me.

I saw pink glittering through the slime in front of me where a box of my tiny treasures smashed to splinters. I reached into the muck and grasped a smooth hard rock. It was a small quartz cross my son gave me many years before. I grasped the contaminated artifact to my heart and sobbed without shame. The world was too much with me.

There was no place to walk, nothing to touch that was not foul and nasty, contaminated. This was my home! The floors of the halls from the toilet to the living room couch were encrusted with thick brown residue, smeared up the walls and on the furniture. All of the bedroom doors were also blocked with furniture. The floors in the halls were torn up, splintered and shattered, strewn with plant life. My manual wheelchair was lying dead on the floor: reeking and drenched. The Everest and Jennings semi-recliner was a prize: I kept it like new because they don’t make semi-recliners anymore and that is what I need. The door to the linen closet was open: bedding and towels three feet up were soaked and soiled. Under the bottom shelf a Jacuzzi portable whirlpool was ruined in its box. So many hours this machine had eased my pain.

The bedroom next to the bathroom is my office, where my computers, copy machine and office equipment, and a multitude of irreplaceable documents are kept: my writings for 55 years, my poetry and notes for books in progress; documentation for 35 years of work as an advocate for disabled individuals and as a Consultant for Equal Access; architect’s plans and photos for access projects completed; my medical records. All of these documents were tucked away in plastic bins or fireproof boxes in large locked metal cabinets and locked steel file cabinets around the room, next to an oak computer desk, a maple desk, and my $7,000 computerized traction bed.

The room was in shambles, like someone had ransacked it. Locked fireproof boxes were tossed across the room like paper bags, turned upside down, full of water. Locked cabinets and desk drawers were dripping: opened gushing putrid water. Plastic totes were full of brown slimy water: documents floating, clotted and illegible. There was no crevice that this insidious slime
did not breach. I was incredulous. Most of my irreplaceable documentation was lost. My heart stopped. It was like my work, a vital part of my life, ME, never existed. I was bankrupt!

Near the door was a stack of clear totes. I was in the process of reorganizing my winter clothes. The unused totes were full of sewage water: the clothes were wet and fouled, clumped on the floor. Office supplies, a laptop, two portable hard drives, copy machine, CD rewriter, DVD player, four typewriters, intermingled with clothes, bedding, shoes, brand new pants and fleece from Lands End, toiletries, computer programs, camera bags, suitcases, and a box of books on what to eat for Cancer purchased from Amazon and not yet read. Strewn about was anything that floated by and was ensnared by this gross collage.

My life-long desks, pristine solid wood, drawers swollen shut, cemented against me, to be broken into with tools of destruction, would reveal putrid clotted vital documents devoid of recognizability or purpose. The terror throughout my house was tearing large chunks from my flesh and leaving me hemorrhaging into the rancid muck. On the floor I noticed my tiny Gund teddy bear, fallen from great heights, gulping sewage, staring up at me, oozing dung, lost and alone.

My hand reached out to him, until I saw my computerized traction bed, covered with stuffed animals, ruffled pillows and pretty flowered comforters, like a quagmire oozing slop into its sophisticated mechanisms. I knew then that relief from spinal pain, comfort as I had known it, would never be the same. I lost my lifeline to normalcy. I had lost medical equipment that I could never replace in my lifetime. I laid my face upon the foul and putrid bedspread, caressing yesterday, and wept to exhaustion. All at once I felt hopeless, panicked and numb.

The middle bedroom was a storehouse of my professional books, stored pedantically in briefcases on a rolling cart for easy use. Over 35 years I had amassed a library to rival institutions. All were gone, in the flash of a sewage surge: all saturated and unreadable. I saw the color of my blood oozing into the debris below and I was weakened with its letting.

Large bins of medical equipment I use every day were overturned and filled with gunk: traction accessories, a multitude of electrical devices for heating and cooling, massagers, two leg
braces, passive night braces and heel pillows, an Ultrasound unit, Air Circulation Legs, two passive exercise machines, and on and on: an arsenal to ward off pain and deterioration, soaked, slimy, ruined. I couldn’t think, or feel or cry anymore. it was as if something broke inside of me. I was defeated, destitute, shattered. More winter fleece and pants were one huge clotted mass, a spongy bog wrapping itself around smeared paper pages and electrical cords. Would I ever be warm again, or safe?

The master bedroom had a double bed, used when my children visit from out of state. The pastel patchwork bedspread was deceptively pretty, until I touched it: it turned to stinking gelatin. I bought this pillow-top mattress for my mom: it was expensive and comfortable. I wrapped it in plastic to protect it from potential spills. Now it was a balloon full of water, waiting to burst. As we all experienced with our protective totes and plastic covers, the water rushed in and did not drain away. There was no way to stay the waters of destruction from their pernicious course. We are mere tinder, tossed about by willful tides.

My honey maple cabinet sewing machine of 50 years was next to the bed. I used it to make my clothes, baby clothes, drapes and pillows, everything, including beautiful Raggedy Ann and Andy dolls with pink cheeks and a real heart. Ruined! My sewing chest filled with accessories collected through the years, and patchwork patches saved from special garments over the years, pretty lace in various colors, flower appliqués and spools of thread, was filled with sewer water, to the tiniest thimble, was spitting straight pins onto the ruptured floor. My parents gave me this cherry chest for my birthday when I was 16. My mom bought this house I bought from her when I was 21. Gone! All gone! How fragile is one life passing by.

Two oxygen concentrators and a portable oxygen machine sat on the other side of the bed dripping sea water and silt. It was incomprehensible to me that I lost most of my medical equipment. I didn’t know what to do. I was paralyzed with fear. How would I survive? I had taken such good care of the equipment, and still it was gone, all gone: through no fault of my own. Could I survive? I had no answers. I was impotent.

Two passive exercise machines were flat on the floor, tossed there by the tides, soggy and rusting. And then I saw the most gross indignity. My power wheelchair, smeared and stained
with feces, upholstery saturated, mechanisms dripping: spent. I could not wrap my mind around this loss. I could only remember me and my service dog riding through malls, on boardwalks and into meetings, so grateful to be doing it on our own. I could not see, for all the tears were blinding me. I knew that I had lost too much right here. I mumbled weakly, “It’s gone. All gone.” No one was listening. Thousands lost everything in this “Super Storm,” dubbed a National Disaster: that would leave thousands upon thousands destitute, and the government listening with ears clogged by fiscal crisis. It would become survival of the fittest: with no help for the weak. It would become a National Tragedy, like Hurricane Katrina. I must be strong. I was hemorrhaging. Life was ebbing from me.

I fought the tears and vowed not to be a victim of this loss. But then I saw my Christmas tree strewn across the floor, lying passive beneath books, knitting needles, pillows, broken glass, a laptop, and a kitchen pot. I remembered it standing tall with tinsel and sparkling lights, year after year: hung with tiny toys saved from my children’s childhood, and any treasure that made my heart light up. Each ornament was a special memory invoked, endeared, and an accumulation of all the years and all the joy. My Christmas tree was a beacon of hope and joy and peace for me on cold winter nights. To see it sucking slime, it wasn’t right. I lost it yet again, and wept to exhaustion, unashamed, for my Christmas tree, my wheelchair, my hospital bed, my life. And I was done with crying for myself. All was lost and ruined and ugly. And I must find a way to salvage what I could of this my ebbing life. The stench of sewage, decay and fire all mixed together in this my house, was gagging me and I threw up.

In the hallway was a closet some use as a guest room: it fits a single bed. It gives access to the attic. I used this space for storage of functional tools: vacuum, large battery-operated hedge cutter, hedge cutters for the cemetery, a chain saw, George Foreman Grill, new Osterizer, Convection Oven, Brother Printer, sewing machine, fabrics, formal dresses and coats, my sons’ childhood memorabilia, textbooks and classic movies. Five-foot metal cabinets lined the walls. The first was office supplies: staplers of various sizes, computer and copy paper, stationary, presentation books, loose leafs, plastic pages, folios, folders, envelopes, computer programs, and computer bags. The second had small appliances, pots and pans and holiday dishes. The top
shelves were a storehouse of emergency and holiday food, organized, and replaced at expiration. I was proud of my secret stash, handy for unexpected guests: neatly tucked away.

I remember a number of times I went into this closet while the worst of a wind storm passed by, because it was in the center of the house surrounded by rooms: sheltered, protected. It seemed to me the safest place in the house. During Hurricane Sandy, this room gulped in and retained water like a thirsty fish tank. It became a tangled mass of necessary items made worthless, locked away or not. With loss piling upon loss, I became most painfully aware that nothing was safe or secure from this insidious Monster Storm that raped my home. And, no matter how much you do the right thing or prepare for a secure future, it can all be torn away in a millisecond by a force of nature, and you are alone, bleeding and unclothed. All of my plans and dreams, all my props and crutches, were torn away, I was lying in a pile of dung, anonymous. I was exhausted.

As I turned the corner, I glanced toward the bathroom that had puked this revolting indignity across my treasures. Its mouth was open wide and stained brown, from spewing excrement down my hall: reeking, festering, spreading plague. I was not prepared to forgive the unforgivable, so I moved on, dazed and overwhelmed.

As I passed by my bed, leaving, I longed to lie down and make my spinal pain go away. I wanted so badly to be comfortable: to reclaim my hospital bed, call this storm a fraud, tear these horrific images from my memory. I ached for yesterday. I feared that I would never be that comfortable again. I doubled over sobbing hysterically for all that was lost, for the innocence of my cloistered world that I could never regain. I was aware and alone. But I still had no way of understanding the terrible awfulness of being disabled during disaster.

I left the house through the kitchen, the route I customarily used to enter my home of 48 years. Cabinet doors were open, and expensive stainless steel cookware and appliances were scattered and pummeled, thickly crusted with feces. I was nauseated. My brand new ceramic top kitchen stove that my son and his wife had just given me was ajar and full of water. I gasped in disbelief. Why did I think that my appliances would survive? I was a vessel taking on the waters of injustice. There was too much destruction to calculate, and there would be no recourse to
recompense the loss. I knew that I would never in my lifetime have anything so elegant again. It was leveling. I was numb.

And so it went, loss upon loss: stove, refrigerator, dishwasher, dryer, washer, commercial freezer, and microwave, all filled with filthy water, all ruined in one rush of fickle fate. My kitchen, my cooking, Christmas dinner putrefying in the freezer, all gone. Mom was made effectively inoperable. Grit, leaves, silt, feces and slime was dragged across the floor and into every receptacle: violated. I could no longer cry.

I followed the stinking trail of debris from receding waters, through the foyer and out the side door. Turning to look back, I witnessed the gross course of destruction made by raging water battering the doors open, hours before. I was amazed at the difference a moment can make. I was raw, exposed, and vulnerable. I vomited up the stench of my house: the putrid, acrid, nauseating, smothering, tearing smell of armageddon, my comfortable nest! I gulped the damp musty air outside and was overwhelmed by its freshness.
I was alone, living in my car, not eating, not sleeping, not wanting to go on. I was walking around day by day in a fog, isolated, numb, consumed by reality: looking into the eyes of the world, seeing nothing, feeling nothing but grief. Not realizing I was one among thousands, I validated my loss. For during Hurricane Sandy I was cut off, we were all cut off, by massive power outages: from the visuals, from the overwhelming truth, the destruction, the drowning, from the suffering of thousands. So, in those first days before I met the others, the ghosts of the lives of other survivors, I was wandering around searching.

I instinctively knew the survivors as well as I knew my own features. and I needed to touch their flesh. I was searching the faces of men, looking for bleeding, for empty eyes, like mine. I recognized those like me, who lost everything, disbelieving, bewildered people, wandering, with no place left to go: belonging no where, owning nothing. I relived over and over the terrifying moments, as I followed slime and grit, into the devastation of my home, my life. The smell of my home, that rancid, acrid stench of extinction, burned my nasal passages daily, and I wanted to embrace someone who couldn’t get that stench out of his nostrils either. I needed to cradle broken hearts.

Within the context of having lost everything to a natural event that was no fault of my own, of having nothing left, of feeling very sad and panicked, I wandered without purpose, occasionally accomplishing necessary tasks. I entered CVS, looking for antibiotic and bandages for my fingernails, severely infected by contact with the sewage water entombing my treasures. I was neither responding to nor interacting with my environment: I was hardly a part of the world. There was no reason for me to be there.

I navigated my wheelchair up and down aisles overcrowded and blocked by carts of boxes and merchandise being loaded onto shelves stripped by frantic Hurricane Sandy shoppers. I was confused by the disorder, and frustrated, as displays of toilet paper and shampoo came cascading down on me. There was no place for me here, and my equipment. I was in the way, at
time of crisis. Store clerks scowled, as I bumped into displays and rolling carts, taking out end caps of water bottles and stacks of baby wipes. Standing, also in the way, at every turn, was a woman with a shock of grey curls, a red wool coat, and gold-trimmed glasses. She moved quietly, without purpose. She never looked at me, but clung to me. I recognized her immediately. She had empty eyes.

Neither one of us spoke to the other: we knew. We went through the store like that, silently meeting: passing. I needed to listen: she had something to say. But we were hurting too much to reach out. I took care of business and exited sliding glass doors that snapped closed behind me. The air outside was crisp and damp. The sidewalk was narrow and hazardous. As I navigated toward my car, there, coming toward me, were empty eyes. It was the woman in the red coat. I looked directly at her and said quietly, “Did you lose your house too?”

Words spilled from her like water from a broken dam. “I live in south Seaford. But, I only sustained minor damage.”

I swallowed deep and choked up a large glob of self pity. “I lost everything: my house, my furniture, belongings, $50,000 in medical equipment.” Every time I said it, it seemed less real. I had expressed my pain.

“I lost my son-in-law,” she said out loud, seemingly matching my pain.

I stopped breathing and tried to process words I did not anticipate. Surely I had heard incorrectly. “What do you mean?” I said with puzzled stupidity.

She seemed anxious to explain. “My son-in-law was crushed by a tree.”

Time stopped. I grabbed the words and rolled them around in my mind. I believed her. “I didn’t know anyone died in the flood.” I responded sincerely.

“Oh yes. Twenty-six people,” she said. “Two children were torn from their mother’s arms by the winds on Staten Island.”
“Oh my goodness! I didn’t know. I am so so sorry.” There were no words . . . She understood. She wasn’t looking for comfort. She was trying to hold on to her son-in-law.

“He was a good man, a good husband and dad: he was a good person.”

Her statement was written in stone: untouchable, unchangeable. I responded with a serene smile of understanding.

I was incredulous. The storm seemed so benign where I was sleeping that night. I felt cheated and stupid, that I didn’t’ know. This monster had destroyed my life and hers, and I had no visuals to process. “I didn’t know,” I said.

“Was the accident in Seaford?” I asked. What did that matter?

“No, they live in Lloyd Harbor. It happened in Lloyd Harbor.” She was in so much pain. She wanted to talk about the man. I wanted to remember him.

“What happened?” I said, almost whispering.

She was not crying. She was remembering what they had told her happened. It was like, if she told the story enough times, she would finally believe it. She needed to remember every detail. She needed to pass them on to someone. I needed to listen.

“They were evacuating. My son-in-law had put their two little girls in the car.” I pictured two little girls safely secured in the dry car by a father taking care of his family: two tiny faces in rain gear, droplets splattered across their foreheads, watching daddy running through the storm with salvaged armloads of clothes and necessities. I was once that tiny child being shuttled safely away from our flooded house by responsible adults. I felt their excitement, their fear and anticipation.

“A tree fell on him!”

“Oh my gosh!” I exclaimed. It was horrifying! It was real. It was what his sweet babies saw! There were no words! There was no comfort! There was only listening. There was a maimed and broken family, compelled to accept reality. My house, my precious lost house and
all my belongings, seemed so inconsequential now. People died! A daddy died in front of his two little girls. I was ashamed of grieving for a house!

“He put his daughters in the car. He was helping his wife. The tree fell onto the driveway. It crushed my son-in-law. It killed him! It struck my daughter.”

“Is she alright?” I gasped.

“No.” she said. “One whole side of her body is all black, where the tree hit her. She has broken bones. She is in terrible pain.” I pictured the mayhem: the mortal injuries in the deluge, screaming for help, babies crying, hysteria, flashing lights blasting silence. It was awful! It was too much to bear. A daddy was broken and gone on that monstrous stormy night.

“Is she going to be all right?” I insisted. How could she ever be all right?

“Yes,” was the quiet response.

“Did the little girls see what happened?” I asked, fearing her response.

“They saw everything!” she said solemnly. We were silent together.

I looked into her tortured face, and felt the inconsolable pain of a wife and children. I was overwhelmed: impacted by the loss of one unique person, the agony of a family broken and changed, forever. I was humbled.

I understood that I had lost very little in the scheme of things. My house was not a person. My former life could be reinvented. None of this was what I wanted to accept right now, but it was true. It would be truer tomorrow.
It has been seven weeks since the sewage surge tore through my home, and I still wake up each morning weeping uncontrollably. I wake with tears cascading down my cheeks, without sound, without grimacing, without thought: like there is such a deep void inside of me that the mechanism of crying is malfunctioning. I open my eyes to a room I do not know: black and white pictures of sharply twisted flowers line the walls. I want to cover them. I want to take them down. But it is not my room. My room was blue, with pictures of my children covering the walls, so that they were always with me. My room was comfort. My room was filled with equipment to alleviate intractable pain from spinal cord injury. There is no place like that for me now.

Hotel furniture and a giant flat screen television fill empty spaces devoid of me. My service dog Pollyanna, lying beside me on the bare hotel bed, looking thin and frail, is facing the door where people walk past in conversation: like a sentinel, she watches, yelping in her sleep, wrenched from the soft solace of pillow pets she slept beneath at home. Staring back at me from the mirror I see a worn and wrinkled woman I do not know: but I can hear her screaming my address.

Family, friends, passers-by, want me to leave this hotel and rest in their comfortable homes to heal, and smile and join the ranks of men again. They do not understand I do not want their lives. I want my own. But my life is broken, and the world goes on. There is no place left that is mine. There is no comfort. I own nothing. I belong no where. I have nothing to give right now. There is only gross physical pain and a longing for the comfort of my hospital bed and the medical equipment lost. How can an able-bodied person understand my loss.

So I am here alone and hurt, where I belong: with other bewildered homeless people with empty eyes and screaming hearts, longing not for their possessions, but their lives, their memories, tiny treasures that nobody else valued. I need to be here in this place where no one tells me it will be all right, and everyone longs to go home and cries in disbelief when the light strikes the morning. I need to heal with tortured and broken people, and to put the agony of a
lifetime lost into perspective in my own time in my own way, without judgment, without comfort, without guidance.

My soul knows where it is going next. And I must process in my own way, in my own time, the mechanisms of loss, change, identity, memory, acceptance and regeneration. Right now I do not want to go on. I want to be right here, where nobody cares about me and I do not have to consider anybody else. And that is okay.
On October 29, 2012, I was at peace with the world. True, I had a hard life, a very painful life, a life filled with medical, legal and structural challenges. But, I had created outcomes unimagined by most, quietly, over years, believing that I could, accepting no failure. I had accomplished progress for disabled people unattempted, because we were a beaten-down class of people. I loved my chosen work, advocacy. I was very good at what I did. I had a strong sense of support, security, and serenity.

That night the earth ruptured, spilling sewage, slime and scum across my safe haven. Indeed, thousands of lives along the East Coast of the United States, and Long Island were torn apart by SuperStorm Sandy, later to be spit out by FEMA. That was the night sincerity and belief ended for all of us and we learned about inept, unprepared government agencies, and what it feels like to be the underdog in a world that goes on without you. We learned that we did not belong. Overnight, for many thousands of survivors, the world became a horrible, unstable, outrageous landscape of bureaucratic crap, rancid officials, muck, outlandish decisions, poverty, rejection, half-hearted gestures, indifference, and callousness. A searing longing tore inside each of us, to go home. But there was no place left to go, except the slimy crypt of our lost lives.

And in this atmosphere of rejection and loss, I represented yet another layer: disabled during disaster. I was to learn the lesson of a lifetime, because I was disabled.

It had been a difficult road since the sewage surge for me, obviously physically, consumed in pain, absent my equipment, barriers everywhere. But the most insurmountable barriers had been in the minds of bureaucrats, governmental agency’s complete stupidity, inability and unwillingness to deal with anything related to disability or special needs. This created delays, denials, problems with paperwork, funding, living accommodations and communication. FEMA officers were perennially deaf, or just plain dumb.
Within this mindset, for three months I had been trying to make FEMA and all of its tentacles aware that I was not moving from the hotel to an apartment, because I could not physically function in an apartment, and I could function here in the hotel. I said it over and over — to every official, agency, badge-holder, phone caller, computer screen, piece of paper, finger tapping on keys. Still, FEMA never checked the box for disabled on my application, and agents threatened me on the phone and came to my hotel door to convince me to get out. It seemed that I was a cog in their carefully-coded, legally-allowable wheel.

After FEMA Agents came to my hotel room after dark on January 11, we seemed to reach a consensus that I was disabled and I would not be forced into an apartment. It seemed like the powers that be would finally stop hassling me. How easily we accept the apparent. The final drama in this sorry tale culminated within days.

On January 14 flyers were handed to each FEMA resident of the hotel, by a hotel employee. The paper said there would be a meeting on Wednesday, January 16 in the hotel lobby between 12:30 and 8 p.m. with FEMA and Nassau County Housing, to inform FEMA residents of their option to move on from the hotel into apartments and other temporary housing. The paper said we were expected to attend. On January 16 I had the flu. And, I had no thought of attending the meeting because I had just been assured by FEMA that I could stay at the hotel. I spent an uncomfortable day in bed, as I heard young FEMA agents scurrying past my room to the meeting, in conversation.

About 11 p.m. I noticed the red light on the house phone blinking. I dialed the operator. She said I had a “package” from Nassau County. Odd. The next morning I asked someone to go to the front desk and pick it up. It was a letter. Inside were three typewritten pages with 81 apartments listed. The envelope had the name of the Director of Housing and a phone number. I was shaking, because I realized the housing issue was not resolved. I called the number and left a message that I would not need their services because I was not going into an apartment.
The next day I went to my house to pick up my mail. When I returned, the house phone was blinking. I called the front desk and a woman said my “caseworker” had come to see me. I said I did not have a caseworker. She said, “Well they assigned you one.”

I wondered how this young lady, who brought two FEMA agents to my door after dark, knew that “they” assigned me a caseworker. “Do you want the card or not,” she said. A few minutes later she handed me the card and left quickly.

I looked down at the white business card. The words Adult Protective Services smacked me in the face like a sledgehammer. I stared, sure I had read it wrong. But there it was in bold black letters, Adult Protective Services.

I was scared, confused, sick to my stomach and angry all at once. I was shaking all over. What the hell were they going to do to me next? Had I fallen off the edge of the earth into Hell, or was Hell a four letter word called FEMA. I didn’t know what they wanted, or who did this, or if they did anything. I only knew I didn’t like that card. I wanted to go home, where young hotel clerks with attitude could not unlock my bedroom door on the whim of a county card.

I called the phone number, my voice trembling, and left a shaky message, “I don’t know what this is about, but I do not have a caseworker and I do not need help.” I hung up, feeling really stupid. I called back and went to the phone number the caseworker referenced if she was unavailable. I stopped following the County chain of uselessness after five consecutive answer machines. Diffused by the inefficiency of their system, I fell asleep more annoyed than worried. It was a nuisance, not real: so I thought.

The next morning I arose with a list of phone calls and tasks to accomplish. We, the survivors, were so engulfed with paperwork, documents, appointments, meetings, and phone calls since the flood, that it was like we had a full time job. I had no time for nonsense today. But nonsense has a life of its own, and the County of Nassau was triggered to wreck havoc on my life.

At 9:30 a.m., the phone rang and this pleasant-enough voice announced her name and title. I felt faint for a moment and then thought, I have nothing to worry about. Wrong! She said
she had to meet with me. I asked what this was about, wondering if this was a bureaucratic maneuver or something else. I was in unfamiliar territory. She gave me a non-answer. I persisted, “Did you get a complaint?” She said she had, that I was in danger, that I was not entitled to know who reported, and that she had to “investigate,” so when could we meet.

I was shaking all over. I went into panic mode. I started defending myself, against what I didn’t know. I told her all the good things I had done, how strong I was, how invincible and competent. I wouldn’t let her hear me cry. All of a sudden, I was a severely disabled lady in a wheelchair, scared the system was going to lock me up for being different. How did I get here? I was so alone, in a world full of people who didn’t wear their difference on the outside. They were safe.

We spoke for 45 minutes and I assured her I needed no help and would not meet with her. She said she did not think her boss would accept that. We ended amiably. I heard no more.

It had been bitterly cold for days. The pain in my spine, chest, head, legs, demanded more of my attention the colder it got, the longer I was without my equipment. It was a constant reminder of how different my medical condition made me from everybody else: a fact I had been denying on as many levels as I could for all of my disabled life. This whole flood thing made me feel like such a cripple, and put the heavy burden on me to carefully hide my limitations and look like everybody else. It took all of my energy. But I could handle anything. For 35 years my life had been one enormous challenge after another, medical, legal, structural, attitudinal, discrimination. I was surrounded by barriers I must climb over. Doors were closed and locked against me and I learned to make a key. Every challenge made me more creative, stronger. I was afraid of nothing.

I heard no more from Adult Protective Services for a week. It was 9:30 on Thursday, January 24. The caseworker with the card called my cell phone. She said that I must meet with her. I told her no. She told me that she would bring the police to my hotel room and I would meet with her. I felt weak, nauseous, trapped. This was not happening!
I said, “You are threatening me with the police! You are threatening me with the police?”
I was incredulous!

She said, “Let’s make this easy. I just need to see you for five minutes, to talk to you, to
make sure you are all right.” That didn’t make sense to me.

“I was fine until you stuck your official fist in my face,” I thought.

I spoke no more to this woman. She was obviously deranged. “May I please speak to
your supervisor,”

I was connected to a pleasant woman who, when she heard my name said, “How can I
help you,” like she didn’t know what it was about. She thought I was stupid.

I explained that this caseworker had threatened that if I didn’t meet with her she would
bring the police. The supervisor said, “She didn’t threaten you. She told you. We will bring the
police if you don’t meet with us.” She was crazy too.

I said she had no right to threaten me with police. I did nothing wrong. She just kept
prattling on. I had fallen into Social Services hell. I asked to speak to her supervisor.

The second supervisor was an inflexible woman who said if I did not comply with their
demands they would bring the police to my hotel room and force me. Her words came from a
book and her mind was fossilized. I turned my face away from her cold heart.

I did what I had to do to keep them from coming today. I scheduled an appointment for
Monday at 1 p.m. She changed it to eleven. I told her I would not meet with them without a
lawyer and a video camera. She mocked me.

But it was the weekend and all free lawyers, legal hotlines, the Attorney General, the
Justice Department, all legal services were closed for the weekend. I wondered what the
criminals did for weekend legal services. I called my Congressman. They would not “get
involved with an APS issue.” I was starting to feel guilty. I didn’t know what I was guilty of.
I had been fighting for the rights of disabled people for over 35 years, accomplishing unbelievable change; and now I was being discriminated against and harassed, simply because I was disabled. It was disheartening. It was disgusting. It was incredible that this antiquated action was being foisted upon me, the master advocate, accomplished barrier buster, nimble scaler of great stone walls. I didn’t tell my children. I was ashamed.

On Friday evening my son called and asked me what was wrong. I reluctantly told him what was happening. It was humiliating. I cried.

My son spent the rest of the weekend calling and emailing everyone he could think of, at FEMA, Nassau County Housing, Social Services, Adult Protective Services. There were responses saying it was outrageous: some offered help on Monday. But, despite his exhaustive efforts, Monday morning would come with no assurance that I was not going to be hauled away by power-crazed county workers and gun-toting policemen.

I had been unable to find anyone who was willing to meet with these people and prevent them from laying their hands on me. I was terrified, for no matter what I did, one could look at me and see that I was disabled. I was disabled! These people seemed to equate disability with inability. I was terrified.

The advocate in me, the disabled person, had done much soul searching over this long and tortuous weekend. And I cried a lot. I didn’t know what was going on, because APS offered no explanation, except that I had to meet with this strange agency that was acting like the Gestapo. I only knew that I was being singled out, compelled, specifically because I was disabled. The more I thought about what was happening, the surer I was that I could not comply. It was against everything that I had modeled over the years: about being an independent, barrier busting, self-sufficient, strong, disabled person: despite your disability, despite your pain, despite the challenges.

It was more than I could bear! It was against everything I fight for: against who I am. There was no choice. I would not let the system compel me to be discriminated against. I would not let the system make me a cripple. I decided, since I had accumulated no tools over the
weekend to fight with, I decided, uncharacteristically, on flight. By Sunday afternoon I was resolved. I had a plan.

It was a cold and snowy Monday morning. My son was still contacting people, trying to get the bureaucratic machine to stop turning. And, although the powers that be were assuring him that no one would show up at my door today, I didn’t trust the system.

I calmly packed enough food and clothes for several days, seriously not knowing if I would be chased down by misguided police cars and arrested. I was terrified of today and governmental systems without brains. I tucked my service dog under my arm and quietly left the hotel before dawn.

I went to my parking-lot office and jumped onto Optimum, behind an office building. I took care of business and emails for several hours, turning on the car intermittently for heat. My service dog, snuggled beneath layers of fleece, slept beside me, relieved that I wasn’t crying anymore. I was at peace with my decision.

I went to the bank, aware of every police car, and put the FEMA check in that I had been carrying around for a month, in case they detained me. Now that was safe.

Then I went to my house and parked on the street out front, not crying as I usually did right here since the flood. For right now, I was more me than I had been since that day that washed away my life in sewage: I was standing up for what I believed. I was the universal disabled person, changing action toward us, changing perception of us. I felt clean and serene. I sat there for hours in the cold car watching huge white snowflakes cascade silently to the desolate soil of my mutilated neighborhood and spread a winter wonderland before my eyes. Pollyanna watched the snow excitedly with me, until the quiet rhythm lulled her into sweet sleep. We were home. We were content.

My cell phone jarred me back to reality. I was sitting in front of my house with no walls, floors, electric or toilet bowl: Fema was insane, and APS was chasing me around with
policemen. I was still disabled. I ignored the phone. It rang again, and again. Finally I picked it up.

“I’m in the lobby. Are you coming out? You were supposed to meet me.”

I said nothing.

“Could you come to the lobby to meet me.” It was not a question.

I said nothing.

“You said you would meet me in the lobby.”

I waited a moment. Then I said calmly, “I am not at the hotel.”

“You what! You are not at the hotel? Where are you?” She exclaimed.

“I called you. I left a message on your machine not to come. I told you I would not meet without a lawyer. I couldn’t get one over the weekend.”

“You left?” It was obvious she didn’t expect that of me.

“Yes,” was my simple response.

“Where are you,” she said, obviously frustrated.

“That is my business.” I was not intimidated. I was not afraid anymore. I made my point.

“If you meet me for five minutes, I will close the case. I need to see you.”

I didn’t care what she needed. But I did want her to go away, dissolve back into the sewage surge.

“I will meet you on the corner of Grand Avenue in Massapequa, and I won’t get out of the car.” I said. I expected her to show up with policemen, as she threatened.

I called two people to witness the meeting. While I was on the phone, she called. “Where are you? What make of car are you driving?”
I drove down Grand Avenue and didn’t see a police car. There was no place to park, so I parked in the nearest parking lot.

A few minutes later, a mousy woman with a straight bob haircut, grasping a clip-board to her chest, walked up and said, “This is not me. My boss makes me stalk people. This is not my personality. I hate it.”

“Why don’t you get a different job,” I said sincerely. It seemed an obvious solution.

“I understand how you feel,” she said. “I really understand how you feel.” She had no idea how her threats had traumatized me. She was a frivolous lady enforcing the mandates of a broken system for a paycheck, without the conviction of her actions. (I later learned the APS ladies had no authority to threaten me with police without a formal hearing, compelling witnesses, before a judge.)

She stood shivering in the cold afternoon wind next to my car and said she was closing the case. I said, “So I will never see you again?”

She said, “That’s right.” I scanned her face for empathy. She was just a page with no words, hardly worth reading.

We engaged in light conversation. She said she knew I didn’t need help the first time she spoke to me. She shivered, putting on her gloves. I wondered why she harassed me for two weeks and threatened the police. But she was just a broken system malfunctioning. As she walked away, I felt sorry for her, for her lack of conviction. I closed the car window.
Give me a Place to Stand and I will Move Mountains! - Hope on Hold. 2-24-13

I become aware of a new day emerging, as sunshine bores through crevices in room-darkening hotel curtains, searing the stiff cloth with truth. My eyes reluctantly open to face the light, as I struggle to keep them shut, and reality at bay. I am weeping, spontaneously, uncontrollably, from imprints that won’t fade, clutching scattered slivers of my life with bleeding fingers, stroking sweet memories turned rancid and grim. I am exhausted with the weight of it. Tears are the only constant now. I awake each morning to ghosts, screaming uninhabitable addresses, unthinkable truth, shadows of tormented homeless people. I am awake.

I grow sicker each day, without the benefit of my medical equipment: for I am disabled, and every day is one more crisis to bear, until the last: and then we have to deal with FEMA too. When you are weak, terminal or old, time is a vulture poised to gash and gobble your flesh: you must stand stronger than the others, focus on the horizon, and keep walking.

My weary heart screams, “I want to go home. I want to belong. I want to do relevant things again. I want to do relevant things again! I want my treasures. I want people to remember me before I fell. I want to remember me before my world went black.” I want to slay the nightmares, but my weapons were mangled and swept away.

And reality screams back at me, “You have no home! Your house is an empty shell: without walls, without floors, heat, electric, a toilet bowl, a kitchen, without furniture and belongings. Your house is without comfort and security, growing black mold, foul smells and unknown strains of bacteria. Your house is a wasteland, devoid of history. You never existed. Apocalypse! You are chewing rancid morsels of sweet yesterdays, and gathering scraps of sewage soaked memory. It is disease. It will take you down. You will perish, unless you let it float away. It cannot be saved.”

I look into the mirror and I see a woman wrinkled beyond recognition by one fleeting blow. I see a crowd of faces, lost and wandering, dreading the dawning of each new day. I see a
child without toys, hysterical, because there is no place left to play. I see pets squirming, in boxes, cars and blankets, hidden away. I see a walled-off class of people, the Hurricane Sandy homeless, survivors not victims, traumatized: keepers of scattered slivers of lives shattered forever by grim reality, disillusioned, hope on hold, slipping away, looking for tools to rebuild, cast off, ignored.

I waiver unbelieving through a bleak mine-field between reality and hopefulness. Every opportunity for aid, every promise, explodes and disintegrates: there is no help. There is only disorder and apathy.

I see cash as the great equalizer, money for repairs, for hope, for tomorrow: great mounds of money lie between obliterated lives and home. People who worked their lives away are unexpectedly destitute, in the hands of others, with no control of their own fate, living in their garages, houses without walls, and their yards: desperate to retain some autonomy. I see the survivors creating their own positive outcomes, and reaching out to help each other: the human spirit rising above the failures of the system.

People require hope. Without hope, there is no reason to get up in the morning and choose to go on. America is nation-building in countries far away, and forgot its own, the people of the SuperStorm: who wander streets alone, hungry, disbelieving, contemplating suicide. Hurricane Sandy Recovery has become a National Tragedy: our national shame; a sad chronicle of governmental failure.

But we are a nation of mongrels: immigrants all mixed together in one pot, enhanced by the qualities of each, forged by centuries of pioneers, mellowed by history. If you give us a place to stand, we will move mountains!
A hotel room is traditionally a small space with cheesy furniture, stiff white towels, and multi-colored indoor-outdoor carpet that looks spotless but harbors microscopic critters. It is a facade, an appearance, a caricature of home. However, for a person who has lost everything, a hotel room is comfort, warmth, security, a link to independence, sanctuary. It is the only stability left. FEMA calculates hotel room space in time of disaster by price points and enforceable codes, and people as movable pieces on a game board that expires every two weeks.

It was almost four months to the day since I became a vagrant: roaming through the bowels of hell, searching through sewage for my treasures, a pawn in FEMA’s game of unrecoverable life. I was holding it together. But I was hardly all right. I entered the covered walkway to my hotel room, at the hour when waning winter sunshine brings a subtle chill to the day, returning from a day in the yard of my mold infested home. My clothes were shabby and stained, hair unruly, and my hands were vile. I was exhausted from crying. It was a typical post-Sandy day. I just wanted to go inside and scrub the day off.

A man in blue jeans approached me in the distance. I was unable to see his face, but he had grey hair and glasses. We met at the bottom of the black stone staircase, just outside my door. He had a tattered, desperate look. I immediately recognized him. He was one of us, the survivors – those who had lost everything in the SuperStorm of 2012, Hurricane Sandy.

He rounded the last post of the iron fence to the parking lot, looked me straight in the eye with compelling urgency, and said, “You’re FEMA aren’t you?”

I was startled by his recognition of me, and flattered. He had looked at me, not through me. I responded quietly, “Yes.”

We, each of us, understood the bond.
He was was obviously frightened. “FEMA’s paying for your room?” he said without introduction.

I understood his urgency immediately. I said, “Yes.”

“I have to leave. I got a call from FEMA.”

Everything that he was feeling, I had felt: the desperation, the fear, the vulnerability, the sheer terror of being told that you don’t belong, that you can’t stay, but you have nothing to go back to and no place to go forward; that empty, gut-wrenching reality that you did everything right, and now everything is so wrong. His fear triggered the advocate in me. It was 1970, when I saw a man in a wheelchair locked out of the public library on a cold rainy day.

“Was your house damaged?” I said.

“I lost everything.”

“I am so sorry,” I said. “Well, you are covered. They will pay for your hotel room.”

He repeated that FEMA had called to tell him he had to leave the hotel. “I have no place to go.”

“On Friday they extended the Transitional Sheltering Assistance (TSA) Program, the Hotel Assistance Program, until March 10.” I said. “It is o.k. You lost your house. You can’t go home. You are covered.” I was so sure. It was the right thing.

His face was blank, unbelieving. Insecurity was so much a part of our lives now.

“Where did you live?” I inquired.

”Lindenhurst. Cuomo was standing right in front of my house.” he replied.

“I’m sorry.” I said sadly. I knew Lindenhurst was really bad. But we all had really bad stories and really sad hearts. Oddly, none of us felt sorry for ourselves, just sorry.
“Listen to me,” I said, being pushy, “You don’t have to leave!” I was now an authority, giving out permissions.

He moved nervously about, looking for something solid to hold onto. “An insurance inspector who used to be a FEMA inspector told me early on, FEMA is going to deny you and deny you, and you have to keep appealing. Just keep appealing. And you will eventually get what you should.”. I told him. I had learned by dealing with FEMA that this was the truest advice anyone gave me.

But, he wasn’t convinced. He wasn’t ready. He was too much in the moment. We stood there together, him and I, trying to find some measure of security in fragments of information, success and failure, each of us had.

I told him to call FEMA, go to the FEMA website.

“Go to the American Red Cross.” I was running out of viable suggestions. They were sparse.

“The Red Cross told me they would help me, except, I am not working. If I was working, they would help me,” he explained. He told me he was a utility worker who did not work for two months each winter because of the weather. He said he was going back to work on March 11. He only needed the hotel room until March first.

“I don’t work,” I insisted, like it would help. “I am disabled.”

“That’s different,” he explained.

I asked him what the FEMA caller said, because I knew they are all over the place, in professionalism, accuracy, and purpose. I knew that their communications were haphazard, confusing: lacking transparency and clarity.

He said he wasn’t sure. She wasn’t clear. He couldn’t understand her. That sounded right! Even the messages FEMA left were difficult to decipher. The letters were ludicrously unclear. They were an unfocused, transient bunch of people from all over: jabbing facts at you,
impossible to locate afterward, moving on to another location before clarity or resolution, never following through. FEMA was an odd collage of documents and disorder: frustrating, accomplishing little. I suspected that he was a victim of FEMA shock, the trauma caused by the actions FEMA takes against the Hurricane Sandy victims, and its inaction.

I told him that it was announced on television on Friday that the Transitional Sheltering Assistance (TSA) program, the Hotel Assistance Program, was extended. That was the way it had worked. Every two weeks everybody covered by the Hotel Program was under threat of being thrown out into the street with no place to go. So far, at each two-week deadline it was announced that the Program was extended. Rumor is that this will continue until it is warm enough for people to live in their yards. Hearsay is that people in Breezy Point are living outside in tents in the winter cold. We each know people who were forced to go back into their homes without walls, without floors, without heat or kitchens. We each lost confidence in the system because of the way it treated us and those around us. We have watched FEMA consistently ignore, abandon, and devalue the survivors of Hurricane Sandy, and convert Recovery into a National Tragedy and the survivors into disbelieving, wandering refugees.

I told him the television said they were supposed to call each person to notify him that he was extended. I said maybe that was the call he received that was unclear. I never got a call.

I suggested that he call FEMA to clarify what it was about. He said he would go into the FEMA Headquarters in Lindenhurst tomorrow to get an answer. That seemed like a good plan. I suspected that the call he got was really to inform him he was covered for another two weeks.

Sadly, I heard little that FEMA did that was positive, helpful or kind. I heard only terrible experiences of people being rejected, denied, devalued, depersonalized, threatened, dismissed, and thrown out. There was a current of frustration and hostility toward FEMA circulating among survivors. And there was misunderstanding by the public of the reality of the Recovery process. There was a strong bond among survivors for each other: for we were a new class of people, middle-class homeless people by natural event, looking for a way back, for stability, security,
help, support, equity, justice; receiving nothing but indifference and callousness; supporting, maintaining and helping each other.

“Nobody is helping us.” he said. “Nobody cares!”

“I know,” I said.

Because that is the way it feels: everywhere you turn, a door slams in your face. You are told the money is gone, you can’t stay, you don’t belong. That is the experience of the survivors I meet! It doesn’t matter if they have no place to go, or small children, are sick, cold, or broke. I know that there are caring people out there. I just can’t see them.

There is little help, aid or support within the Recovery System: the systems are disorganized, unfocused, illogical, and uncaring. The media reports that each Sandy homeowner victim is receiving $30,900 in aid. I have met not one person who received such a grant. And, if you had Flood Insurance and paid premiums for that insurance, FEMA deducts that amount from any repair grant they allow to fix your home. People who had no Flood Insurance, received immediate pay-outs that far exceed those of insured survivors. So, instead of benefitting from being responsible, homeowners wait months longer than the uninsured, and receive a laughable pay-out.

But the most disheartening, is the public’s indifference to the plight of Hurricane Sandy survivors. This was a “massive event.” And, agencies and ordinary people are hiding behind that catch-phrase to go on with their lives and not be inconvenienced by those who are hurting and abandoned. There is so much gut-wrenching suffering among survivors, so much sadness, loss, and longing. And, the world went on without us. Nobody cares!

Locally, I see a divide at Merrick Road. The people below Merrick Road on the south shore of Long Island sustained loss and devastation in varying degrees, depending on how high their house sat on land. Some, lost basements and furnaces; some lost playrooms and garages; first floors; living rooms, kitchens and bathrooms. People who lived directly on the water, some of their houses were totally spared and some actually floated away. Many people, either because they lived on the water, or, like me, lived nowhere near the water but lived by a Sewage
Treatment Plant and had a massive sewage surge throughout the house, lost everything. The survivors have an unspoken bond, and watch out for each other.

But sadly, the people north of Merrick Road never looked back. They prepared for the storm like the rest of us, but when their homes were spared, they watched the news, and then went on with their lives. A few took in friends or family who lost their homes, and they are heroes. But most went on, preparing for Thanksgiving and Christmas, and left the churches to feed and house the refugees, with no thought of what the holidays must be like for us. Christmas was the same as it always was for them, because a geographic quirk spared their homes from the “post-hurricane cyclone” that gobbled up our lives. I can only observe what I see.

So here we sit: the utility worker from Lindenhurst: the couple next door from Point Lookout with three screaming children; the 30-something couple on the other side of me, hiding their Yorkie under the covers when there is a knock on the door; the woman upstairs from Long Beach who fell in the shower and broke her wrist and ribs; the elderly church worker from Nassau Shores with an old car filled with carefully-wrapped antiques; and me from a Seaford sewer surge, who listens to their stories. We are each here, living in a hotel room begrudged to us, clutching a bag of our tiny treasures, in FEMA shock.

The utility worker walked past my room this afternoon and told me that FEMA did indeed throw him out: unemployed, with no place to go, refusing to give him any explanation. Everyone who leaves like this, takes a little piece of my heart with them. And I know that there, but for spinal cord injury, goes me. And I wonder if I am next!
Morning Most Difficult: Impressions of Loss. 3-3-13

I open my eyes. I am in a box without light. I hear a woman sobbing uncontrollably. She has forgotten I am here. Awareness scratches its filthy claws across my face. The day dawns once more, slashing hope. I exist in a world without tomorrow. Today is too much to bear. Yesterday is a recurring nightmare that will not fade. Mangled memories are soaked in sewage and tears. I follow walls, perimeters, around and around, looking for an exit that is not there.

I am a little girl sitting on the freezing cold curb in front of a forest-green house caressing a rotting teddy bear without eyes. I finger tiny, slivered fragments strewn across the pavement, that are mangled furniture, belongings, my past: bulldozed into oblivion by the County. Crushed! My hands bleed into the mutilated soil: wasteland of my legal address. Splinters fester. Cars race past, without slowing, without seeing: having someplace to go, a destination. Their dust chokes my bloodshot eyes. I shiver with reality.

We stand long outside the entrance to our homes, afraid to turn the knob. We know! There is nothing inside: nothing we can touch! There is a terrifying landscape of obliteration, mixed with sweet memories. There is a wound in the floor that sucked the life from this place, and will not heal. It fests and grows with each passing day. Time is our enemy: mold flakes and floats from walls that will not dry, without money, There is a divide growing. Apathy brushes past invisible survivors: we become a class apart. It is so difficult to walk amongst the rubble, but impossible to turn away. Others judge us unkindly for seeking restoration.

The coastline is decimated: with cars hanging from telephone poles, and water gushing out of windows of houses. Beaches were sucked out to sea and flung into the streets: creating
new channels, destroying transportation networks. Structures turned to tinder. Neighborhoods were devastated: homes burned down and floated away. Sewage washed through bedrooms. Babies were torn from mother’s arms. Young men were crushed. Life is lost! Communication was severed. Essential functions shut down. Food ran out and gas caused panic in the streets. I could not hold back the waters or keep the cyclone from its deadly path: it was too powerful. It was armageddon: apocalypse! Loss is stark reality!

Memory is chewing glass. Tomorrow is running across hot tar.
Sandy’s Fickle Fury. 3-14-13

When the post-hurricane cyclone hit Long Island, its monstrous arm spun across our fragile landscape like a scythe slicing grass. It decimated whole neighborhoods and towns, while sparing isolated homesteads with illogical precision. I have heard this same story, same ending, different towns, with intermittent regularity. The fickle fury of natural disaster marks its gruesome path with random accuracy.

I recently met one survivor of such a random sparing, sheepishly harboring survivor’s guilt for being untouched in a neighborhood where most homes were devastated by the flood waters. She felt, “like there was an umbrella over my house.” I asked her if her house was built up high. She lifted her hand and indicated with her fingers, just a few inches. She didn’t understand why her home was spared. I am not sure that we are meant to know the reasons why. It happened! I venture to think that it is what we do with what happened to us, that matters.

She spoke of a house in south Merrick, on the Bay, located on a peninsula surrounded by water on three sides. I have been there a thousand times, being the daughter of a man who built most of the bulkheads, pilings, finger floats and marinas in Nassau County: creating the docks that took on water like sinking ships in the neighborhoods that flooded. I, being the progeny of generations of bay-men, decoy carvers, clam diggers, tasted oysters clinging to the seagrass on her boggy plot before her house was built. Alas, all of the land below Merrick Road was originally mudflats, marshland, ditches, cattails, swamp grass: man claimed it for his home. How can we then be angry at the land that reverted to its natural habitat when a meteorologic aberration stressed it?

I respect the land the bore my ancestor’s names, as I respect the unpredictable, raging sea, that swallowed so many of my ancestors, their sons and fathers, following in their chosen occupation. The salt water of Long Island is in my history and in my veins: I can read the bays and ditches of Long Island like a blind man reading information from a page of braille. Mudflats were my childhood playground, jumping ditches, picking buttercups amongst sea grass, digging
clams with naked feet in cotton bloomers. And all the while the bay breezes fluttered fragrant through my long blond frolicking curls. But on one stormy night in October the golden south shore turned terrifying and torrential, blasted and bleak.

The woman and her husband had evacuated for previous hurricanes, but decided to remain in their home for Hurricane Sandy. After all we were all confident: the weather reports as the hurricane traveled up the East coast, were quite benign.

Actually, the National Weather Service made a decision not to issue hurricane watches or warnings north of North Carolina. Weathermen reported 74 mph winds, barely a Category One Hurricane, downgraded to a post-tropical cyclone before it landed in Atlantic City; no significant damage along the coast. Until Jersey! Suddenly, there were state and local officials on television warning the public of a curve to the west at about the level of North Jersey, the hurricane joining with a middle-state storm, a cold front, a northeaster. The reports were ominous, frightening! It was too late for many of us to act. Many didn’t believe the eleventh-hour hysterics, given the rantings last year about the “Storm of the Century” that fizzled across Long Island. Most of us lost our electric: before the storm hit. After that, you knew what was happening only right here, in the dark.

I left the sweet solace of my hospital bed, because my sons wouldn’t stop calling, urging me to get out. I went to a converted garage surrounded by tall trees a few miles away, where the wind was so quiet, that I felt silly lying on the floor waiting for the storm to pass. But, on the Merrick waterfront, boats were bashed against splintering docks and finger floats jumped onto bulkheads. rain pelted black waters, sifting sand through whitecaps, slopping onto patios, swelling, pounding the shore.

And a man and a woman sat in their home, prepared to wait out the hurricane, with candles and flashlights. As the storm progressed, the rain was relentless: and the wind slashed mighty trees and tore their roots from saturated soil, chewing chunks of structures into tinder. The homeowners questioned their decision to stay as the winds grew more fierce, too late, wandering from window to window, seeking relevant information. But all was black and cold, as
the storm spit out mighty power lines. There was no comfort. There was no communication. There was only anticipation.

A flashlight darted toward the bay at the peak of the peninsula, the location of the most imminent approaching danger. The man strained to see the bay beyond the murky downpour, seeking information too late to make a difference. The bay was a mass of skating whitecaps, crashing against docks, washing over lawns, battering boats. “It’s o.k. Hon.” He believed what he saw.

“The other way! Look the other way!” There was urgency in her voice.

He turned his head toward the east and peered into his neighborhood. “OMG, I don’t believe it”. He exclaimed.

A river roared toward the house, a wall of sea water advancing. She hurried to the window, and was horrified, to see through the darkness, raging, frenzied water rushing toward them, strewn with debris: patio furniture, tree limbs, household items, lumber, chunks of siding, life preservers, and motor boats. There were no streets, no yards, only water, as far as she could see, rushing water, churning rubble. She was terrified. The comfort of her home had suddenly become a terrifying trap. There was no obvious means of escape. No vehicle could provide transportation. No structure could offer shelter from nature's mighty wrath. Raging waters were the master of the moment: in control, eclipsing choice, smothering security. There was no place to go but where they were.

The fury of the storm increased, the deluge swallowed up their yard. They peered from windows at the swirling floodwaters, realizing that there was no higher, safer place to go. They thought of the children they could not call from this heatless, lightless room, and they regretted having no choice, and staying behind. There would be no rescue until the storm was done with its awful rampage and it was safe for rescue workers to approach. There would be no help in time to save lives. They were on their own, surrounded by an angry sea.

And in those final moments of uncertainty they looked at each other and were comforted by the history they created together in this space. As they watched from inside, aware of options
closing quickly, and longing for daylight, the whirling tempest approached the concrete steps to
their house, lashed them, spit-up foamy wreckage upon them. and seemed to stop. It sat there
turbulent, for hours, threatening, teasing, slowly receding, as the homeowners respectfully
waited: barring alternate choice. In the end, not a drop of water entered their lovely home. The
homeowners were grateful, confused, humbled, traumatized, harboring survivor’s guilt: marked
with an indelible imprint.

So it happened, that on the night of October 29, 2012, wind and rain swept across Long
Island with insidious precision: the tide rose and sea water engulfed homes, reclaimed virgin
marshland. Two homes stood on a primal bog that night: one was spared and one was swallowed
up, at the inclination of the tide. And that made all the difference!

And we all understood that it is wonderful to live on the shoreline of Long Island. But,
we must respect the genesis of this land, and the authority of the sea. And when the sea enforces
its original right of ownership, to borrow or reclaim the land we love, we must acquiesce to its
will or relinquish our claim altogether. The sea is a powerful and unpredictable force: with
dominance over man and land alike. We can only borrow paradise, not own it.

Disabled During Disaster - Wendy Wagner - 45 / 69
A house is not a home. A house is a structure, a definable space, an estimate-able property, a piece of real estate that can be transferred, knocked down, flooded. A home is history, sensation, comfort, recollection, security, sanctuary. The survivors of Hurricane Sandy each had a home: lost a home, treasures, a lifestyle. Some had a house.

FEMA validates a house but not home. However, FEMA has formulated its own definition of a house. A house is a shell: walls, floors, heat, electric. It is stripped-down, patched-together, barely safe or sanitary, space: basic function. And as Hurricane Sandy destroyed everything that many survivors owned, FEMA forces them back into barely safe, barely functional, empty shells. These are the people who have not been forced back into houses without walls, floors, electric, heat or mold removal, because FEMA abandoned them without explanation. These are the people whose houses did not float away, were not condemned. The people forced back into functional empty shells are the lucky ones. FEMA has downgraded the American dream: it is the American nightmare.

Tens of thousands have been forced to live outside of their homes, with no place to belong, under constant threat of eviction, unwanted, uncomforted, unclothed, because their home is standing, but totaled: and FEMA gave them a laughable grant, without explanation, without mercy. They cannot repair their houses, because there is not enough money to repair even one room: there are no walls, floors, bathroom, kitchen, electric, heat, not even a toilet bowl. There are no contents, furniture, belongings, left. Their home is nothing, only fertile soil where mold and bacteria breed. Every day their house moves closer to being condemned. These people wander about, bewildered, frustrated, disillusioned, terrified, ignored by the systems, denied by the general public: a class alone, living in an alternate universe, created by the SuperStorm, not living at all, pacing putrid time.

I first experienced FEMA when Hurricane Sandy destroyed my house, terminated my home: wiped out my past, present and future. Before that, I only knew of FEMA through media
reports. I believed the promise: I believed it helped people. Hurricane Sandy left 200,000 Americans along the East Coast homeless and destitute. All of the survivors experienced FEMA or chose not to.

My house was insured for $300,000. It was totally paid off, except for $3,700. The contents were insured for $100,000. I lost all of my furniture, belongings, most of my clothes, $50,000 in medical equipment and $10,000 in office equipment. FEMA, all Insurance, County, and Fire Inspectors said my house was totaled, with great sympathy. In November, the County declared my house too dangerous to enter without a respirator, because of sewage and mold contamination, and inspected it from the front yard. Some inspectors called friends to help me, and even offered to come back and put up walls. The houses in my neighborhood sell extremely fast, because it is close to bus, train, highways and parkways, stores, the bike path to the beach, and Ocean Parkway to Jones Beach. The school district is excellent. Houses in my neighborhood are a great investment.

I didn’t live on the water. I didn’t live near the water. My neighborhood never flooded before. I lived there for 48 years. But, I lived right above the Cedar Creek Sewage Treatment Plant. The houses on the west side of the street are four-floor splits, plus a basement. Most, lost the basement: some, lost the family room also. The houses on my side of the street are one-floor ranches: we all lost everything. Salt water was not the worst! Sewage damage was throughout the house: it seems that it came up the toilet and also in the front door. Sewage was on top of my hospital bed in the living room. There is a storm sewer directly in front of my house. Many people in my neighborhood believe that the Sewage Treatment Plant malfunctioned. Everything was lost to sewage contamination: a horrific way to let go of your lifetime keepsakes and tiny treasures.

I was told by eyewitnesses: from 7 p.m. until 12 a.m. water rose rapidly up from the ground; a river rushed up the center of the street toward Merrick Road; 6 feet of water entered my house. Those who stayed, report it was terrifying: the violence, the power of the water. I had water and sewage damage up to 48” above the floor. It was like a tornado hit inside of my house: furniture, equipment, appliances, belongings, objects great and small, were thrown around with
alarming violence, smashed and encrusted with sewage. I cannot get the putrid, acrid stench of devastation out of my nostrils. My hospital bed went on fire. My front door was torn off. A cinder-block wall outside the side door was thrown against the house.

That is the reality of the event and the loss. The reality of the response and the help, are a life apart. The survivors must deal with both. Inadequate response for restoration by governmental agencies has turned this Natural Disaster into a National Tragedy in America, and it has become our national shame.

While everyone realized, at the end, that the storm was huge, damage was devastating, and the victims included hundreds of thousands of survivors, the government did not react in a timely or effective manner for the magnitude of the event: management, personnel, funding, housing, emergency survival and support services, were inadequate. Response of FEMA, the agency designated to manage the event and aid survivors, was so slow, that it was extremely detrimental to the victims.

There was no housing, no food, no gasoline, no electric. We were told that FEMA could not bring in trailers to house the homeless, because the area was so congested. They did not bring in gasoline. Without gasoline and operating gas stations you had to remain close to your property or wherever you were going to bed, because if you used up the gas in your car it would remain where it stalled. And, they were dragging abandoned cars away to remote dumping grounds. There was no food. Fast food stands and restaurants alike, were closed down. They had nothing to sell, and no way to cook it. There was no way for the public to cook food, because most people, even if they had homes, had no electricity and no heat for weeks. There was little food, and less water, in the few supermarkets that were open.

The Red Cross handed out sandwiches and hot dinners, blankets, and cleaning supplies, after a few days, in devastated neighborhoods and parks, if you could get to them. They had boxes of donated used clothes, because most of us lost our clothes and shoes. For months, the Red Cross and churches were the only source of nutrition for many. It turned out that the local
churches would become the most solid source of support for housing, food, cleaning and sanitary products, counseling services, and, ripping out, building and renovation assistance.

Six weeks after the event, houses were stripped of contaminated furniture, belongings, walls, floors, and insulation: FEMA finally put in an appearance – inspection. The reality, the inspector’s report, and what FEMA translated into money, would not agree! The FEMA inspector spent 1 1/2 hours inside my house, measuring and taking pictures. She was sympathetic, said she put in a strong report, and reported the case to the Special Needs Hotline. Nevertheless, FEMA ignored my case for six more weeks, denied I was disabled for three months, claiming they never got paperwork from my insurance companies, paperwork that I submitted three times.

But it turns out the waiting was the easy part. Then came the rape of the survivors, the stripping-down and dehumanizing of Hurricane Sandy victims, the abandonment by America of those in need of help. After 2 1/2 to 3 months of waiting and believing in the system promising support, the grant letters started arriving. The grants were outlandish, ridiculous, pitiful. After all of the time, phone calls, paperwork and documentation that FEMA demanded, they were insulting, to our efforts to cooperate. Decisions would have been ridiculous, except that they were not decisions at all, because there were no explanations: only one or two words prefacing the dollar amount. Grant letters are generic: one form letter for all purposes, written so that it says absolutely nothing. There is absolutely no transparency. Dollar amounts are so outlandish as to be irrational. Not just for me, but for most! Grant amounts translate into no help, and leave a survivor with the inability to renovate his house and reclaim his life.

Over and over this sad story resonates, while the media reports that FEMA is awarding each homeowner $30,900, and that if people apply for the SBA Loan, they can receive up to $40,000 more for their possessions. I was not allowed by FEMA to apply for the SBA loan, because I am disabled and make so little. I was not allowed to apply for the $10,000 Empire State Grant, because in order to apply you must first receive the maximum FEMA Grant. Not even close! The public thinks SuperStorm Sandy victims are being taken care of. Sadly, nothing could be further from the truth!
My house was totaled. All repair estimates came in at $105,000. The estimates are for house repairs/renovation only. I also lost all of my furniture, belongings and appliances; $50,000 in medical equipment; $10,000 in office equipment. Nothing was covered, because it was a flood. When I get back into my house, it will be empty: they will all be empty. On 1-11-2013 FEMA sent me a Grant letter designating $5,035 for “Home Repair” and $7,989.51 for “Personal Property” (which of course must go toward house repairs), for a total of $13,483.86. When I opened the letter and read it, I could not breathe. My house is totaled and FEMA allotted $5,035 for home repairs! My eyes clouded over and the words went away. I shuddered, as Obama walked across my grave. I could not believe what I was reading. It was a mistake! Reality could not be this horrific. Was I dead and I just didn’t know it yet? But, it was true: the second half of our nightmare was upon us, those of us in the alternate universe.

I appealed the Grant Decision and requested Re-inspection of my house. FEMA made a farcical pretense at re-inspection, sending an Inspector and a “Disability Expert”, who stood by the car and talked to me. They prefaced this meeting by explaining that they were going to evaluate the access, adaptive equipment and medical equipment loss. I asked how they could do that, when the house was stripped and gutted: totally empty, except for a hole in the floor where the toilet used to be. Nothing was left! Being an access expert myself, I knew that FEMA officials were making no sense at all with this explanation. But an Inspector went into the house alone, and refused to accept my pictures of the losses. The Disability Expert stood by the car trying to convince me to sign a blanket authorization that they could share all of my information with whoever they chose. When I refused, he called their Legal Department and tried to get me to talk to them on his cell. When I refused, they sent a short middle-aged pit bull who threatened that they would do nothing to help me if I did not sign the paper. I refused. FEMA shared my confidential information anyway: ever since I submitted financial papers to them, I have been getting “we know you are destitute” letters and emails.

The FEMA re-inspection awarded me an additional Repair Grant for my totaled house of $645.45. I was incredulous, but half expected it. I never thought it was a legitimate attempt to reevaluate, given the fuzzy rationale they verbalized for re-inspection. I tried to get an
explanation. I was told the amount was “appropriate” and we could manage, with “free help” available. I am hearing this story over and over.

We, the survivors excused the waiting, the redundancy, inefficiency, ineptness, nasty people, unanswered telephones, constant threats, because of the magnitude of the event. We believed that FEMA was trying to help us: we trusted the system. We tolerated dysfunction within the system, lack of comprehension of the implications and impact of the event on real people. But we learned that to FEMA, people are numbers: houses are numbers: nothing more! FEMA workers are apathetic caricatures, propagating unremitting loss, hopelessness, helplessness: highly paid, transient, serial, disaster trainees, who depersonalize and dehumanize pathetic, tattered people in need. The survivors of Hurricane Sandy have learned that, in response to natural disaster, systems break their promises and fail. There is no help!

Presently, FEMA lacks transparency, logic, rational process and procedure, organization, focus, humanity: it is so out of touch with reality, human suffering, recovery, restoration, and hope, as to make it non-functional and irrelevant. It operates with personnel so transient, they lack continuity, it lacks consistency. It is an outdated and irrelevant system that has lost sight of people, human suffering, and home.

FEMA must be investigated, re-organized, updated, monitored and made accountable. It leaves battered, bewildered, broken people in its wake, not from the event, but from the lack of assistance after maximum effort and cooperation by the survivor: lack of empathy, humanity and because of the apathy of the program.

Since Hurricane Sandy the meaning of home has changed forever for hundreds of thousands of Americans, made refugees by the destruction, and by what FEMA has forced them to return to: “functional space.”. Many are not structures, or are structures that are not safe, are toxic, hazardous, barely habitable: houses without walls and floors, kitchens, furnaces, bathrooms. Agencies will not even pay for mold removal. Houses are being patched together by laymen, and quickly fail in functional use. FEMA strives to get people out of the system as quickly as possible. There is no follow-up. Homeowners of lost or totaled homes are forced to
move on to rented apartments, rooms, couches, houseboats, trailers, mobile homes, RVs, basements, garages, yards: inappropriate accommodations, not long-term solutions.

Grants for restoration are pitiful. The condition of houses is demoralizing and horrific. Many of us have been without a home for five months because FEMA gave us an unrealistic, outlandish, repair grant. Many people just abandoned their homes and moved off Long Island, because they have no money to restore their houses, and no options for help.

The program does not return survivors to some normalcy after disaster. FEMA actually prevents people from getting real help, by delays, false and misleading promises of aid, and untimely, inadequate to the point of absurdity, final grants. When they are finished giving us nothing for our homes and property, all the ‘free help” is gone, used up, worn out. It prevents resolution, by overwhelming survivors with paperwork, documentation and denials; repeatedly losing, misplacing paperwork: by using vague, private, covert codes and processes to maintain limitless proprietary power and generate unclear, inadequate, ambiguous, cryptic decisions. There is no help: there is no transparency.

I do not claim there are not professional people at FEMA who try to do the right thing. But they are high-ranking, inaccessible, bound by out-dated processes and procedures, and their commitment to the survivor moves on with their next assignment location. The system is designed to thwart contact and communication, recovery and resolution.

In the end, FEMA gives survivors laughable assistance and tells them to go find a way to help themselves. It tells people they can restore their homes with the pittance that FEMA allotted, plus free help. Realistically, Hurricane Sandy free help is scarce, unskilled, empty promises, filled-up answer machines, hotlines manned in other states by people who disclaim knowledge of aid programs: unresponsive programs, services, and agencies: non-help. Meanwhile, our homes sit vacant, growing mold and bacteria, being looted and stripped, and receiving exploitive offers of buy-outs of the land by house flippers. The system is designed to benefit everyone except the survivor of disaster. Materials that were donated for rebuilding were withheld from homeowners, and are now being sold to contractors at huge profits. Benefit monies that were raised by famous people and concerts were not passed on to survivors.
Everyone is profiting from Hurricane Sandy, while the homeowners are victimized and abandoned by systems breaking promise. FEMA fails.

FEMA devalues houses, allotting cryptic, unrealistic, pitiful grants for legitimate house repair and restoration necessary due to natural disaster: using out-dated processes and procedures to evaluate and decide. Therefore, FEMA devalues home, the bedrock of society: disrespects people, the strength of our country; destroys hope, neighborhoods, chunks of America; and the next generation, the children who lost their nest, their toys, their rock.

The system does not work. FEMA needs to be re-evaluated, reorganized, updated, re-designed, monitored and made accountable. Americans devastated by disaster, people, our neighbors, our neighborhoods, are broken, bewildered and expiring, because FEMA does not help them: does not validate home, promote restoration or recovery. Through FEMA, America is abandoning, failing her own people miserably. We are survivors of Hurricane Sandy: we are victims of FEMA.

The survivors cannot rebuild their homes, because, without money, for years the survivors are going to be trying to patch their houses, their lives, their lifestyles together, with spit and sea grass. And, everyone knows what happens to houses made of grass.
Climbing a Ladder in the Snow. 4-11-13

Living with pain, immobility, disability, in a National Disaster is like climbing a ladder in a blizzard, with howling wind tearing you from safe footing, blinding snow lashing your face: suspended over a swirling, bottomless pit, without mercy, without reason. Frozen rungs burn fingertips longing to let go, striving to hold fast, fearing below. Hold on. Be strong. The weak fall, or are pushed out of the way.

In disaster, by necessity, there is only time for routine, process and procedure. There is no time for difference, specifics, special cases. There are hospitals and nursing homes for the weak and infirm. Those who hold up the line, are trampled, stepped over: that is history. The Program, the Plan, Progress, is imperative to success. Statistics demonstrate results.

All of this is logical, reasonable for the greater good, for efficacy: but it is not reality. One person in every five living in society in America is disabled. One in ten has a severe disability. Disabled people are the world’s largest minority. We must learn to deal with disability, diversity, with intelligence, empathy and procedure. We must not let systems define, interpret and react to disabled people as freaks or annoyances: abuse or victimize them. We must not let systems turn functioning people into cripples, for the convenience of the system, because of their own internal inadequacies. It is the responsibility of each disabled person to teach uninformed, unaware, resistant people and systems that disability is as much a part of the process as it is of life. Disability is part of the equation: it must be part of the Plan.

Uninformed and inappropriate reaction to the disabled person, places responsibility to fit into the existing system, the prevailing mindset, estranged society, on the disabled person, and puts pressure on him/her to be all right. The pressure to fit in, not slow down the mechanisms, be normal, or step aside, is palpable. The message is, “You are in the way.” We are taught to hide our limitations, and smile when it hurts, to be accepted. Whether the disability is obvious, or invisible, you are in the way as long as you need something different. Different is time, thought,
and pause. Modern society has no tolerance for unequal time distribution among individuals. There is only black or white: adequate, or faulty.

Society does not understand the functioning disabled: that some people live with severe symptoms, and function as productive rational individuals, fit in, contribute, excel. And yet, if we need to pause for a moment, perception of our personage instantly changes. We are at all times compelled to stand straight. Be strong. Don’t drop the rope!

It is a regrettable fault of human beings that they relate and react to what they see and what they hear. The value of one human being cannot be seen with the eye. Vision is faulty. Perception is clouded by individual history, preferences and biases. We are all dressed in the same fragile derma, some with cuts and abrasions. Derma is superficial: there is so much more.

Likewise, our value cannot be identified by word of mouth. Words are flexible tools, useful to facilitate a purpose, subjective, not necessarily accurate representations. Words can be manipulated, colored, changed. We should believe what transpires: action is reality, value.

What I do is who I am.

And so it follows that there is unrelenting climbing of the ladder in the snow, for disabled during disaster. Hold tight! Don’t slip! There are those waiting for you to fall: to prove that you are incompetent, irrelevant. There are those who want you to move on, disappear, stop taking up space. You are in the way.

The quandary is the hierarchy of need in disaster. Everybody is in need: dire need. There is no room, no tolerance, for additional need: unrelated need. In real life, a disabled person deals with difficulty, every day, in every situation: existing is a challenge. When life stops, when the world holds its breath for disaster, needy people are an unanticipated, unwelcome burden.

The loss sustained by a disabled person can not be understood by an able bodied person: they have no field of reference for it. It is core suffering, not circumstantial loss. Disabled people do not need people to share their pain. They do not want pity, they want to be accepted and included, as they are: given a chance to function on their own terms, without judgment. We are
each of us imperfect beings in an imperfect world: everyone has some cross to bear, and a little bit of hero in him.

It is always hard for the disabled person, physically, environmentally, socially. But, in disaster it is hard for everyone, not just disabled people. However, disabled people live with constant, unanticipated challenges every day, and adjust to deviation and dissonance readily. Able bodied people often live relatively comfortable, predictable lives. They may have difficulty adjusting to being victim. They may have less tolerance for breach of their continuity, status quo.

In reality, society, disaster management, would be happy to pass the burden of disability on to hospitals, nursing homes, incompetent custodial institutions. Disabled people try to stand up and look normal so agencies leave them alone. Disabled people spend half of their lives pretending to be o.k., first so no one will put them away, and then so loved ones will not feel bad that they are not o.k.

When you are disabled, in pain and in your home, it is like a policeman who, by habit, sits with his back to the wall in a restaurant. You are in your own environment, operating on your own terms, secure, safe, confident. You are in control. You have your back to your own wall. You are normal, within your environment, your sanctuary. You are valid, acceptable, accepted. You are content.

Nobody is ok being disabled, compromised, living in severe pain. It is abnormal, extremely difficult, caustic. But, one day certain people wake up, and in a split second nothing will ever be the same, and everything will always be difficult. There is choice: face it, or deny it, deal with it or rile against it, be strong or be pathetic. Choose to go on or exist and be acted upon. From that day on, there is no more life as you knew it, but you can create, enhance life. You want to do it on your own. You learn to handle your disability in creative, innovative ways. Your own actions make you free from dependence on others. The world can learn much from the process of living disabled.
How do we fix the systems? By accepting disability as part of the diversity and individualization of life and writing it into the script. Disabled people need very little in the grand picture: they contribute much to the greater good.

So, do not look away when a disabled person walks your path. Attitude and biases of people and systems make life intolerable, not disability. We do not ask for help unless we need it, just like you. sometimes we hold up the line, but so do you, for different reasons. Life is complicated. Disaster is awful, for all of us: in the same and different ways. Hold on. Be strong.
Shadow of FEMA. 7-2-13

There is value in losing everything, in being destitute in a world of plenty, in a world of things. When you have lost everything you struggled and sacrificed for all of your life, rather than a void to be filled, there is a crystalline strength in you to be accessed. You see clearly. You feel, untethered. You know truth, You fear nothing. Possibility is unlimited.

Nothing worse can happen to me. I have nothing left to lose. Nobody can hurt me more. That is very liberating, and sad. I tell no lies.

The agency of the United States Department of Homeland Security, called FEMA, is outdated, and out of control. It needs to be investigated and held accountable for its actions and mistakes: re-thought, re-structured, re-designed. FEMA has become a pale shadow of its original intent, which was to coordinate response to a U.S. disaster that overwhelms local and state resources.

Present day FEMA runs rampant over people and circumstances, wreaking havoc on good and honest men, making a disastrous event into a human relations nightmare, an avenue to destitution and bankruptcy. FEMA treats people with callous disrespect, and gives them outrageous token assistance that is much more a hindrance to recovery than a help. People walk away from their homes, because they are being offered nothing: no help, assistance, options, no hope. People walk away from FEMA disrespected and bleeding. I watch broken peers walk into the surf, shoved out of shelters, with no place left to lie down, and I am diminished.

The problem is not the resources of FEMA or its limitations, it is the attitude, training, process, procedure and accepted outcomes. FEMA gives people only the ability to walk away from their homes, or paste together disorder and destruction, in the name of restoration: to become an unlivable sinkhole when FEMA is safely removed, working on its next disaster. FEMA is hindrance: negative help, professional bullies.
This is the country I love. I wish I could say something more positive about its effort to manage disastrous events. But, the only productive way to interact with FEMA is to point out their glaring failures, and hope that someone will respond with critical analysis and action. It is time to stop limping off alone, licking our wounds. We must stand up together and acknowledge how much damage FEMA does, for change to happen. There is momentum in truth, to action.

I am not afraid of FEMA. I lost everything. Then, FEMA destroyed all of the intangibles I had left. I join a crowd of survivors who have been hurt, not helped by FEMA. Perhaps we are irreparably hurt. Perhaps we can recover, despite FEMA.
Beware of Do-Gooders with Axes. 8-12-13

Loss is a hierarchy of values, unique to oneself, impossible to comprehend from the outside. Loss is layers of priority, woven intricately across your life, a tapestry of history, experiences, memories, possessions, ownership, and environment, withdrawn. It is exhaustion of the tiny treasures in your life, tangible and intangible, that soothe you, nurture you, buffer, energize and propel you. The greatest losses are intangible, impossible to grasp without heartstrings.

The survivors of the SuperStorm understand the hierarchy of loss. Loss for them focuses on home, their history hemorrhaging across a painting in progress by an artist concentrating on a date of completion, not the hues: loss upon loss wiped away as a mistake on the canvas, an intrusion in the gestalt, smeared by a cold hand without pulse.

I had a home. It was beautiful to me: pretty, muted pastels, soft fabrics, comfy pillows, cozy workspaces, solid wood furniture, functional, all that I needed. My home was memories: my children scribbling everyday adventures across the walls, carving their dreams into Mimosa they straddled, imaginations soaring, unfettered; rolling in fragrant grasses with abandon, looming green foliage affording security: inspiring me, delighting me, as they grew strong and tall, like the trees in my sweet garden. It was all that I wanted: all that I needed.

The rocks in my garden were collected from the world: fondled, contemplated, transported to this fertile land, their history intact, lovingly placed with deliberation and intention, substantial and validated. My garden reeked of mountains, forests, meadows, beaches, streams, waterfalls, oceans, and Indian preserves, with igneous, sedimentary, metamorphic. Smooth Florida ocean rocks, Nova Scotia conglomerates, river rocks from Maine rested beside Mermaid’s toenails from Noyack, vibrant sunset shells from Sanibel, slipper shells, spotted clams, olives, angel wings, paper figs, murex, whelk, curls, and conchs. I picked each up because it was special, like the people in my secret garden.
I nurtured a sweet garden so many years ago, to shelter my children from the busy street, to give them unspoiled acreage to own: before baseball and two-wheel bicycle rides to Jones Beach expanded their world into tomorrow. Those were years of innocence, when neighborhood children flocked to our verdant sanctuary, for a summer’s day of riding toys, sliding water fun and hours of good climbing trees, imagining and inventing, rehearsing tomorrow, dripping ice pops into the cool dark earth, dirty feet running across blankets of soft grass. Those summer days of noisy children with dirty hands in my garden, needing me, wanting beyond any place to be here with my children and their toys, lived on each morning, in songbirds summoning me to tall hedges with deep strong roots, and soaring climbing trees. Memory whispers timeless messages across the heart. How simple, yesterday.

Then came years when bikes turned into cars. Heavy traffic on the street triggered adapting the yard for greater functionality. A street, that had once been dead-end host of neighborhood softball games, now wrapped around the new Cedar Creek Park and down to Seaford Harbor Elementary School, providing access to marinas and taverns. Cars were being hit in the street regularly by drunks. I placed white rocks where the grass used to be and two toyotas slept peacefully through college.

In those days, Cedar Creek Park was a bone the County threw at homeowners who protested the County’s repurposing of the marshland stretching south from our homes all the way to the Great South Bay: a playground for fishing, bird-watching, romping and exploring, ecosystems wiped out, mutilated, usurped by local government, to create a bedroom for sewage tanks and a chemical plant to spew the oppressive stench of chemical sewage into the salty air at 2 a.m, each night, as infants sleep in their cribs.

On October 29, 2012, SuperStorm Sandy engulfed our neighborhood with raging floodwaters, spewing sewage that tore our lives apart. My house gulped down the putrid slime and puked up everything I owned: my secret garden stood resilient above the onslaught, quiet sentinel. And as spring breezes ruffled lush lacy foliage, I sat each day in my fragrant green sanctuary and believed in restoration and nesting.
FEMA, the government agency for Hurricane Sandy survivor’s assistance, let us all down: providing outlandishly low assistance grants, that made timely return home impossible. FEMA prefaced the assistance with, “You can do it with free help.” In reality, during such an extensive event, free help, any help, was virtually non-existent. The survivors were on their own: destitute, living in substandard, makeshift quarters, due to governmental failure. The Hurricane Sandy Recovery effort is a National Tragedy: America’s shame!

Temporary Housing was doled out by FEMA. People dropped out of Temporary FEMA Housing every day, not to go to HUD apartments or permanent housing, but to substandard private accommodations anywhere, just to get away from the bullying and constant threats of being thrown out by FEMA agents at their door.

So, under threat again of being thrown out of the Hotel by FEMA in three weeks, I accepted an eleventh-hour offer of free help from an international church group seeking a house to restore. They had a house to restore on Monday, but it fell through. Consequently, they had 10 volunteers coming from Alabama on Sunday. I was called on Friday by the Director, who outlined what they would do in my house: check the roof leak, and possibly patch it, empty insulation and toys from the attic, insulate the walls, and sheetrock. I asked if that was all. He said yes.

I trusted this group because they had gutted my house. They had been kind, thoughtful people, who seemed competent enough. They never overstepped their authority, in their past interactions with my house.

I pulled up to the curb, prepared to ease my accessible van between formidable hedges enclosing my ravaged, gutted home, as I did each day since the malevolent event. I was comforted by this precious remnant of my life left looming, strong, surviving, like me, the terrible storm: my yard, filled with shadows of squealing children from yesteryear. I spent hours here every day, nurtured by memories.
My van hesitated, then stopped. Oddly, I pulled up to the wrong house, one that was in the process of being bulldozed, it seemed. My internal navigation had failed. Clearly, the hedges I passed through each day to a restoration project limping along without funding, were not here.

No, my house was standing green and solid in front of me, clearly visible: naked, exposed, vulnerable, on a totally bald lot, sterilized, automobiles speeding past. My yard was obliterated. My garden, was mutilated, demolished, gone! The ground was still steaming. My eyes clouded over and bled profusely a lifetime lost. Loss upon loss pummeled me and I was overcome. Hope threw a lance through my heart and I bled out in the street. I was all gone. There was nothing left of me. Nothing left!

A mob of burly workers, were hacking, chopping, slicing, ripping up roots that were pulling back with 60 years of brute strength and cherished history, unwilling to yield the land of their birth, struggling against insanity. Strangers raked wet dirt over my white pebbles, standing on my rock garden, loading six-foot-long pivots into belching yellow dumpsters, to transport what was left of my life to some stinking landfill, my yard to wither in the hot summer sun, and die, unattended, unloved, the last vestiges of an unjust, uncaring world gone berserk.

I was empty. My world was only devastation and loss. Gasping green vines hung limp from the dumpster screaming my name. My heart shrieked so loud my head exploded and membranes rained down on the fragrant dirt, and soaked into my land. I could not breathe. It was armageddon. Goodness was gone.

A big, rough man with a pleasant face walked toward my car. A grey-haired woman stood on my oozing land, pointing, amid swinging blades: men with axes trashing my land without permission. Strong men struggled with massive roots that would not relinquish their right to survive and howled for me to save them. The violence smothered a field of white pebbles and smooth pink river rocks. They had obliterated every piece of foliage, every living thing, from the street to the windows: privet hedges, Roses of Sharon, Wisteria, Forsythia, mom’s American Beauty rose bushes, pachysandra, and oak trees my sons planted. The ground looked like it was
put through a sifter. Insensitivity swallowed my past, sucking songbirds, purple violets and lily of the valley, sweet blooming Privet, through the jagged, closing chasm.

The man walked over and leaned against my van, resting his sweating arm across my mirror, “Wendy?” he said. I wanted to throw his arm off my property.

“What did you do?” I whispered, breathless. I was shocked, devastated, appalled. I did not understand. I felt faint, enraged, hopeless, terrified. “What did you do to my yard?”

He turned away from me, toward my raped land, and declared with callous disregard, “Looks good, doesn’t it!”

I wanted to tear his head off and smash it to the pavement, at his arrogance. His lack of feeling confirmed he was not human.

“Why did you do that!” I said. “You had no right!” I could find no words. It was too horrible. “This is my land.”

“It had to be done.” he said. “It looks better.”

“Better than what? You had no right. This is my property.” I insisted. Everything was spinning. I could not see, for the tears.

He stood there with his back to me admiring his delinquency.

“Is Grace here?” I mumbled. She was an administrator: he was the foreman.

“She’s over there,” he pointed. He called to her, like nothing was wrong. She walked toward my van. I was slipping away.

“Hi.” she said cheerfully. She was an arrogant woman with a perennial smirk. I wanted to lunge from my van and strangle her, as she did my garden. I was face to face with the Devil.

“What did you do to my yard? “. I said. “How could you do that?”

“Your neighbors like it.” she smiled.
“You talked to my neighbors, but you didn’t call me?” I said. “Why did you do this? This is my property!”

“In this Program,” she said, “we must make the house better. This is better.”

“No! No, this is not better.” I said. “You trim a hedge, you don’t demolish a yard. You had no permission to touch my yard! This is my property! You had no right!”

The two stood against my van, ignoring me, prattling, “It looks good. This is the least of your worries. You should be grateful. People have a lot more to worry about than something like this. You have a lot more to worry about than this.” They were arrogant ego-maniacs, trampling on property rights and choice, in the name of charity. I was revolted by their smug self-righteousness.

There was nothing I could do: it was all gone! My ability to function, in a wheelchair, living alone, on a busy street, was gone! It was no longer safe, secure, or private. The damage was irreversible. As a person with multiple melanomas, there was no longer shelter from the sun. The firm rocky surface for my wheelchair, exists no longer. They didn’t get it!!!

I guess the church trashed my yard because they had 10 volunteers from Alabama with nothing to do. The building materials were not delivered until 3:15 p.m., long after my yard was demolished by men with axes. They obliterated my present and my past, to provide busy work.

I lost my home to a terrifying natural event. I lost my environment to terrifying control freaks feigning charity. Beware of do-gooders with axes! They will tear your heart out!
It was the end. The final deadline in a marathon of deadlines, that told me, all Sandy Survivors, “You do not belong. This is not your home.” It was the final confirmation of America’s lack of preparedness to deal with disaster and protect her people in time of crisis. Today was terrifying, because it is me they are evicting this time: but it is all of us. I was being thrown out of the hotel, but, in a few months survivors are to be systematically thrown out of DHAP/HUD temporary housing apartments, the second stage of their housing marathon.

The government is not prepared for Recovery. Survivors are pleading to deaf ears, at televised rallies and to legislators, for recognition of unrealistic deadlines.

I had witnessed the others, one by one, dragged from hotel rooms by paid bullies representing broken systems: people hanging on to hotel room doorways with bleeding fingertips. And I contemplated what I would do, when they came to get me.

It was a raw cold day. Once again, I/we were abandoned by every entity of the Disaster System supposed to help survivors return home. I spent my first full day officially without temporary housing, without one phone call from Case Workers, Agencies, Programs, or Charities, inquiring if I was o.k. It was jarring to realize how bankrupt disaster systems ignore, deny and pass over you, and that one can fall from hero to derelict, not by your own actions, but the actions of inadequate, broken systems assigned to help in crisis, that have failed. I floated in a cold hissing mist that numbed my senses and isolated me, the whole long day.

The final deadline was issued via U.S. Mail by the Health and Welfare Council of Long Island on a cold November 8, 2013. The letter was a very carefully-worded legal document, obviously designed to protect the Unmet Needs Roundtable from culpability if their action caused me bodily harm. In a way, it was a relief, to be cut off from their judgmental, unsympathetic consideration: help clearly communicated to me only offered to procure my potential NY Rising Grant.
They picked up my tenure at the hotel on September 15, 2013 when FEMA ended the Temporary Hotel/Housing Program, and FEMA issued a non-answer to my 504 Appeal for Reasonable Accommodation on the basis of my Disability. FEMA’s TSA program had been a series of bullying and threats of eviction every two weeks since Sandy hit. At termination of the TSA Program, FEMA dismissed me with a barrage of internal machinations and misrepresentations, clearly stating they do not validate or respond to Appeals. DHAP/HUD was assigned to provide the next stage of appropriate housing for 12-18 months for all Survivors.

The problem for me has always been that I am disabled, with severe medical and physical consequences, that were completely accommodated in the adapted environment of my home pre-Sandy. It has been hideously difficult and painful for me to be without that environment. I cannot function in a generic space, a high-rise apartment, a basement, a house up to 50 miles away from my medical care, options offered by uninformed, unconcerned case workers. I requested being permitted to remain in the hotel, where I am functioning.

DHAP/HUD absolutely refused to keep me at the hotel, and refused to consider every single viable option I suggested that could accommodate my needs. Still, DHAP threatened since June, that if I did not sign their paperwork (which states that I would then be cut off from returning to FEMA programs) “today, the last possible day” that they would list me as “non-compliant” and close the case. The Red Cross, NY Rising, all the “charities” that got the Robin Hood/Concert donations for the Survivors, refused to consider temporary housing for the lady in a wheelchair waiting for a Buy-Out of her now-toxic house. The world has become a caricature: compassionless officials with pearly white eyes that can not process images.

FEMA/DHAP insisted, “Drink the sand. Drink the sand and we will help you.”.

I said, “I cannot drink the sand. It will kill me.”

They called it cooperation, compliance, but it was sand. I choked down the putrid grit offered by hypocritical bullies, and puked up the bowels of my devastated home. I gasped, tears burning my abraded face, and fell into the muck.
I thought of all the people throughout history eliminated by barbarians because they were weak or disabled: in concentration camps, slavery, war-time death marches, and the man on the hijacked Mediterranean cruise ship thrown overboard in his wheelchair by terrorists.

I said to FEMA, “I did what you asked. Help me to go home.”

They replied, “Go to DHAP/HUD. They will build you a castle.”

I said, “You promised.”

FEMA responded, “Promises are words. We have lots of words. Do you want some more?”

I ran against the fierce, cold wind, sobbing, but I was sinking fast into the shifting sand. I was smothering.

One year post Sandy I hold these truths to be self-evident: that, no men are equal. The weak and infirm hold up the line, are disrespected, left behind, trampled. He who is different must endeavor to be the same and keep up, or be dismissed and exterminated by broken, out-dated systems. Agencies and Programs for helping, are businesses and figureheads, not facilitators. There is no help for those who fall down. If your life was a pillar of good works, no one cares. Individuals do not exist in systems.

Every person could fall down from a freak of nature, through no fault of his own and be dismissed, forgotten, smother in the shifting sands of broken systems. You are on your own. If you give your power away to barbarians, you lose your ability to take care of yourself, to revive. Do not drink the sand. Sand kills people!
Afterword

As of December 2014, my Mom is continuing her effort to work through the many obstacles of the disaster recovery system as a disabled individual.

- Shannon Wagner, December 26, 2014