

# International Disability Rights Affirmation Conference (IDRAC)

Friday November 18, 2016 - 8:00am- 3:00pm

Saturday, November 19, 2016 - 8:00am - 1:30pm

Sojourner Auditorium, Virtual Ability Island in Second Life®

[http://maps.secondlife.com/secondlife/Virtual Ability/54/170/23](http://maps.secondlife.com/secondlife/Virtual%20Ability/54/170/23)



Speaker: Shyla the Super Gecko (KriJon Resident)

Title: "9/11: The PWD Story"

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[12:30 PM] LV (lorivonne.lustre): Hello everyone.

Today's presentation is being transcribed so those without audio or who require text only can participate in real time.

A little explanation about this service.

Voice-to-text transcriptionists provide a translation of the key ideas discussed, NOT a word for word transcription.

Voice-to-text services provide an in-the-moment snapshot of ideas and concepts, so that those who are unable to hear or to understand the audio program are able to participate in real-time.

You will see the transcription in Nearby Chat.  
Transcription is provided by Virtual Ability, Inc.

The transcriptionists are:

Carolyn Carillon  
LoriVonne Lustre

The following initials in the transcription record will identify the speakers:

SSG = Shyla the Super Gecko

[12:30 PM] Fidget: Welcome to the closing presentation of Virtual Ability Inc.'s IDRAC (International Disability Rights Affirmation Conference) 2016.

My Second Life virtual world name is Fidget, and I'm stoked (yes, that's a slang term from one of my many physical world ages!) to present our next speaker, "Shyla the Super Gecko!!"

In the physical world, Shyla is a former storm chaser, outdoor adventurer and comedian who, to pay the bills, developed industry specific solutions and implemented enterprise wide systems for Fortune 500 companies. Shyla is a published author, editor, blogger and poet. She is also a caregiver.

In this virtual world known as Second Life, Shyla is a Super Gecko and wears a pink cape to note the distinction. She enjoys customizing, building and texturing in Second Life. She creates theme builds on her Nautilus Island parcel to benefit organizations in Second Life assisting People With Disabilities.

You can read more about Shyla and her basic thoughts on this presentation on the Virtual Ability Inc. blog -- I offer the link for your future reference.

<http://blog.virtualability.org/2016/11/idrac-2016-speaker-spotlight-shyla.html?m=1>

Shyla's skill sets in both worlds grow from enthusiastic curiosity, dynamic interaction, and researching bellwether—I like the word bellwether and I use it in the sense of a person or person-behind-an-avatar who assumes the leadership or forefront of a profession or industry, or advocacy.

Shyla is that—a leader advocate, facilitating those around her so they may also step into the forefront—creating a ripple effect that has more and more people sharing their stories of diversity, capability, inclusion, and community.

One of the results of that facilitation is today's sharing of "9/11: The PWD Story"

A half hour would not give me enough time to introduce Shyla's accomplishments and body of work—and it would not leave time for the presentation! I will say, that Shyla and her presentation are "pretty super"!

There will be a "Comments, Questions, Food-For-Thought-Sparks Discussion Period" at the end of Shyla's presentation.

During the presentation please make notes, in a way that is easiest for you, to remember what you want to ask or contribute. Shyla will answer questions during that discussion timeframe, so please hold your questions until the presentation is complete.

Join me now in "nearby chat" with a series of warm welcomes and outrageous applause as Shyla makes her way to this virtual speaker stage!

Welcome Shyla!

[12:34 PM] LV (lorivonne.lustre): <transcription begins>

[12:35 PM] KriJon Resident: Hello and Welcome (smiles). I'm Shyla, a PWD (Person With Disabilities).

Before we begin, I would like to do some housecleaning.

There may be questions or people who can provide additional information as the presentation progresses. If you think of something to add, please open a notecard, and write it down.

There will be a discussion, question and answer period after the presentation, and I would very much like to have such things shared at that time (smiles).

Some of the information in today's presentation is disheartening. If you become uncomfortable at any time, please feel free to leave.

You may come back later or IM me later for the text of the presentation, or not, it is up to you. There is no need to excuse yourself. (smiles)

Finally, the events of September 11, 2001 mark a solemn day for me and many others.

Although I was not in New York at the time of the bombing, I knew people in the towers who did not survive.

For many weeks I did not know their fate, because they were people I worked with, but I did not know their families.

Many people I know had similar experiences. This event touched many in a very personal way in America and beyond.

So I ask, before we begin, that we treat this, and everyone involved, with the respect and dignity each deserves.

If you do not feel you can do this, I ask that you leave now in respect to the thousands who lost their lives on September 11, 2001 and those who loved and knew them.

Thank you.

As I researched this topic, I found it could go in several directions. I have tried to take what is an enormous amount of information and present it in a very brief period of time.

It is incomplete, with huge gaps in information. Even the topics we do touch on today are, inherently, incomplete.

First, we will discuss why this topic is important (I believe critical), to both PWD and non-PWD. Then I will share a few of the stories of PWD impacted on 9/11.

We will discuss the plans that were in place, and in so doing, try to get a glimpse of the mindset at the time by looking beyond 9/11 at other PWD experiences in emergency situations.

We will consider the effort to implement changes as it relates to emergency planning for PWD.

We will see some things have not changed. PWD who are present may be very aware of these things, and they are worth writing down in your notecard for comment after the presentation.

Finally, I will close with some action remarks about what each of us can do to help move things forward. This will be especially targeted to what PWDs can do to ensure their safety when the emergency plans in place, if any, do not.

We will end with time dedicated to discussion and questions and answers. I will also put out a memorial prim so that people can take copies of this presentation, the slides and a list of citations with links.

This year marked the 15th anniversary of the World Trade Center bombings which occurred on September 11, 2001. It was highlighted by numerous shows, replays, memorials and events.

I could not remember much about PWD and 9/11. I was not disabled at the time. In 2001 I was recovering from back surgery, but did not consider myself PWD.

Perhaps this is why I don't remember. PWD were not part of my "tribe". Today, I have joined the PWD tribe, as most all of us will at some point. Some sooner, some later.

What I can say about joining the PWD community is it wasn't easy for me. I was prejudiced by societal views which have turned out to be untrue in so many ways.

But in 2001 I wasn't concerned about these views. I don't think I was unique in this as an able-bodied person-

but this reality for able-bodied persons explains many of the issues PWD face today in emergency planning and management, as I hope this presentation helps show.

This year, as my understanding of the PWD community and the issues we face continues to grow, I was moved to look at our 9/11 stories.

Our stories are very difficult to find. This presentation is the result of opening and closing hundreds of web pages searching for them.

I found them on disability sites and in US government reports. I clicked numerous links to archived pages long ago moved or sites long ago abandoned.

And they were on main-stream media sites, where PWD were primarily un-named sub-characters to their able-bodied heroes.

Heroes saved the woman in the wheelchair and the blind man. One guy in a wheelchair, the media reported, didn't get out on time.

I found only one main-stream media story which consistently named the PWD saved. But all the un-named references led to piecing together a puzzling question, "Who were these PWD?"

What I share today is important because it is about our narrative, our stories and how often we, as PWD, become 'objects' or 'things' without names. Less than human.

When we are not human there is less need to plan for us, as we shall see. It is imperative this change for PWD today and in the future. Why?

Because disasters are on the rise. From 2000-2009 we had three times as many disasters than from 1980-1989. Most were related to weather.

As you listen to the stories of PWD in this presentation, please know there is a concept in emergency planning which asserts that not all disasters are natural; most are the result of human error.

Where we choose to live, how we live, how we build, and how we PLAN and RESPOND all play a significant role in whether a severe event becomes a disaster.

Emergency planners are faced with determining how ready they can be given budget and resource constraints. This leads, inevitably, to decisions which value some lives more than others.

But I hope to show that this planning limitation need not impact PWD as greatly as it did in 2001, nor as often as it still does today.

This slide of the World Trade Center Memorial and Towers is in memory to the approximate 200 PWDs who died on 9/11 whose stories could not be found.

[12:43 PM] Sabre (sabreman.carter) is Online

Of the close to 3,000 deaths related to the terrorist attacks of 9/11, some 200 are estimated to be PWD.

If 200 were PWD, I could only find two of their stories. For the rest, the narratives are vague or broad and lack specificity. But we know they perished.

We know because we found their wheelchairs, or they were identified through forensic means as PWD.

We know because of the stories of some able-bodied people who survived.

Stories like the man who said his last image of the 80th floor as he began his descent was of people in wheelchairs and with walkers waiting to be rescued.

No emergency responder made it as high as the 80th floor. Orio Palmer, a New York firefighter who died on 9/11, is thought to have reached the highest floor that day. He only made it as high as Floor 78.

This is how we can piece together the unnamed People With Disabilities who died on 9/11. But I did find two names of PWD who died on 9/11. They sound like two wonderful people. Let me share what I learned about them.

This is Colleen Fraser. She was on Flight 93 when it crashed in a field in Pennsylvania.

Her legacy is one of strong community commitment. She had been recently appointed to Chair of the New Jersey Council on Developmental Disabilities.

She was flying to attend a work related workshop on 9/11.

Her life was spent working to get people with developmental disabilities out of state run institutions and integrated back into their communities.

She played a significant role in altering the state of New Jersey's attitude and service concepts toward the developmentally disabled.

She was a strong, vocal advocate of the ADA (Americans with Disabilities Act) and was present at its first congressional hearing. She worked vigorously to improve women's health-care.

I suspect, if she had been asked the day before 9/11, she would have shared a plethora of goals and work she had left to do. Colleen Fraser was 51 the day Flight 93 crashed.

The second story is Ed Beyea's. The mainstream media spoke of him mostly as "the man in the wheelchair".

Ed was 42 and became quadriplegic as the result of a diving accident when he was in his early twenties.

He mastered an oral joystick well enough to land a job as a data entry clerk for Empire Blue Cross/Blue Shield in the World Trade Center.

On the day of the attack, as many of his co-workers exited, his friend Abe Zelmanowitz stood by him as Ed declined a stranger's help down the stairs.

Ed was worried his weight would make it difficult for untrained persons to transport him without breaking any of his bones. Ed opted to stay and wait for help.

Also with him that day, as she usually was, was Ed's aide Irma Morant. The three agreed Irma would head down the stairs and relay Ed's location to an emergency responder so they could come help.

Abe stayed, refusing to leave Ed's side, as Irma headed downstairs. She did locate some firemen and gave them Ed's location and advised he would need oxygen due to the dusty conditions.

Then Irma exited the towers to safety. Meanwhile, at Ed's side, Abe spoke to loved ones over his cell phone. They begged him to evacuate, but he would not leave Ed alone. Abe and Ed had been friends for twelve years. They were sure help would come. It never did. Both Ed and Abe died when the towers collapsed.

I found there were more stories about the PWD who survived. But even so, only one main media story repeatedly gave a PWD a name.

That is the story of John Abruzzo. John is sometimes referred to as 'a man in a wheelchair', but more often his story provides his name, and those of one or more friends who helped save his life.

John survived the first World Trade Center bombings in 1993. He remembers it took hours for him to evacuate the towers that day, with the help of friends.

Sometime after the 1993 bombings, an evacuation chair (evac-chair) was placed on John's floor.

Although reports vary, John's own words indicate neither he, nor his friends, ever practiced using the chair, but he knew it was there.

John says in some articles he is not sure how evac-chairs were distributed in the towers, just that he had been provided one.

On 9/11, he and his friends and co-workers figured out how to strap John into the chair and began to descend the stairs.

Their stories reveal the evac-chair didn't always fit easily through all the corridors. It was hard work. Still it was better than in 1993.

When they reached one of the lower floors, they found a triage unit. Workers there told John's friends they could leave John there. There were other PWD at the triage unit, but his friends refused.

John was carried down the remaining floors. What took hours in 1993 took only 90 minutes in 2001 with an evac-chair. When they exited, John was placed in an ambulance and whisked away.

His friends were caught, minutes later, in the debris of a falling tower. They ran for cover. Ed and his friends and helpers all survived.

Without an evac-chair, they would not have been able to descend as fast and would have all perished.

Had John been left at the triage unit, he would not be with us today either. All those at the triage unit died on 9/11 when the buildings collapsed on them.

There was the woman in the wheelchair who was saved by Michael Benfante. Michael was repeatedly named in articles and interviewed often on his own.

But the woman had a name and life too. Tina Hansen had juvenile rheumatoid arthritis and used a lightweight wheelchair at work, just in case she had to be evacuated.

She, too, had been provided an evac-chair, but forgot it was under her desk. Two co-workers, Michael and another person, assisted Tina down the stairs that day, ensuring she survived.

Tina participated in post-9/11 government assessments and shared her employer, the Port Authority, did not practice fire or emergency drills.

The Port Authority is a government agency working jointly for New Jersey and New York. They oversee transportation services in the area of the Port of New York and New Jersey.

In some interviews, Tina states she is not sure why she forgot she had an evac-chair, but in one government report she cites the lack of drills as one reason she may have forgotten it was there, right under her desk.

Tina appears to have been very hesitant to seek public acknowledgment of her experience on 9/11, one reason her story and name may have been missing from main-stream media reports.

There were two blind men who received media attention when they survived. The media referred to them mostly just as 'a blind man' or 'the blind man on the 68th floor'.

We shall see later, these two men were not the only blind and low-vision PWD who survived that day. But they are the two who receive most broad media attention after 9/11.

Omar Eduardo Rivera was the blind man on the 68th floor. When I looked for his picture online, I found it was often confused with the other blind man in the media, who we shall hear about next.

Omar did not think he could get down 68 flights of stairs on his own.

He released his guide dog, Dorado, so the dog could survive. At first he heard Dorado running away, but then Dorado stopped and returned.

The dog nudged Omar's leg and refused to leave without him. It was enough to encourage Omar to attempt the descent.

Along the way he met a co-worker who helped him make it down the stairs. Omar, his service dog and the co-worker all survived.

The other blind man was Michael Hingson. His story is very different in one-way from those we have heard so far. Michael was on the 78th floor of the Towers.

In his case, his employer held regular fire and emergency drills. He recalled this made him feel empowered and prepared for an emergency.

When the decision was made to evacuate, Michael and his dog, Roselle, knew what to do and how to do it. He credits the emergency drills his employer performed with saving his life.

One thing I didn't expect was the stories of PWD impacted by 9/11 who were not in New York, not in Washington DC and not on one of the hijacked planes.

Their stories are important too, for they remind us that what happens one place can have a huge impact much further away.

Take Brian Cortez. Brian had been fighting for a heart transplant. He was rejected as a viable candidate because he was deaf and disabled.

His family, friends and even teachers fought to get Brian on the transplant list, and finally the decision was overturned and he was put in queue for a transplant.

Shortly after the attacks on the twin towers, but before the Federal Aviation Administration (FAA) began to allow planes to fly in the states again, a heart match was found for Brian.

The heart was in Anchorage, Alaska, but Brian was in Seattle, Washington. With planes grounded, there was no way to get Brian the heart he desperately needed. Brian was running out of time.

After intense negotiations, the FAA authorized a small plane to fly the heart into Seattle.

Brian received the transplant and survived.

Let me add as a footnote, there was \*nothing\* about Brian's condition which prevented him from understanding or following the care instructions associated with a heart transplant.

I hope you all have found something to take note of on your note cards.

If not, please take a moment to scroll back and write down any thoughts that come to mind before we continue.

(pause)

Everyone ready?

Now we are going to discuss the emergency plans in place on 9/11. This slide has strong words. These are words from PWD's. I selected them because they are strong, honest and to the point.

The first are from Dave Hinsburger, who writes a PWD blog in Canada which has received numerous awards. He writes:

"It's just outside my door. The gathering place. The place where those of us with disabilities are to go in a crisis. Should there be a fire, an earthquake, a disaster of any kind, it is where we who move differently, who move mechanically, who move [sic]

"I have been aware of this place, and places like it, for my entire existence as a person with a disability. On moving in to my apartment, a high rise, I'm told about it as I sign the lease. I'm smiled at. People are pleased that there is a plan.

"People want me to be grateful for the plan. Grateful that I have been thought about. But I haven't.

"9/11 taught me that."

The second is from a blog called Reunify Gallery. They write:

"The plans others make for us (meaning PWD) are usually not going to be as good as the plans we make for ourselves—especially if you are a person with a disability."

After the 1993 bombing of the World Trade Center, there was agreement a plan was needed for PWD, but the effort was fragmented at best.

The final plan, of which I could find no documentation, was in part poorly communicated and in part lethal.

This is not my opinion, it is well documented in government reports as well as the events and narratives available from 2001.

Somewhere between 1993 and 2001, much of the effort to include PWD in emergency planning for the World Trade Centers lost traction.

Not just from within the government, but from within the PWD community as well.

For example, although there were evac-chairs in the towers in 2001, I could not find evidence of who purchased them or when.

Some information suggests each tenant made an independent decision about whether to purchase such chairs for the floors they occupied.

Other documents suggest evac-chairs were purchased by building management for all floors.

Ed Bayea's employer Empire Blue Cross/Blue shield insists they purchased an evac-chair in 2000, a year before the 9/11 attacks.

But Irma Morant, Ed's aide, insists there was no chair, and even if there was, she believed only the fire department was trained to use such equipment.

In contrast, John Abrezzo and his friends used an evac-chair with no training and without concern about "who" was authorized to use such equipment.



Even today, whether evac-chairs are for lay people or emergency responders causes debate. So it is not clear whether evac-chairs were part of a "plan" by building management or were provided as part of individual tenant plans.

The same is true for fire and emergency drills. Michael Hingson's story is one of preparedness through his employer's conducting of such drills.

I found no evidence that any other PWD participated in such drills, except one, The Associated Blind, whose story I found in a government report, not media reports.

The Associated Blind not only conducted fire and emergency drills for their mostly vision impaired staff, but they coordinated with building management and the New York Fire Department.

On 9/11, \*all\* of The Associated Blind's 9th Floor employees successfully evacuated the Twin Towers.

Reports indicate their employees were calm, much like Michael Hingson. This is credited to the drills these employers held.

In 2001, however, the primary plan appeared to be that PWD were to make their way to a designated gathering place and wait for help.

All, and I will repeat that, \*all\* PWD who followed these instructions perished when the towers collapsed on 9/11.

If there are thoughts the extreme nature of 9/11 explains why gathering places did not work that day; that in different situations 'gathering places' are effective,

let me present some additional stories which demonstrate gathering places, in an of themselves, are not effective, not a plan, and not a solution for PWD ever

(Sadly, most of these narratives provided no names, though many are a part of government reports.)

A US government report cited the experience of a woman in a wheelchair with severe rheumatoid arthritis.

While at work, a bomb threat was received and she was told to stay put and help would arrive. The woman waited.

After some period of time and out of sheer fear, she self-ambulated herself out of the building. No one had been tasked to help her or seemed aware she was in the building.

Another PWD reported their workplace lost electricity and lights. The PWD felt they could ambulate down the stairs but asked if someone could take their wheelchair.

Citing liability concerns, the request was denied and the PWD was told to wait and someone would come to assist.

After two hours under emergency lights, the electricity was restored. No one ever came.

I found numerous stories like this, some with more disturbing outcomes and with more disturbing comments made to the PWD's seeking assistance.

Gathering places are not an answer -- they simply allow those creating emergency plans to say (and perhaps feel) they have included PWD.

Gathering places pass the buck to an unknown entity to be responsible for saving PWD, and often that unknown entity is not informed of this expectation.

But there are several take-aways from the PWD stories of 9/11. Some very good ones. The first is drills work!

PWD on 9/11 who participated in drills that led them not to gathering places, but rather to fully exit the buildings, survived.

Beyond this, PWD who participated in drills reported being calm, feeling self-sufficient and confident of their ability and what they needed to do.

But we know of only two employers who held such drills. If we move beyond 9/11, we hear other stories of grave concern surrounding drills.

PWD still report emergency plans and drills which ask them to engage in actions they cannot perform. For example, some PWD cannot walk, crawl under a desk, 'stop, drop and roll', or use stairs instead of elevators.

Paul Ray, a quadriplegic, reported when he worked for Ford Motor Company in Dearborn, MI, he participated in his first emergency drill 18 months after being hired.

Working on the third floor, and being unable to use stairs, Paul went to the elevators. The volunteers redirecting people to the stairs were surprised to see him, had no plan for him and were not sure what to do.

Paul also said he had never seen an evacuation plan prior to that drill.

A social worker in New York City who uses forearm crutches to ambulate was in a high rise visiting a client when they had a drill.

The plan did not include PWD, so they asked her, simply, to not participate in the drill.

A PWD in Oklahoma reported there was a fire in their building and there was no plan for their evacuation.

Afterwards they requested the employer include them in the plan, but the employer refused to update it.

It is against ADA requirements to not include PWD in evacuation and emergency planning. Sadly, however, this is rarely enforced for various reasons, not the least of which is many PWD never file complaints.

A 2005 National Council on Disability briefing found PWD \*rarely\* make formal complaints about discrimination in emergency or disaster planning.

They also found the impact to PWD in emergencies is far greater than the number of complaints reflect.

From personal experience, I have had employers who do not update plans because they do not know how to effectively provide for the safety of their employees, PWD or not.

This is also not considered 'reasonable' under the law and does NOT protect employers from liability.

Our second valuable lesson surrounds communication. The National Council on Disability (NCD) has worked diligently since 2005 to increase the availability of PWD emergency planning communication at all levels.

PWD, employers, community based organizations, emergency planners and responders, government organizations, etc., all have more information available than ever before.

On the other hand, the NCD has recommended government sites provide PWD communications in a variety of formats other than .pdf, including audio.

For the most part, all reports and planning information I researched are still only available in .pdf on government websites.

Worse, some appear as in this blue box. A .pdf image which is scanned improperly. In this case, both selections have the word 'disabled' in them.

But as you can see, what they are attempting to communicate is illegible.

Communication progress has been made at Disaster Recovery Centers. All are now supposed to include a sign language interpreter on-site or via remote video. They are also supposed to have caption amplified phones, amplified personal listeners and emergency information available in braille or audio. This highlights another issue during the events of 9/11. Live closed caption services suffered due to the stress of the situation and long hours of coverage. In other words, the people typing the CC captions were, understandably, overly stressed and overly tired. The result was many deaf people across the country had to unscramble words, sometimes key words, to properly interpret information. Some stations showed images of the towers on fire or collapsing without any closed captioning. Imagine seeing these events live with no explanation of what is happening. On the opposite end, some stations had text, but no audio, leaving low-vision and blind people completely unaware of the events if they were tuned to such a station. Although New York had a reverse-911 telephone system which could call 1000's of person with emergency information, even TTY, it was not used. I found no explanation as to why, and the various reasons some things were done or not done are too numerous to hazard a guess. In summary, as long as PWD are not integrated into drills and communication efforts, the stranding and lack of consideration of PWD in emergency situations is likely to re-occur.

Finally, I read hundreds of pages of reports on emergency planning for PWD and other at risk communities, such as children and the elderly. The good news is the PWD community is being engaged more and changes are being made. Sadly, there is more discussion than action. This is often true in government efforts, and PWD are no exception. The result, however, is it has been 15 years since 9/11, and still many PWD are told to wait for help. To go to the 'gathering place'. There is much PWD can do to change this. PWD must ask to see the plans that are in place in their own communities, work places, rentals and ensure they have a plan of their own for their residence. PWD must identify deficiencies, assist in resolution and report when such requests are ignored or denied. Many PWD in the twin towers changed things after the 1993 bombings. Tina Hansen got a lightweight wheelchair which she always took to work. 9/11 caused many PWD to change even more... Many considered their place of residence and determined how they would escape without assistance in case of an emergency. Some established plans with friends, neighbors and co-workers. And for some, these worked on 9/11. Some decided it was not worth being polite in an emergency. They decided they would yell, scream, and make whatever ruckus necessary to ensure their survival. Some became advocates of planning, working hard to ensure plans included their particular needs in realistic ways. Ultimately, there is a societal and legal responsibility to include PWD in emergency planning and resources to help make this happen.

Sadly, these resources vary from location to location, so I cannot list them all here. But you can Google them. If you can't find them, reach further and ask, \*ask\*, \*ASK\* for them!

I'd like to open this up to discussion, but before I do, I will say again, finding these stories was not easy. They weren't there front and center.

I will guess you have all had some thoughts today, some memories or identification of some sort.

I challenge all of the PWD here today to write about it a bit. This is your story, your narrative, and your VOICE matters. Then look for one person you can share it with.

Just one person will be one more that has heard your story than before. If all PWD's did this today, millions would hear our stories who had never heard them before.

Before opening to discussion and question and answers, I ask again that the guidelines presented at the beginning of this presentation be kept in mind.

Questions are welcome – there was much information I could not include in this time allotted.

Please feel free to share your thoughts.

The goal is to promote thought – therefore there is no need to debate. We can consider our position on various thoughts independently while maintaining a supportive environment.

Let us be respectful of the memory of those lost on 9/11, as well as the many people alive today, some possibly here, who knew them.

Let us be respectful of each other.

Thank you.

We are open for discussion and Q&A.

[01:13 PM] Dhira Giha: amazing detective work

[01:14 PM] Gloriejoy (joycie.string): We have exit signs in each room, many doors and egress windows, easy to exit

[01:14 PM] Mook (mook.wheeler): COMMENT: Shyla, your incredible research highlights the critical importance of self-advocacy and the role of organisations for PWDs. Two quotes from two PWD advocates encapsulate this:

'When others speak for you, you lose.' -- Ed Roberts

'As long as we remain silent, we will be told by others what to do.' -- Adolf Ratzka

[01:16 PM] Carolyn Carillon: SGG: So true

[01:14 PM] Bridgette Rossini: If a PWD has a complaint of discrimination or lack of an emergency plan for them, where can they report it?

[01:14 PM] Carolyn Carillon: SGG: They can report to the ADA,

The main reason they don't report is because this is a LONG process

But this is my life

We're important to people

This is a key area where we should be filing complaints

Go to your employer first

Say "I'd like to be included. I'd like to work with you"

But if you're turned away, file

[01:15 PM] Bridgette Rossini: It might be a good idea to suggest to the ADA to make reporting such issues with more ease

[01:16 PM] Carolyn Carillon: SGG : It is so true  
The ADA process can be exhausting  
It'd be wonderful to streamline certain aspects  
Essentially, you file & then it's reviewed  
Then there's discussion  
There's no penalty  
None of this  
We sit at a table and negotiate  
If they refuse to negotiate, the government will act  
We're getting closer  
It's really worth it  
I try to have a sense of humour about how long it takes  
[01:17 PM] Bridgette Rossini: Unity brings power  
[01:20 PM] Carolyn Carillon: SGG: Absolutely true

[01:16 PM] Leandra Kohnke: On the topic of being on committees I would like to share.  
My husband was temporarily disabled with a broken leg he could not put weight on and he was using a scooter and crutches for six weeks. He was on the fifth floor of one building of the hospital building when a fire alarm went off. The elevators were shut down. He reported how upsetting it was to roll to the top of the stairs. Everyone just walked past him and exited. He was left alone. The firemen did not know to go up to him because he was not in the list of official employees. The firemen had been told there were no PWDs on that floor. In the end he evacuated himself by bumping down on his behind dragging himself. It was only as he got to the bottom of the 10 flights of stairs that firemen noticed him and helped him.  
He was very upset and made many complaints in writing to everyone he could. His reward was to be assigned to a committee to fix this problem. He enacted many changes after a full building audit. However without the audit being repeated each year, things fall apart, break or get forgotten. And he had to be hard nosed and very vocal in his complaints. He never considered this until he was in the position of a PWD himself..

[01:18 PM] Carolyn Carillon: SGG: Not the first story I've heard like this.  
It's a common story  
My gosh, I'm so glad he was able to ambulate in this way.  
You bring up two great points  
I was in the same place  
On 9/11 I wasn't disabled  
I didn't think about it  
If you're able-bodied  
I hope this has shed some light  
So you can also advocate for us  
Say "Have we included everyone?"  
As for being vocal, rock on  
After we saw the bombings on 9/11  
We relaxed  
Nothing happened  
So people with passion make things happen  
They rock my world

[01:20 PM] Gentle Heron: [13:18] Viv013: Hi, wouldn't ramps be better than stairs for escape routes? Old stairs can be remodeled. The stairs could be 1/2 steps & 1/2 ramp or 1/3 ramp & 2/3 steps.

[01:20 PM] Carolyn Carillon: SGG: True

Many municipalities do not require upgrades

They are grandfathered in so they don't have to pay the fees

This is one of the challenges we face

But the evac-chairs are helpful

[01:20 PM] Gentle Heron: [13:19] Dhira Giha: I thought there was a woman wheelchair user (neuromuscular disorder) on Flight 93. She was the director of a center for independent living. Am I remembering incorrectly?

[01:21 PM] Carolyn Carillon: SGG: I believe ...

We talked about her

Let me bring her up

She was on Flight 93

This is Colleen Fraser

She was at the first hearing of the ADA

She just got a new position

She was involved in independent living as well

She worked hard

I would have liked to have known her

Any other questions?

Thoughts?

[01:22 PM] iSkye Silverweb: There is always the argument, "There isn't enough money. That's the reality." How do you respond to that?

[01:23 PM] Carolyn Carillon: SGG: Yeah, this is the argument.

Drills don't cost a lot of money.

And they made a huge difference

Evac-chairs are not particularly expensive

Remodeling a building is super expensive

But not evac-chairs

[01:23 PM] Leandra Kohnke: You make the money and threaten to sue.

[01:25 PM] Carolyn Carillon: SGG: Yes you can

[01:23 PM] Gloriejoy (joycie.string): Worth it

[01:23 PM] Vulcan Viper: Just one more reason why we need to stop using money; change to a resource based economy.

[01:25 PM] Mook (mook.wheeler): There is the constant excuse, where all this is concerned, about "the needs of the many outweighing the needs of the few" where money is concerned :/

[01:23 PM] Carolyn Carillon: SGG: The other thing to think about...

We have to be realistic

I've been an emergency responder

I've been through the training

We have to prioritize  
One service we can provide to ourselves  
Is to make it reasonable  
It's a horrible term  
Reasonable  
We are allowed a reasonable accommodation  
But that's the key  
If we're a disabled person  
And we don't think it's safe to get out  
Can we come up with that reasonable accommodation  
I worked in a 2 story building not on the 2nd floor  
But if I was  
Can I be relocated to the 1st floor  
That's a reasonable request

[01:25 PM] Gentle Heron: [13:23] Bridgette Rossini: I would imagine the liability of being sued if there is a lack of planning for a PWD who survives a disaster and reports it...

[01:25 PM] Carolyn Carillon: SGG: I found no cases of PWD who survived who sued the building management

But we think it's so easy to file a suit

It's not easy!

I've tried to do it

We need to convince the attorney that it's a winnable case

There are exceptions in legislation regarding emergency events

If you listen to anyone who's experienced a disaster

You can sue

But getting the \$\$ is a different story

[01:26 PM] Bridgette Rossini: This is true but if one suit is won, it makes a path for future cases to be won.

It's not about the money, it's about the reputation of neglect for PWD

[01:29 PM] Carolyn Carillon: SGG: Totally agree

[01:27 PM] LV (lorivonne.lustre): [13:25] Gentle Heron: Another horror story: In Colorado, the number of pages in the handbook for emergency responders on how to deal with animals is FAR more than the number of pages how to deal with humans with disabilities.

[01:26 PM] Carolyn Carillon: SGG: This is a critical point

We're talking about PWDs under one umbrella

But we don't all fit

Our disabilities range

Depending on the environment

It takes a lot more training than a few pages

It's important to advocate

There are ways to be included that aren't expensive or unreasonable

PWDs are going to find their environment makes a difference

If we work for a big corporation, reasonable has more resources

But for small companies, it's different

Who we work for

Where we live

Makes a difference

[01:28 PM] Fidget (fidgetswidgets): It's important to speak up. Write up. Sign up. Communicate and keep doing it.

[01:30 PM] Carolyn Carillon: SGG: I agree

[01:28 PM] Mook (mook.wheeler): We are beginning to sound like "collateral damage"

[01:30 PM] Carolyn Carillon: SGG: Yeah

Totally agree

[01:29 PM] Gentle Heron: @Mook- that was my point in bringing up the number of pages dealing with animals vs with PWDs.

[01:29 PM] Gentle Heron: [13:26] iSkye Silverweb: "Anybody can sue anybody about anything." but there is no guarantee you'd win the suit or that it would even go anywhere.

[01:28 PM] Carolyn Carillon: SGG: True

You still have to find an attorney who takes it forward

We have seen major suits in planning before events have happened

They're restructuring emergency planning in large urban areas

I'm trying to think where they were

I'm going to cheat & Google

Not sure why I didn't remember

There are some wonderful videos

[01:29 PM] iSkye Silverweb: "suits in planning" double meaning there

[01:29 PM] Carolyn Carillon: SSG: There was one in DC

One in LA

But they are winning & that's important to our cause

That'll bring about better legislation

If you click the twin towers, I believe I have both the slides & the notecards

Are we good?

I know we're at our limit

I don't want to cut anyone off

Here are the resources I used for this presentation.

I'm going to close really quick

All these resources are behind me

On my right

On your left

I am also putting out these towers which includes this script as well as a notecard with these citations.

Two orange towers

Thank you for letting me share this today.

They include this script & a notecard with these citations

I want to thank you all

I'm glad you appreciated this

I hope it's been helpful

Thank you!



[01:33 PM] Gentle Heron: Oh gosh Shyla, such important information! Thank you for the hours and hours of research you put in for this.

[01:33 PM] Barbie Alchemi: This has been excellent. Thank you so much

[01:33 PM] Fran Serenade: THANKS TO YOU. IT WAS SO HELPFUL.

APPRECIATIONS.

[01:33 PM] Mook (mook.wheeler): Thank you Shyla, this was incredible

[01:33 PM] Susan Toth-Cohen (zsuzsa.tomsen): Very powerful, thank you SO much

[01:33 PM] Dhira Giha: Very valuable information. Ty for doing this work and sharing it with us. Excellent!

[01:33 PM] LV (lorivonne.lustre): <transcription ends>

[01:33 PM] Gentle Heron: I have many thanks to give today.

Thank you to our audience members for attending this conference today.

Thank you to our presenters for challenging our thinking and giving us so much new information.

Thank you to LoriVonne and Carolyn for so much typing! Your efforts allow us to include our Deaf community members.

Thank you to Mook for transcribing all the videos.

Thank you to today's greeters: Fidget, Jos, Fran, Vulcan, Leondra, Kara, Slatan and Claire.

Thank you to today's introducers: Orange, Svea, Vulcan and Fidget.

Thanks to iSkye and Eme for behind the scenes support.

I'm open to suggestions for topics and speakers for next year's IDRAC conference.

Thanks everyone.

Now go forth and invite others into our communities.

[01:34 PM] Shyla the Super Gecko (krijon): Yay for transcriptionists!

[01:34 PM] iSkye Silverweb: LV and Carolyn thank you SO MUCH for transcribing the sessions of the conference!!

[01:33 PM] Carolyn Carillon: Thanks Gentle & everyone ... great conference!!

[01:34 PM] LV (lorivonne.lustre): Thanks everyone for such an amazing conference!

[01:34 PM] Barbie Alchemi: Thank you everyone!

[01:34 PM] Shyla the Super Gecko (krijon): Greeters and behind-the-scenes people

[01:34 PM] Fidget (fidgetswidgets): \*\*cheers iSkye and Eme\*\*

[01:34 PM] Vulcan Viper: I live to serve.

[01:34 PM] Fidget (fidgetswidgets): \*\*cheers for Gentle\*\*

[01:34 PM] Gloriejoy (joycie.string): This conference was a vacation to me and all of you contributed to my vacation