Good afternoon and welcome to the opening plenary session - Natural and Manmade Disaster Planning, Response, and Recovery: Roles for a DD Council.

We have a great panel of presenters representing DD Councils, AIDD, and NACDD and they are: Beth Stalvey, Executive Director of the Texas Council on Developmental Disabilities; Aaron Carruthers, Executive Director of the California State Council on Developmental Disabilities, Myrainne Roa, Executive Director of the Puerto Rico Developmental Disabilities Council, Ophelia McLain, Director of the Office of Program Support for the Administration on Intellectual and Developmental Disabilities, Donna Meltzer, Chief Executive Officer of the National Association of Councils on Developmental Disabilities, and Sheryl Matney, Director of Technical Assistance for ITACC.
Learning Objectives

• Understand and explore three primary roles within three primary areas a Council could consider before, during, and after a crisis;

• Explore leadership opportunities when connecting with government and others; and

• Understand the purpose, process, and function of a Cooperative Agreement.

Today our learning objectives are to explore roles and areas a Council can work before, during, and after a disaster; leadership opportunities; and the purpose, process, and function of a Cooperative Agreement.
Disasters – What is the difference?

The difference between natural and **man-made disasters** is the element of human intent or negligence that leads to human suffering and environmental damage; many mirror natural disasters, yet **man** has a direct hand in their occurrence.

For this presentation, we have included natural as well as manmade disasters in the focus – so what is the difference? Man-made disasters include human intent or negligence with a person having a direct impact on the occurrence.
Here is a quick listing of examples of natural and manmade disasters...Many manmade disasters mirror natural disasters, but the difference is the human element.
During this session, we will focus on three primary areas for a DD Council to be involved – Planning, Response, and Recovery.

For this presentation, we will refer to these three terms with the following meanings:

Planning - the process of thinking about the activities required to achieve a desired goal;

Response - a reaction to something; and

Recovery - the action or process of regaining possession or control of something lost.
As we think about the areas of involvement, we want to make the connection of how these areas translate to the three primary areas of activity for a DD council within the framework of Advocacy, Capacity Building, and Systems change.
Today we will hear from three DD Councils about their experiences with natural and man-made disasters. First we will hear from Beth Stalvey representing Texas, then we will hear from Aaron Carruthers, representing California, and then Myrainne Roa, representing Puerto Rico.
Texas
60 State Disaster Counties
43 FEMA Designated
Response
Response

• Designated Disability Staff Positions

• Daily Coordination Calls
  • 100+ participants
  • Case management

• People with Disabilities Assisting in Response
  • Preparing food at stadium/shelter
  • Donation sorting- clothes/food
Recovery
Lessons Learned

• Past planning efforts led to improvements
• Case management essential to connecting services
• Schools and special education
• Transportation
• Gaps in existing support
• Trauma experienced by individuals with I/DD
• Organizations have limited capacity to help when their business, finances, staff impacted
YOU KNOW YOU'RE FROM CALIFORNIA WHEN...

THE FOUR SEASONS: FIRE, FLOOD, EARTHQUAKES, AND RIOTS
Hi

And a good one

This never

I am

4:03 PM

But we are locked in

Concealed helicopter

Can't hurry things.
SCDD

SCDD ADVOCACY BRIEF
December 5, 2016

Senior advocates call for Coordinated Response During Disasters

As the nation prepares for the winter months, advocates of people with disabilities are calling for the implementation of disaster preparedness and response plans for the needs of people with disabilities.

"We need to ensure that people with disabilities are not forgotten during disasters," said [person's name], senior advocate. "Our community is often the last to receive assistance and the first to be hit by disasters."...

[Text continues with various advocacy points and calls to action.]

The SCDD advocates for the following:

1. Increased funding for disaster preparedness programs specifically designed for people with disabilities.
2. Ensuring that all emergency plans include provisions for people with disabilities.
3. Training for emergency responders on how to effectively assist people with disabilities.

"We are committed to ensuring that people with disabilities are included and protected during disasters," said [another person's name], SCDD executive director. "We need to prioritize the needs of our community and work together to create a more inclusive and disaster-ready society."
Goal 4 (Health & Safety):
Educated in person through training, technical assistance, outreach, and in person informational materials:
138,136 Self-Advocates
26,873 Family Advocates
13,419 Professionals and Others

Electronic Information Distribution: 251,431
Capacity Building
- Reach out to Office of Emergency Services
- Reach out to local law enforcement

Advocacy
- Support trainings that incorporate disability and access and functional needs

Systems Change
- Change the trainings and curriculum
- Train-the-trainers (loops back into capacity building)
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Hurricane Maria

On September 20, 2017 Puerto Rico suffered the onslaught of Hurricane Maria, an atmospheric event that changed the lives of Puerto Ricans, including the lives of people with disabilities.
Hurricane Irma

However what many people don’t know is that Puerto Rico suffered devastation 14 days before under Hurricane Irma.

- 1,079,465 Households without power
- 77,000 households without water
- 22 hospitals working with generators
Hurricane María

• Total Blackout

• No Potable Water Service

• No communications

• One Radio Station Operating
Challenges for People with DID

- The state government prepared only one special shelter for people with access and functional needs in the metropolitan area.
- Dialysis centers were damaged and had no electricity; services did not restart until 1-2 weeks after the hurricane.
- The deaf population had no idea as to what was happening; no one had electricity, news channels were not operational.
Challenges for People with DID

• Some shelters had no water either, and survivors were required to collect rain water to see to their needs; water not apt for consumption.

• Lack of operating pharmacies created a shortage of medications.

• Many people with disabilities lost assistive equipment during the hurricane. Insurance plans denied replacement; FEMA was slow in providing because they required insurance denial; most suppliers were not yet working because of their own losses. People had no wheelchairs, hearing aids, and other critical equipment for daily living.

• Family members, many of whom are the sole caregivers of people with disabilities, had to leave the homes in search of supplies or to coordinate disaster aid.
Challenges for People with DID

- Oxygen producers on the island were decimated. Therefore, there was not a sufficient oxygen supply in the island.
- People with disabilities that required medical equipment 24/7 were required to purchase generators to sustain their lives.
- Emergency supplies that were being handed out to survivors were high in sodium and not apt for the cultural and dietary needs of PWDs.
- Elderly people were left at group homes, did not have adequate water or electrical supplies (generators).
What we did

After approaching the state to identify what was being done to help the community with disabilities and developmental disabilities, and realizing that what was being done wasn’t enough we created a Network to, with our limited staff:

• Visit Shelters, Nursing Homes and Hospitals
• Identify Needs though a Survey
• Created a call Center
• Establish a Collection Center
• Call and Coordinate Donations from within the island and from many, many generous supporters outside the island.
How did we Advocate

• Sharing with FEMA the information of the needs of people with Intellectual and Developmental Disabilities
• Conducting Efforts to Obtain Donations to fulfill needs
• Fighting to get our community at the table
• Telling our Story to Anyone who will listen
Capacity Building

- Creating the Puerto Rico Disabilities Community Relief
- Gathering and Disseminating Data
- Offering Technical Assistance to Shelters Administrators, Municipalities and NGO’s
- Training the Community and Emergency Responders
Puerto Rico Disabilities
Community Relief Network

• Puerto Rico Protection and Advocacy Program
• Puerto Rico University Center on Excellence on Developmental Disabilities
• Puerto Rico Assistive Technology Program
• Movement for the Achievement of Independent Living
• Puerto Rico Developmental Disabilities Council

2018 AIDD/TRCC Technical Assistance Institute
PRDCRN

Working to improve the standards of emergency preparedness for the well being of people with disabilities in Puerto Rico.

• By Advancing Policies and Practices that improve the standards of emergency preparedness
Leadership and the Council

As you have heard, leadership by these Councils in a variety of areas was provided to their State, Territory, and also the DD Council Network, and nation.
Change – the work of leaders

All change requires leaders to actively seek ways to make things better, to grow, innovate, and improve;

Being proactive produces better results than being reactive or inactive;

Leaders guiding a change must establish more relationships, connect with more sources of information, and get out and “walk around” more often;

Leaders must continually scan the external realities;

Sometimes leaders seek challenges, but other times the challenge seeks the leader.

And, as you have heard, change was needed to make response and recovery systems better – Change is the work of leaders –

At the beginning of the session we talked about the primary areas of involvement – planning, response, and recovery – and we have heard the experiences of 3 councils – you may have your own as well – what we know is being proactive produces better results than being reactive or inactive – so planning activities are a great way to make things better – getting out and establishing relationships with people on the “front lines” or people who administer programs, supports, and services for people affected by disaster is another key way Councils can provide leadership – making yourselves aware of information – of course, Council leaders continually scan their environments – to see what the realities are – and when the reality is not meeting needs of people with I/DD and their families – that gives Council leadership opportunities to improve and innovate –

Leaders often seek out challenges, but in terms of disaster response and recovery, sometimes, those challenges seek the leader – and provides Councils an opportunity to impact systems.

Kouzes and Pozner
During the last 5 year state plan cycle, just under ½ of all Councils conducted projects and activities to address emergency preparedness and responder initiatives.

In the current 5 year state plans, 10 Councils included a specific focus on emergency preparedness and responder efforts, and an additional 17 Councils have included an objective in their state plan for emerging issues.

Let’s look at some results from Councils over the last 5 year state plans in the three primary areas of activity.
Advocacy

The term “advocacy activities” means active support of policies and practices that promote systems change efforts and other activities that further advance self-determination and inclusion in all aspects of community living (including housing, education, employment, and other aspects) for individuals with developmental disabilities, and their families.

In terms of advocacy activities related to disaster planning, response, and recovery – Councils actively engaged in a variety of activities that advanced self-determination and inclusion...
Advocacy Roles

Advocating that organizations and agencies include people with developmental disabilities and families in planning, training, and policy change work;

Advocating that information about preparation and resources during and after a disaster are available to ALL;

Advocating that information is culturally appropriate;

Advocating that response and recovery services and supports are available and meet individualized needs.

Some of the primary advocacy roles DD Councils assumed during the last state plan cycle (as evidenced by the information in their PPRS)

Pennsylvania worked to ensure people were at the table during emergency planning discussions at all levels across the Commonwealth; Virginia worked in collaboration with other agencies and provided people with developmental disabilities to help plan and train responders; North Carolina integrated individuals with access and functional needs in the Exercises Toolkit for NC Emergency Managers; also the Enhancing Shelter Exercises.

Guam worked in partnership with a network of agencies to ensure the comprehensive Emergency Preparedness Handbook was available to all people

Hawaii – adapted “Feeling Safe, Being Safe” curriculum to reflect “Hawaiian culture”

New Hampshire, North Carolina, California, and VA served on workgroups and task forces that resulted in real change (we’ll see those details in just a moment)
As you know, a great deal of investments by DD Councils are made to build capacity within individuals, families, and service and/or support systems. Related to Disaster planning, response, and recovery during the last state plan cycle, Councils assumed a variety of roles...
Capacity Building roles

- Educating other entities and organizations about how to identify, coordinate services, respond, and support people with developmental disabilities;

- Collaborate with organizations/agencies to expand their ability to provide information and referral, or identify people with DD and their families;

- Coordinate and facilitate communication among responders;

- Gathering data on gaps in meeting needs.

Roles such as educator, collaborator, facilitator, evaluator, data manager, and planner are common across Councils – For example

Alabama trained responders about wandering through the “Take me Home” project and increased skill levels of responders with techniques to de-escalate situations; Alaska and Ohio provided information on how to communicate with people with different types of disabilities; Connecticut, Delaware, California, Missouri, Pennsylvania, Minnesota, New Jersey, Oklahoma, New York, and Ohio are a few Councils that built capacity through education and training.

Several Councils worked to build capacity around Functional Assessment Support team training was a focus for several Councils to include Missouri, Connecticut, North Carolina, Pennsylvania, and Guam.

California focused on crisis intervention team training; training provided by self-advocates to law enforcement recruits and community licensing program analysts.
Systems Change

The term “systemic change activities” means a sustainable, transferable and replicable change in some aspect of service or support availability, design or delivery that promotes positive or meaningful outcomes for individuals with developmental disabilities and their families.

And, in terms of systems change, the ultimate outcome of a Council investment – Councils conducted a number of efforts that resulted in outcomes of improvements to policies and procedures and also improved ways supports or services were made available to people with DD and their families.
Systems Change roles

• Review planned response and recovery systems and look for ways to design or re-design so that people with developmental disabilities and their families have their needs met;

  • Work to ensure information is accessible and available (24/7) to people with developmental disabilities and their families through procedures and policies;

  • Work to ensure training for responders is part of policy and procedures and that people with DD and their families help provide the training;

• Document the experiences of people with DD and their families and assess the system to identify areas for improvement or design;

Guam developed a Special/Functional Needs Registry project (The IIDD Registry) in collaboration with the Guam Homeland Security, Mayor’s Council, and other Government agencies

The VA Council participated on a State Managed Shelters workgroup and helped design a training program for Social Workers who are charged to manage shelters if a locality needs assistance.

New Hampshire helped develop a guide for local jurisdictions called “New Hampshire General Sheltering”

North Carolina identified a gap around prescription refills during a time of emergency and began an initiative for the Pharmacy Board to address early refills.

These are just a few examples of how individual Councils impacted emergency planning, response, and recovery systems in their states and territories.
Now we would like to turn our attention to Cooperative efforts between States and State Councils on Developmental Disabilities. So what is a Cooperative effort? It is when Councils enter into interstate collaborations, cooperative efforts, and memorandums of understanding with each other – it is important for Councils to ensure these efforts are supported in their 5-year State plan.
Let’s take a look at the resources available to guide a Council with a cooperative effort between states and state councils.

Earlier this year, a Program Instruction was released – you have a copy in your packet...

Section 122 of the DD Act addresses cooperative efforts; and,

The 45 CFR 75.33 also provides regulations related to risk assessment, monitoring of financial and programmatic aspects of any cooperative effort.

The Texas DD Council developed and implemented a cooperative agreement with several Councils after Hurricane Harvey – Let’s hear about their experience in developing an agreement.
The Texas Agreement...

- Local level - Council approval
  - Emergency meeting
  - Council approval for TX funds
  - State plan supported the work - catch all (Goal 4) new initiatives and response

- State level – State and DSA procedures
  - Navigating DSA processes
    - Receiving money
    - Bid or sole source
    - Existing contract

- National Level - AIDD
  - Approve the agreement
  - Demonstration project – direct service

Beth Stalvey
Now we will turn our attention to key connections for Councils during a time of disaster. Connecting with your funding source, and NACDD open the lines of communication and can provide your Council with additional support –

We will hear from Ophelia McLain, from the Administration and Donna Meltzer from NACDD
Connecting with the Federal Government

Administration for Community Living
Administration on Intellectual and Developmental Disabilities

- AIDD will check in with grantees in a state of emergency federal disaster area via email and/or phone;

- AIDD may facilitate a follow-up conference call with grantees;

- AIDD uses information to inform work.

Ophelia McLain
Information for the Council Network

National level communication and connections
- Federal recovery/relief
- Communicating needs

Federal Policy
- IDEA
- ADA
- Other laws and regulations

Appropriations
- Relief efforts and funds

Donna Meltzer
Q & A

Presentation and speaker notes will be posted on the itacchelp.org website following the Institute