#### Planning for the Whole Community: Addressing Access and Functional Needs Before, During, and After Disasters

Clinician Outreach and
Communication Activity (COCA)
Conference Call
February 14, 2012



## **Objectives**

## At the conclusion of this session, the participant will be able to accomplish the following:

- Understand the true needs of the entire affected community before, during and after disasters.
- Discuss strategies to engage all aspects of the community in both defining needs and devising ways to meet them
- Identify resources to strengthening the assets, institutions, and social processes that work well in communities on a daily basis to improve resilience and emergency management outcomes

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## **Today's Presenter**



Marcie Roth
Director
Office of Disability Integration and Coordination
Department of Homeland Security
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## **Today's Presenter**



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Centers for Disease Control and Prevention

## Planning for the Whole Community: Addressing Access and Functional Needs Before, During, and After Disasters

Marcie Roth, Director

**FEMA Office of Disability Integration and Coordination** 

February 2012





Benilda Caixeta July 31, 1954 – August 29, 2005

Unable to evacuate before or during hurricane Katrina, Benilda told me the water was rushing into her home just before her phone went dead. Her body and her wheelchair were found floating inside her home several days later.





"My experience tells me if we wait and plan for people with disabilities after we write the basic plan, we fail."

Craig Fugate, FEMA Administrator



"It is time children, people with disabilities or any other segment of our communities who have traditionally been underserved, to be more fully and consistently integrated into preparedness and planning efforts at every level of government."

Craig Fugate, FEMA Administrator



"We don't plan for easy in FEMA ... we plan for real."

Administrator Fugate March 2010



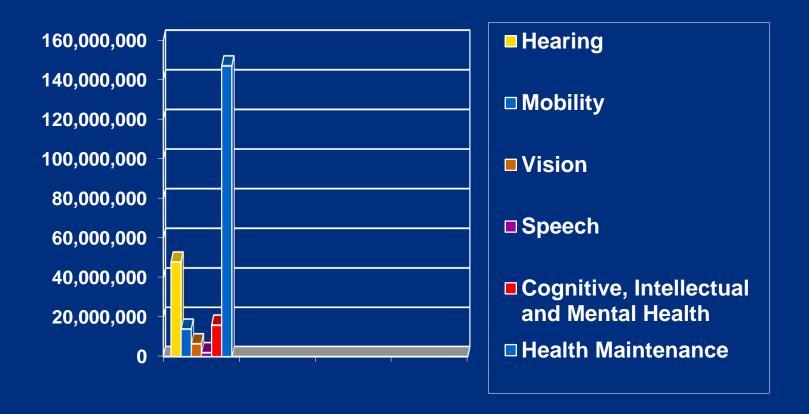
#### Presidential Policy Directive - 8

#### National Preparedness Goal:

•A secure and resilient Nation with the capabilities required across the whole community to prevent, protect against, mitigate, respond to, and recover from the threats and hazards that pose the greatest risk.

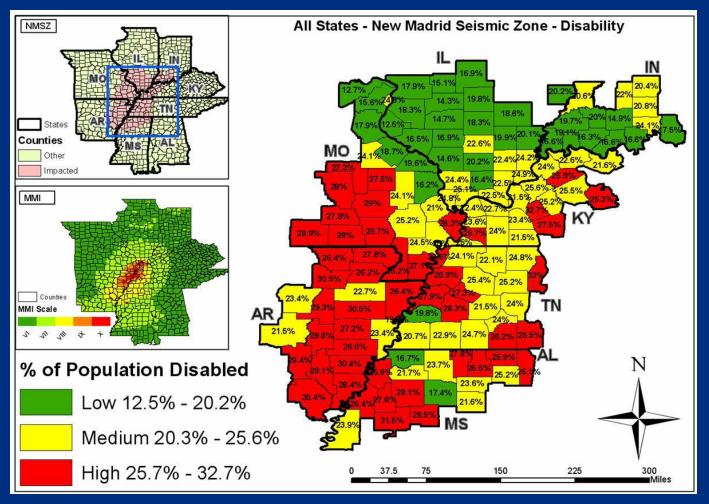


## Types of Disabilities and Health Maintenance Needs





#### NMSZ Percentage of People With Disabilities

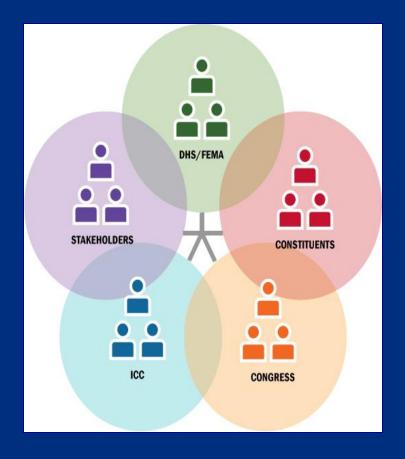




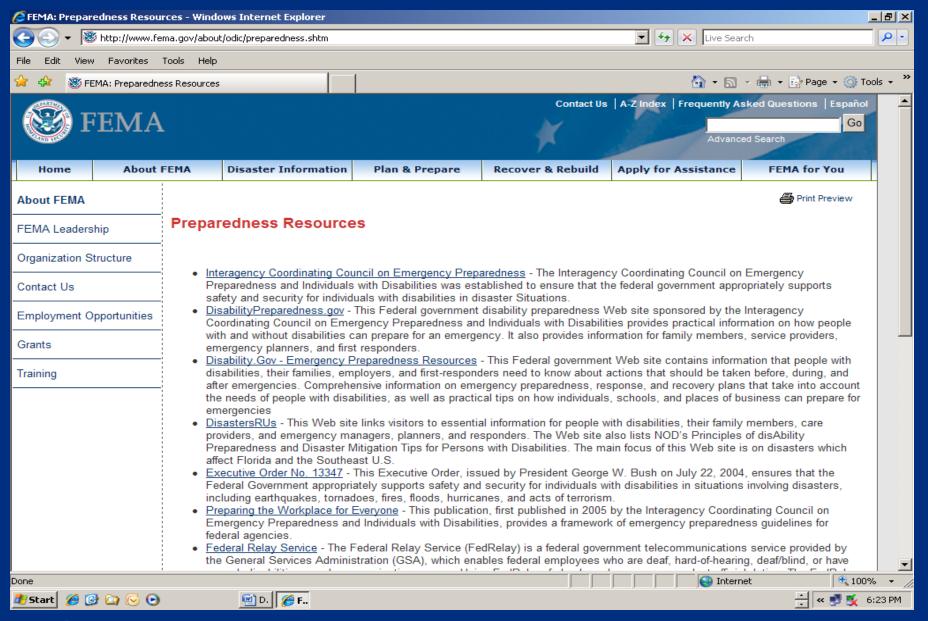
# Office of Disability Integration and Coordination

#### Mission Statement

In accordance with Federal civil rights laws and regulations, provide guidance, tools, methods and strategies to integrate and coordinate emergency management inclusive of individuals with access and functional needs.









# The Office of Disability Integration and Coordination

Our motto:

"Baking it in, not layering it on"





## Federal Laws Prohibiting Discrimination in Emergency Programs on the Basis of Disability

- Americans with Disabilities Act of 1990
- Stafford Act of 1988
- Rehabilitation Act of 1973
- Fair Housing Act Amendments of 1988
- Architectural Barriers Act of 1968
- •Individuals with Disabilities Education Act (EHA) of 1975
- Telecommunications Act of 1996

Each provides affirmative obligations and prohibitions of discrimination on the basis of disability.

No State or local government, or its contractors, in providing services may, by law, policy, or contract, provide services below those standards without violating federal law.



## Department of Justice Guidance to State and Local Governments

The Americans with Disabilities Act and other laws apply in:

- Preparation
- Notification
- Evacuation and transportation
- Sheltering
- First aid and medical services
- Temporary lodging and housing
- Transition back to the community
- Clean up
- Other emergency- and disaster-related programs, services, and activities



## **Key Considerations**

- Self-Determination People with disabilities are the most knowledgeable about their own needs.
- No "One-Size-Fits-All" People with disabilities do not all require the same assistance and do not all have the same needs.
- Equal Opportunity People with disabilities must have the same opportunities to benefit from emergency programs, services, and activities as people without disabilities.



## **Key Considerations**

- Inclusion People with disabilities have the right to participate in and receive the benefits of emergency programs, services, and activities provided by governments, private businesses, and nonprofit organizations.
- Integration Emergency programs, services, and activities typically must be provided in an integrated setting.
- Physical Access Emergency programs, services, and activities must be provided at locations that all people can access, including people with disabilities.
- Equal Access People with disabilities must be able to access and benefit from emergency programs, services, and activities equal to the general population.

## Key Considerations

- Effective Communication People with disabilities must be given information that is comparable in content and detail to that given to the general public. It must also be accessible, understandable and timely.
- Program Modifications People with disabilities must have equal access to emergency programs and services, which may entail modifications to rules, policies, practices, and procedures.
- No Charge People with disabilities may not be charged to cover the costs of measures necessary to ensure equal access and nondiscriminatory treatment.



## "However beautiful the strategy is, you should occasionally look at the results."

Winston Churchill



#### The words we use:

We hear it all the time – "special needs" and "vulnerable". Both terms do damage. When people with disabilities are thought of as "special", they are often thought of as marginal individuals who have needs, not rights. The word "vulnerable" has a similarly unfortunate effect. Vulnerable people must have things done for them; they're recipients, not participants.

Don't think 'special' or 'vulnerable;' think 'universal access.' Integrate access into all aspects of emergency services: transportation, sheltering, education, evacuation, etc. And remember that access is a civil right, not a favor or an amenity.



The difference between the right word and the almost right word is the difference between lightning and a lightning bug.

Mark Twain



### A "Whole Community" Approach:

- Understanding and meeting the true needs of the entire affected community.
- Engaging all aspects of the community.
- Strengthening existing assets, institutions, and social processes.



#### Whole Community:

#### Participation of the whole community requires:

- equal access to national preparedness activities and programs without discrimination
- meeting the access and functional needs of all individuals
- consistent and active engagement and involvement in all aspects of planning.



### Meeting Access and Functional Needs

Individuals with access and functional needs, including those with and without disabilities can be accommodated with actions, services, equipment, accommodations and modifications including physical/architectural, programmatic, and communications modifications. Some individuals with access and functional needs have legal protections including, but not limited to, the right to freedom from discrimination based on race, color, national origin (including limited English proficiency), sex, familial status, age, disability and economic status.

Overall, inclusive planning is expected to increase the communitywide margin of resilience and increase capacity to meet a wide range of disaster related needs utilizing existing resources and reducing dependence on acute medical resources for maintaining health, safety and independence and preventing discrimination.



#### The WHOLE Whole Community:

Individuals who have physical, sensory, behavioral and mental health, intellectual and cognitive disabilities, including individuals who live in the community and individuals who are institutionalized, older adults with and without disabilities, individuals who are from diverse cultures, races and nations of origin; individuals who don't read, have limited English proficiency or are non-English speaking, children with and without disabilities and their parents, individuals who are economically or transportation disadvantaged, women who are pregnant, individuals who have chronic medical conditions, those with pharmacological dependency (i.e.: a chemical dependency/addiction), other individuals who are often underrepresented or excluded and the social, advocacy and service organizations that serve individuals and communities.



# Functional Needs vs. Acute Heath Care Needs









### **Functional Needs**

#### **C-MIST Framework**

- Communication
- Maintaining Health
- Independence
- Safety, services and self-determination
- Transportation



## Personal Responsibility- From Liabilities to Assets:

Personal responsibility before, during and after a disaster applies to people with disabilities just as it applies to people without disabilities. Although ability varies from person to person, educational and outreach efforts, information and tools must be made available, achievable and accessible to everyone.





"No doubt you're asking yourself, what are hatches? And how the heck does one go about battening them down?"



#### Regional Disability Integration Specialists





### Workforce Diversity





## Finding the Experts





#### FEMA SUPPORT

- Regional and State Training
- Disability Integration Specialists in every Region
- Durable medical equipment and consumable medical supplies supply cache and IDIQ contracts
- Requirements for "universal" cots
- Personal Assistance Services mission support agreements and private industry contracts, reimbursement fact sheet being finalized.
- MOAs with National Council on Independent Living and their 450 Centers for Independent Living and the National Disability Rights Network and their 57 statewide Protection and Advocacy agencies
- IB on disability integration opportunities in FY11 Grant Guidance



### Allowable grant expenditures for planning and purchases

#### **Examples:**

- Inclusive meeting practices
- Producing materials and tools
- General population shelter planning, training, equipment and supplies
- Accessible Alert, Warning and Notification systems
- Gap analysis
- Resource tracking
- Cross training
- Analysis and evaluation of potential shelter locations
- Planners
- Neighborhood leadership development



# Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters

 Provide planning guidance for meeting access and functional needs in general population shelters.

 Identify methods for achieving a lawful and equitable program through the delivery of Functional Needs Support Services for children and adults.



#### Assets Not Liabilities











#### NOTHING ABOUT US, WITHOUT US

www.FEMA.gov/thinktank



# Getting Real- Promising Practices in Inclusive Emergency Management www.fema.gov/about/odic





### INTEGRATION AND COORDINATION

When communities integrate the access and functional needs of children and adults with and without disabilities in all phases of community-wide emergency management, they strengthen their ability to prepare for, protect against, respond to, recover from, and mitigate all hazards.



#### Office of Disability Integration and Coordination

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## FEMA

# Overview and Impact of Chronic Disease Patients and Vulnerable Populations during Disasters/Emergencies

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The findings and conclusions of this presentation are those of the presenter and do not necessarily represent views of the Centers for Disease Control and Prevention



#### **Chronic Disease Issues**

- Persons at risk from disaster
- Rationale for engagement on these issues:
   They fall through the cracks
- Critical challenges
- Research and planning

### Health Promotion and Preparedness Persisting Challenges

- What do these terms really mean?
  - "preparedness"
  - "vulnerability"
  - "at-risk population"
  - Who needs to be "response-ready"
  - Who has the expertise to serve specific populations?
  - People with chronic medical conditions fall through the cracks

### Definitions of "Vulnerable", "At Risk" and "Special" Populations

- Potential for loss" or "susceptibility to poor health or lack of access to health care"
- Population-based
  - Locate and enumerate populations
  - Integrate service delivery
- Functionally-based
  - National Response Framework ("special needs") and HHS ("at risk") definitions
  - Additional needs in five (5) areas: independence, communication, transportation, supervision and medical care
  - **PAHPA**

### Pre-pandemic Planning: Determinants of Vulnerability Definitions of Vulnerable Populations

- Pregnant women
- Children
- Persons with disabilities
- Persons with chronic diseases
- Persons with HIV/AIDS, TB, or hepatitis
- Inmates of prisons and jails
- Migrant-, farm-, and other low-wage workers
- Homeless persons

- Immigrants and refugees
- Low-income, single-parent families, and public housing residents
- Racial and ethnic minority populations
- Vulnerable populations in tribal communities
- Other vulnerable populations not listed elsewhere (e.g., elderly, and mentally ill)

#### **Aftermath**

- Environmental destruction
- What don't we have: Power, food, clothing and shelter
- What do we have: destruction of environment, destruction of people, acute conditions that lead to infections, disability, possible toxins in environment
- How do these things affect chronic conditions such as diabetes, cardiovascular disease, asthma?

### What have we learned from past disasters? Using diabetes as an example

- Some documentation of worse diabetes control
- Recommend that anti-disaster programs address psychological interventions in people with chronic conditions
- Since diabetes is considered a chronic disease, treatment is delayed until things become more serious and need emergency help

#### The 2006 California Heat Wave

- During the heat wave, 16,666 excess hospitalizations and ED visits occurred statewide
- ED visits showed significant increases for
  - acute renal failure,
  - cardiovascular diseases,
  - diabetes,
  - electrolyte imbalance, and
  - nephritis

#### **Aftermath: Katrina**

- Of the estimated 288 health center sites operating in MS & LA in 2004, 32% were lost or severely damaged
- Net loss of 6,000 health professionals
- Patients lost their medications and supplies for special health care needs
- Many of the pharmacies were destroyed
- Strain on public health capacity of communities that absorbed the evacuees

### On the Edge – A Report of the Louisiana Child & Family Health Study, Columbia University

Katrina evacuees: Adult Health responses by Housing Type: Trailer, Private, Hotels

Percentage of adults with chronic conditions= 46.3-58.8%

www.childrenshealthfund.org

#### Chronic Disease in Health Emergencies: Lessons Learned from Katrina

- 9.0% of had diabetes (87,000)
- 4.6% had angina or CHD
- 3.0% had Hx MI, 2.0% had had a stroke
- 25.4% adults had at least one of the above conditions
- Based on 2004 BRFSS data, the prevalence of chronic conditions in the New Orleans area

Prev Chron Dis Volume 3: No. 2, April 2006; MMWR March 10,2006 55:244-247

### Top 10 conditions among persons staying in evacuation centers, between Sept. 10-12, 2005

Condition	Incidence/1,000 Residents
Hypertension/cardiovascular	108.2
Diabetes	65.3
New psychiatric condition	59.0
Preexisting psychiatric condition	50.0
Rash	27.6
Asthma/COPD	27.5
Flu-like illness or pneumonia	26.3
Toxic exposure	16.0
Other infections*	15.6
Diarrhea	12.8

<sup>\*</sup> Pertussis, varicella, rubella, hepatitis, tuberculosis and other communicable illness of outbreak concern

#### Shelters: Issue for survivors of all type of disaster

- Lack of sleeping space, meds, Unmet dietary needs
- Acute exacerbation of chronic medical problems especially since >50% were over >60 years old
- 28% had CVD, 16.9% had diabetes,
- Inventory of LA shelters in progress: Wide variation
- AJPH 1990 80:879-80
- U.S. PHS and Am. Red Cross, Katrina Shelter Needs Assessment, Louisiana: Preliminary Draft Report, September 13, 2005.

### **Vulnerable Populations with Pre-Existing Chronic Conditions**

#### H1N1 Outbreak

<ul><li>Asthma</li></ul>	11%
<ul> <li>Other pulmonary disease</li> </ul>	24%
<ul><li>Diabetes</li></ul>	13%
Chronic cardiovascular disease 14%	
<ul><li>Pregnant</li></ul>	8%
Obesity	34%

Data from Epidemiology/Statistics Branch Pandemic H1N1 deaths June 25, 2009; n=99

#### Earthquakes and Diabetes: Kobe 1995

- Higher A1c levels in Kobe, worse health quality
- Other factors such as disruption of lifestyle, diet, access to meds looked at
- Role of acute and chronic stress in people with diabetes
- Recommend that anti-disaster programs address psychological interventions in people with chronic conditions such as diabetes, kidney failure
- Teach people about appropriate diet during times of disaster BEFORE it happens
- Supply a medical information card
- Supply small emergency medical supplies bag

### Lessons observed from Hurricanes Andrew & Charley

- Older adults experienced disruptions in quality of life status and medical care for pre-existing chronic conditions such as CVD, diabetes
- Make assessments 3-5 days post hurricane rather than 10-14 days so appropriate meds and supplies could be deployed to help the chronic conditions in older adults
- Hurricane Andrew: Insulin supplies depleted

### **Chronic Disease in Health Emergencies: In the Eye of the Hurricane - CDC Study**

- Establish a comprehensive understanding of the medical and chronic disease needs of communities using BRFSS as a model
- This information should arm public health professionals with the critical information needed to prepare for medical care of people with chronic diseases after a disaster.

### **Health Promotion and Preparedness: Persisting Challenges - How Do We**

- Assure safe motherhood?
- Protect children and adolescents?
- Protect the aging population?
- Persons with chronic diseases?
- Persons living with disability

- Communicate effectively?
- Engage partners?
- Prioritize within all hazards ?
- Science and research?
- Support innovative programs?

### What can we do? State and local public health education

- Coordinate educational planning and programs
- Implement preparedness education programs based on identified needs
- Maximize use of available local / regional educational resources

#### What can we do

Partner with Red Cross, Medical Reserve Corps,
 American Diabetes Association, American Heart
 Association etc. Make new friends

Each state has a disaster preparedness team AND a DPCP, CVD team etc The Challenge of Teaching People to be prepared: Similar barriers in teaching people self management skills for a chronic condition

#### **Preparedness Education**

- For health care providers, emergency responders
- For people with pre-existing chronic conditions (diabetes, CVD, asthma, seizures, pregnancy etc) and the people who care for them
  - During routine self management skills education
  - Availability of supplies, medications, and emergency kits

#### **Cross training and Competencies**

- PHEP Medical Supplies Management and Distribution Workgroup
- PHEP Community Resilience Workgroup
- Schools of Public Health Training
- Medical Reserve Corps

### Chronic Disease and Vulnerable Populations in Natural Disasters Working Group at CDC

- National Center for Chronic Disease Prevention and Health Promotion
- Office of Public Health Preparedness and Response
- Other CDC Centers, Institutes, Offices
- Public health partners
- State teams-cooperative agreement
- Models exist: CDC funded state Diabetes Prevention and Control Program teams training state emergency preparedness teams

#### Surveillance Needs Before, During and After a Disaster

- Size, functional status, and needs prior to the disaster
- Ability to assess the needs and levels of actual response during the disaster
- Ability to monitor the long-term effects of the disaster

# Strategies for Preparedness Issues and Concerns with Diabetes as an example of a chronic condition

- Training about diabetes for emergency preparedness team at the state and local health department level (models already exist)
- Use epidemiological data on chronic disease burden and share with emergency preparedness teams
- Develop resources list for meds and supplies
- Can be applied to other chronic conditions

# **Examples of Resources and Partnerships**

### CDC Messages: Emergency Preparedness and You

- Gather Emergency Supplies
- Make a Plan
- Learn How to Shelter in Place
- Understand Quarantine and Isolation
- Maintain a Healthy State of Mind
- Adapt as needed

#### Family Emergency plan

- Tailor accordingly
- Have a list of all meds, prescriptions, medical professionals and all medical conditions
- Train people BEFORE the disaster
- Emergency food kit: "Appropriate food".
- Appropriate meds and supplies (tests trips, syringes, meds etc)

### Disaster Preparedness for Persons with Chronic Disease

- University of Louisville Hospital/ Kentucky Department for Public Health grant.
- www.chronicdiseasepreparedness.org

#### WHY PREPARE?

#### WHAT YOU NEED TO DO.

- 1. Get Informed...
- 2. Make a Plan.
- 3. Assemble a Disaster Supplies Kit.
- 4. Maintain Your Plan

#### IF DISASTER STRIKES.

- 1. Sources For Emergency Preparedness Information...
- 2. Community Emergency/Disaster Resource Form...
- 3. Personal Medical Information Form...
- 4. Emergency Contact Cards....

### Help for People with Diabetes Affected by Natural Disasters

- Insulin, Drug and equipment advice
- Drug resources for Evacuees with diabetes
- Health Coverage
- General Hurricane recovery information
- CDC Web site: <u>www.cdc.gov/diabetes/news/docs/disasters.htm</u>
- American Association of Diabetes Educators
   <a href="http://www.diabeteseducator.org/ProfessionalResources/Librar-y/Disaster\_Response\_Toolkit.html">http://www.diabeteseducator.org/ProfessionalResources/Librar-y/Disaster\_Response\_Toolkit.html</a>
- KY Diabetes Prevention and Control Program <u>http://chfs.ky.gov/dph/info/dpqi/cd/diabetes.htm</u>
- American Association of Clinical Endcrinologists http://www.powerofprevention.com/pub/DPcard\_LoRespdf.pdf

### Strategies for Preparedness: Cancer and Disasters

- Continued access to chemotherapy/ radiation therapy in the event of widespread workforce reductions:
  - Lapses in therapy are associated with adverse outcomes
- Priority for any available vaccinations
- Priority for chemoprophylaxis in immuno-suppressed patients
- Comply with all recommendations to prevent spread of disease
  - Voluntary quarantine if advised
  - Keep records of diagnosis, stage of disease, treatment received, providers
  - Keep at least two weeks of medications available at all times
  - Vaccination for self and close contacts

# Identifying Vulnerable Older Adults and Legal Options for Increasing Their Protection During Public Health Emergencies A Guide for States and Communities

- Action Options
- Developing Plans
- Partnering and Collaboration
- Using Data for Action
- Conducting Training and Exercises
- Building, Maintaining, and Using Registries
- Using Law-Based Solutions
- Preparing Individuals and Caregivers
- Sheltering Older Adults

www.cdc.gov/aging

### Strategies for Preparedness: Older Adults Tool Kit

- Maintain access to medications
  - Larger quantities (>60 day supply)
  - Mail delivery
  - "Mobile Meds" model after Meals on Wheels program
- Special needs registry
  - Pre-identify people at-risk
  - Partner with home health agencies/equipment suppliers
  - Meals on Wheels list
- Include State Unit and Area Agencies on Aging, and community based organizations during planning

#### **OPHPR** Grant

## Medication access pre, during and post disasters for people with chronic conditions

- Challenges with having a " 2 week supply " of extra meds
- Stockpile issues
- Develop a consensus conference with the key players (Pharma manufacturers, Health Plans, distribution agents providers etc to develop a plan

### Protecting Vulnerable Populations: Key Themes

- Prevent disease and provide routine care
- Address social needs
- Address custodial care issues and worker safety
- Form partnerships and collaborate with vulnerable populations
- Conduct targeted and tailored education and communications

### **Summary**

- Natural disasters have major economic, clinical and public health consequences
- Current preparedness efforts often neglect, or pay inadequate attention to chronic diseases and vulnerable populations
- Attention to these populations offers opportunities for improved preparedness
- New emphasis offers opportunities for improved preparedness and health protection
- Surveillance, policy development, and assurance remain core functions (all hazards)

### **Summary: Disasters Happen**

- Be prepared
- Know your population
- Chronic conditions happen and don't blow away
- Develop partnerships to teach others about disasters and chronic conditions
- Don't loose the forest for the trees except in the case of hurricanes, tornados, earthquakes and tsunamis



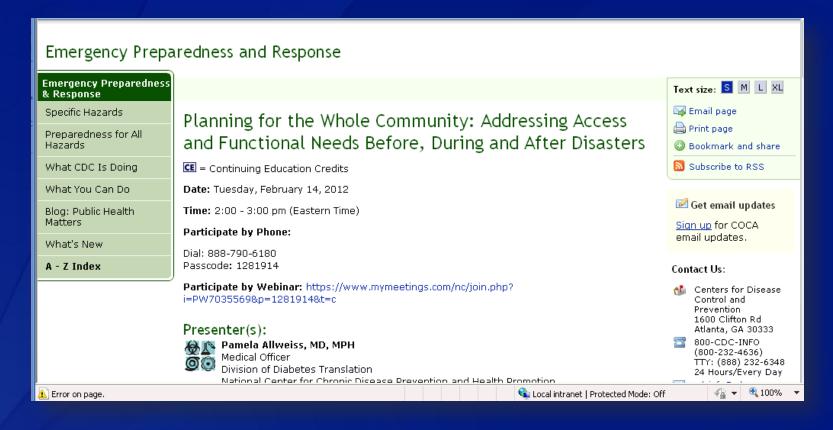
Centers for Disease Control and Prevention Atlanta, Georgia

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http://emergency.cdc.gov/coca

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