#### Whole Community Inclusive Emergency and Disaster Management

Including the Needs of Children with Disabilities Before, During and After Disasters



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#### World Institute on Disability



The World Institute on Disability (WID) was co-founded in 1983 by Ed Roberts, Judy Heumann and Joan Leon.

Thanks to a MacArthur Fellowship "Genius Award" given to Ed, WID was the world's first public policy center controlled by people with disabilities, dedicated to the promotion of independence and full inclusion in society of people with disabilities and committed to public education and to converting policy into action.

#### Today's Agenda

- What is "Whole Community Inclusion"
- Disability Civil Rights
- Disability Inclusive Emergency Management
- Emergency Planning and Disaster Resilience



#### Crisis is an opportunity riding on a dangerous wind





#### **Disaster Losses**

There were 130 major disasters in the United States in 2017, 2018 & 2019 and the frequency, intensity and duration of disasters is on the rise.

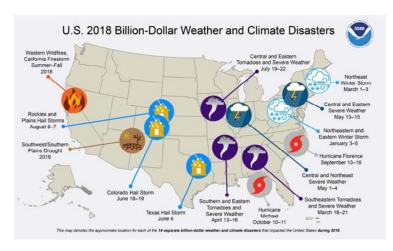
44 of these disasters had losses exceeding \$1 billion dollars each, with only Hurricane Katrina in 2005 exceeding the cost of Hurricanes Harvey (\$125 billion), Maria (\$90 billion) and Irma (\$50 billion) in 2017.

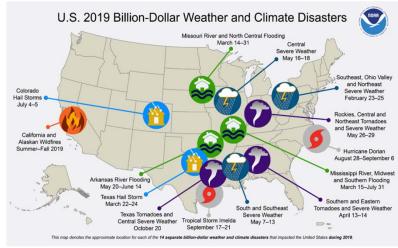
-NOAA



## U.S. 2017, 2018 & 2019 Billion-Dollar Weather and Climate Disasters









### Disability Impacts ALL of US







61 million adults in the United States live with a disability



Join CDC and its partners as we work to improve the health of people living with disabilities.

For more information go to www.cdc.gov/disabilities



The National Survey of Children with Special Health Care Needs identified nearly 1 in 5 children ages 12-17 as having special healthcare needs

The American Community Survey estimates that more than 1.3 million U.S. young people ages 16-20 have a disability.

If children with chronic conditions that last less than a year or who have had at least one chronic condition at any time in childhood are included, up to 50 percent of all U.S. children have a disability.

**-US HHS** 



Over 2.5 million people use medical equipment and devices that require electricity.

-HHS



## Better health for people with disabilities







1 in 7 people

People with disabilities have the same general health care needs as others

#### But they are:



more likely to find health care providers' skills and facilities inadequate



more likely to be denied health care



more likely to be treated badly in the health care system



They are

50%

more likely to suffer catastrophic health expenditure



These out-of-pocket health care payments can push a family into poverty

Rehabilitation and assistive devices can enable people with disabilities to be independent







#### **Disability Definition**

#### **Major life activities:**

Include but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.

#### **Major bodily functions:**

Include but not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.



# Whole Community Impact

What happens to people with disabilities has a direct impact not only on them but on the rest of the society, especially their families and communities.

-World Report on Disability 2011



#### ACCESS AND FUNCTIONAL NEEDS

In addition to people with disabilities, many millions more have access and functional needs, a term described by DHS as: including assistance, accommodation or modification for mobility, communication, transportation, safety, health maintenance, etc.; need for assistance, accommodation or modification due to any situation (temporary or permanent) that limits an individual's ability to take action in an emergency.

Individuals having access and functional needs may include, but are not limited to, individuals with disabilities, older adults, and individuals with limited English proficiency, limited access to transportation, and/or limited access to financial resources to prepare for, respond to, and recover from the emergency.

# Access and Functional Needs

- Children and adults with physical, mobility, sensory, intellectual, developmental, cognitive, or mental disabilities
- Infants and Children without disabilities
- Older adults
- People with chronic or temporary health conditions
- Women in the late stages of pregnancy
- People with limited English proficiency, low literacy or additional communication needs
- People with very low incomes
- People without access to transportation
- People experiencing homelessness
- Others



#### WHOLE COMMUNITY





#### DISPROPORTIONATE IMPACT

According to the United Nations, "children and adults with disabilities and older adults are 2-4 times more likely to be injured or die in a disaster due to a lack of planning, accessibility and accommodation, most are not due to diagnostic labels or medical conditions."

The United Nations Sendai Framework for Disaster Risk Reduction recognizes that "not only are persons with disabilities disproportionately affected by disasters, but – crucially – that their knowledge and leadership skills are essential for building resilient, inclusive and equitable societies".

#### DISPROPORTIONATE IMPACT

Emergency management staff in all jurisdictions have a fundamental responsibility to consider the needs of all members of the whole community, including children; individuals with disabilities and others with access and functional needs; those from religious, racial, and ethnically diverse backgrounds; and people with limited English proficiency.

FEMA Incident Stabilization Guide November 2019



#### **EVACUATION AND ASSISTANCE**

According to the Sacramento Bee "Many of the at least 85 people who perished in the raging Camp Fire on Nov. 8 were elderly, infirm or disabled".

"There are no statistics that show how many disabled people in the U.S. say they could easily evacuate in an emergency, but around the world, just 20 percent of disabled people say they would be able to do so. And only 31 percent said they would have someone to help them in an emergency, according to a 2013 United Nations global survey".

Interruption of medical care and disability services were the primary cause of almost 3000 deaths following hurricane Maria

Almost 15% were attributed to an inability to access needed medications

Almost 10% were caused by unmet needs for respiratory equipment requiring electricity.

Most of these individuals had disabilities related to chronic health conditions.

New England Journal of Medicine , Harvard University and George Washington University



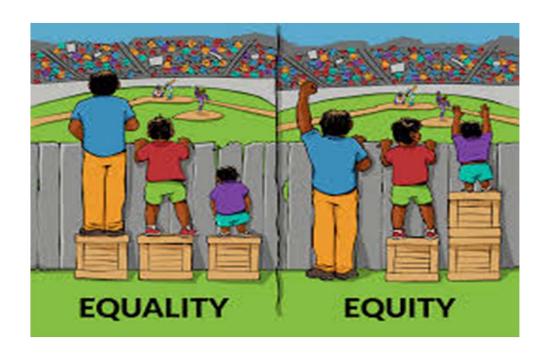
#### HEALTH MAINTENANCE

A new survey of 13 countries released in June 2018 by Healthcare Ready, shows significant concern among patients about losing access to medication during disasters.

When asked how long they could go without access to medication before experiencing negative effects, the survey found "9% of respondents would begin experiencing adverse effects within a day or less and 42% within a week".



#### Equality and Equity





#### Legal Obligations to Individuals with Disabilities

- Robert T. Stafford Disaster Relief and Emergency Assistance Act (Stafford Act), as amended;
- Post-Katrina Emergency Management Reform Act of 2006;
- Rehabilitation Act of 1973, as amended;
- Americans with Disabilities Act (ADA) of 1990, as amended 2008;
- Fair Housing Act of 1968, as amended;
- Architectural Barriers Act of 1968;
- Twenty-first Century Communications and Video Accessibility Act of 2010
- Communications Act of 1934, as amended;
- Individuals with Disabilities Education Act (IDEA) of 1975, as amended;
- Executive Order 13347 (July 22, 2004), Individuals with Disabilities in Emergency Preparedness.
- Telecommunications Act of 1996
- Pandemic and All Hazards Preparedness Act of 2006
- https://emilms.fema.gov/IS0368/DIS01summary.htm



## Federal Law: The Americans with Disabilities Act

- The Americans with Disabilities Act of 1990 prohibits recipients from discriminating on the basis of disability in the operation of public entities, public and private transportation systems, places of public accommodation, and certain testing entities.
- In order to ensure compliance, recipients must provide program access, ensure effective communication, and provide physical access for persons with disabilities in developing budgets and in conducting programs and activities.
- The US Supreme Court decided in it's 1999 Olmstead decision that the Americans with Disabilities Act requires provision of services to individuals with disabilities in the "most integrated setting".



## Federal Law: The Rehabilitation Act

- The Rehabilitation Act of 1973 protects the civil rights of persons with disabilities. It prohibits discrimination on the basis of disability by the federal government, federal contractors, and by recipients of federal financial assistance.
- Any recipient or sub-recipient of federal funds is required to make their programs accessible to individuals with disabilities.
   Its protections apply to ALL programs and businesses that receive ANY federal funds.
- This applies to all elements of physical/architectural, programmatic and effective communication accessibility in all services and activities conducted by or funded by the federal government.



#### Federal Law

"Given the scope and magnitude of a catastrophic incident, waivers, exceptions, and exemptions to policy, regulations, and laws may be available in order to save and sustain life, and to protect property and the environment. However, any such waivers, exceptions, and exemptions must be consistent with laws that preserve human and civil rights and protect individuals with disabilities and others with access and functional needs..."

National Preparedness Goal – July 2014



#### Community Resilience

- Resilience is the ability to anticipate risk, limit impact, and bounce back rapidly through survival, adaptability, evolution, and growth in the face of turbulent change.
- True resilience is only achievable with a full commitment to equal access and whole community inclusion.



### REAADI For Disasters Act HR 3208 & S1755

#### The Disaster Relief Medicaid Act S 1754 & HR 3215 www.reaadi.com



2 minute video <a href="https://youtu.be/THaeYVYQPCw">https://youtu.be/THaeYVYQPCw</a>



#### Stevie Wonder Said It Best:





# Resources for Disability Inclusive Emergency Planning and Disaster Resilience

http://www.disasterstrategies.org/index.php/news

(scroll down to Disability and Disaster Resources)





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