New Toolkit from HHS/ASPR:

Capacity-Building Toolkit for Including the Aging & Disability Networks in Emergency Planning

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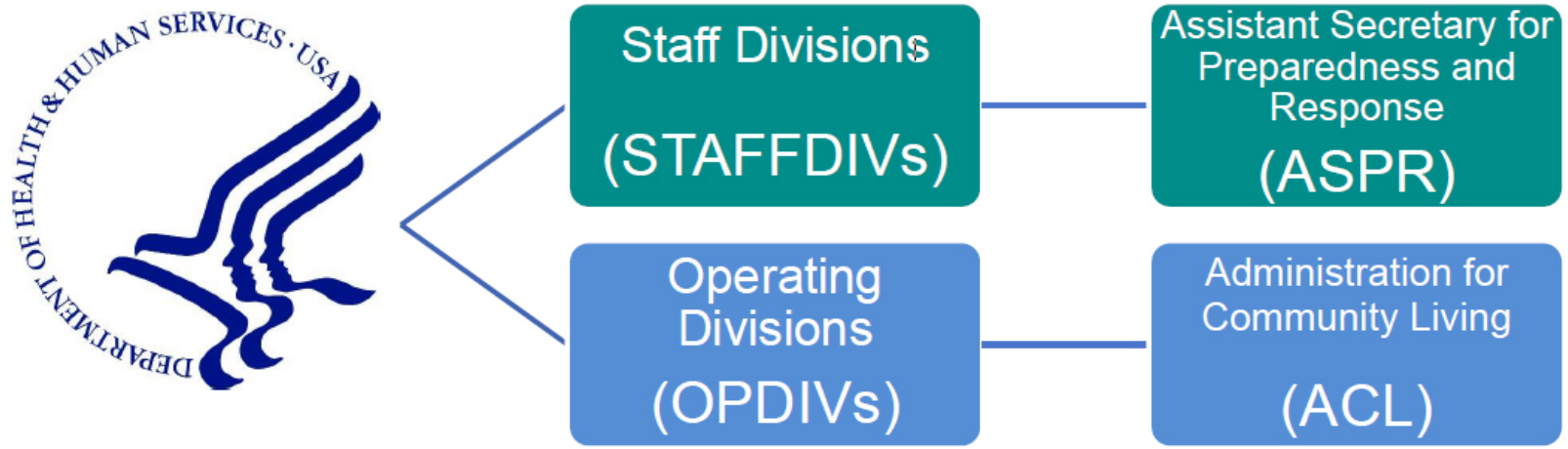
I. Background on HHS

HHS: STAFFDIVs & OPDIVs



ASPR Mission

Save Lives and Protect Americans from 21st Century Health Security Threats

HHS/ASPR Legal Authorities

ASPR was established in 2006, in the wake of Hurricane Katrina, to lead the nation in preventing, preparing for, and responding to adverse health effects of public health emergencies and disasters whether deliberate, accidental, or natural.

The Public Health Service Act (PHSA) forms the foundation of HHS' legal authority for responding to public health emergencies as amended by the 2006 Pandemic and All Hazards Preparedness Act (PAHPA), the 2013 Pandemic and All-Hazards Preparedness Reauthorization Act (PAHRA), and (draft) 2019 Pandemic and All-Hazards Preparedness and Advancing Innovation Act.

- ✓ **Authorize ASPR**
- ✓ **Authorize public health and medical preparedness programs**
  - Biomedical Advanced Research and Development Authority (BARDA) and Medical Countermeasures
  - Emergency Support Function (ESF) #8: Public Health and Medical Response
  - Situational Awareness: Surveillance and Credentialing
  - Grants
  - National Health Security Strategy (NHSS)
  - **Address the Access and Needs of At-Risk Individuals**
  - Education and Training

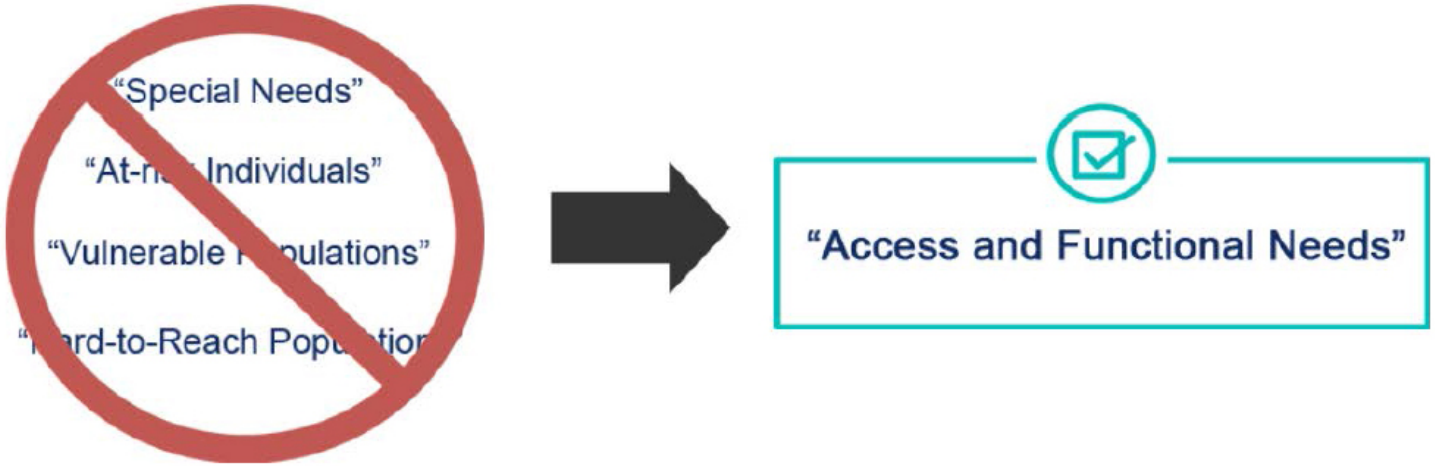
HHS Requirements for At-Risk Individuals

Section 2802 of the Public Health Service Act (PHSA) requires taking into account the *access and functional needs* of at-risk individuals, including public health and medical needs, in the event of a public health emergency. This includes children, pregnant women, older adults, people with disabilities, an others as determined by the Secretary.

Section 2814 of the PHSA establishes the following eight requirements as they are related to addressing the access and functional needs of at-risk individuals:

1. Monitor emerging issues
2. Oversee implementation of preparedness goals
3. Assist federal agencies in preparedness activities
4. Provide guidance on preparedness and response strategies and capabilities
5. Ensure the strategic national stockpile addresses the needs of at-risk populations
6. Develop curriculum for public health and medical response training
7. Disseminate and update best practices
8. Ensure communication addresses the needs of at-risk populations

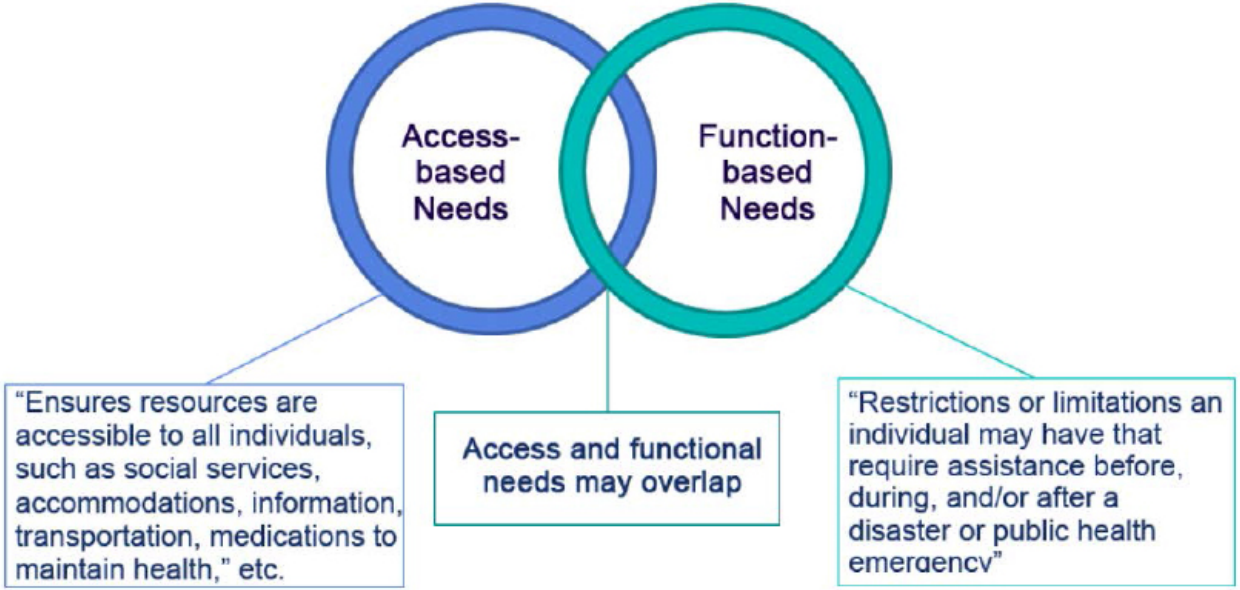
Why use the term “access and functional needs”?



Consistent: DHS Lexicon Terms and Definitions 2017 Edition – Revision 2 Issue Date – October 16, 2017, Access and Functional Needs Accommodation

What are “access and functional needs”?

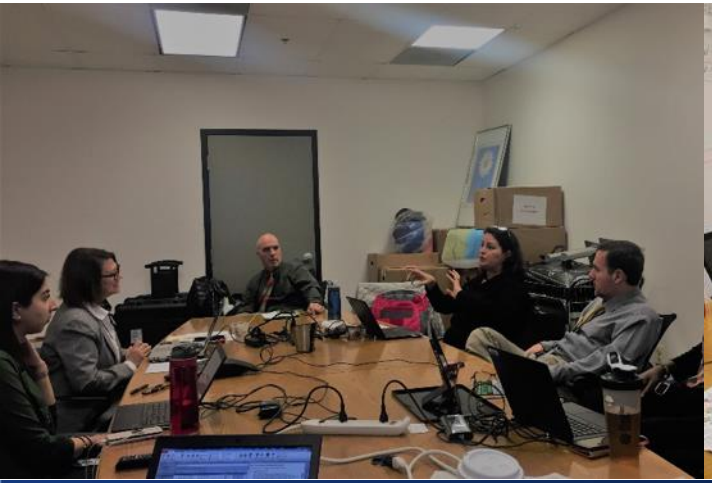
People with "access and functional needs" (AFN) require assistance due to any condition (temporary or permanent) that limits their ability to take action.



II. Building on Best Practices

HHS Coordination

- 2017 Hurricane Response
- Aging and Disability Taskforce (ASPR, ACL, and Office for Civil Rights)



ACL's Aging & Disability Networks

Aging Network Partners

- Area Agencies on Aging (AAAs)
- State Units of Aging (SUAs)

Disability Network Partners

- Centers for Independent Living (CILs)
- Statewide Independent Living Councils (SILCs)
- Developmental Disability Councils (DD Councils)
- Protection and Advocacy Systems (P&As)
- University Centers for Excellence in Developmental Disabilities (UCEDDs)
- State Grants for Assistive Technology (AT) Programs

Examples of Aging and Disability Network Activities in Emergencies

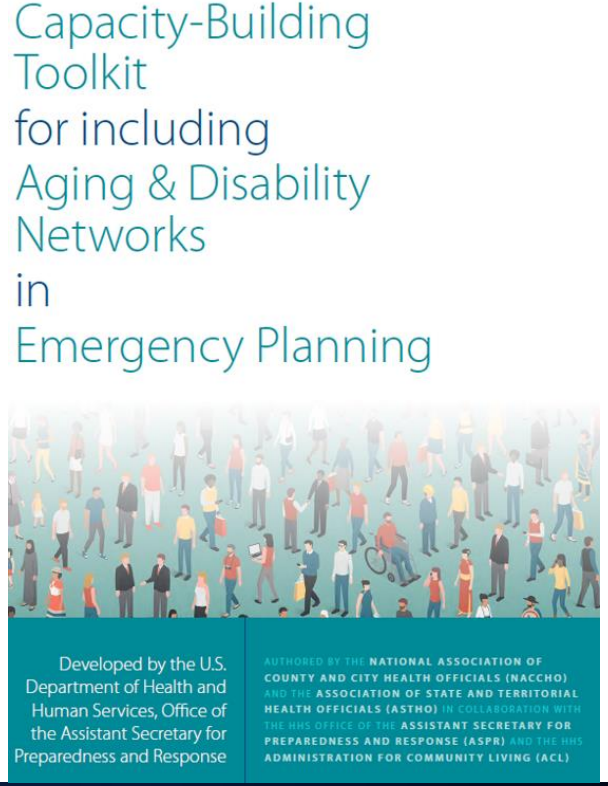
- Conduct wellness checks
- Identify services disruptions, including gaps and barriers to programs and services, and develop remedies
- Provide situational awareness
- Provide case management, information, referral, and legal expertise
- Assessment, replacement, and repair of devices or equipment
- Distribute of food, water, and other supplies
- Locate and/or provide mobility equipment, medications, medical supplies, personal care attendant services, ASL interpreters, power sources for life saving equipment
- Deploy experts to general population shelters to assess accessibility
- Coordinate accessible temporary housing and transportation services
- Facilitate access to disasters assistance

Role of Aging & Disability Networks in Emergencies

- ACL provides grant funding to CBOs for programs to support older adults and people with disabilities so that they can remain in their homes and communities
- Knowledge, experience, and expertise in working with at-risk individuals; they can assist with identifying individuals' access and functional needs and providing outreach to older adults, people with disabilities, their caregivers, and family members
- CBOs have vital role as emergency planning SMEs to ensure that consumers have access to community services, supports, and disaster assistance
- Disruption of services, due to an emergency, creates a risk of older adults or people with disabilities not receiving life-sustaining supports and services, which can have life threatening consequences

III. Capacity-Building Toolkit

- **HHS: ASPR & ACL**
- **National Association of County and City Health Officials (NACCHO)**
- **Association of State and Territorial Health Officials (ASTHO)**



Stakeholder Engagement Process

- ACL recommended national stakeholder organizations with relationships to grantees
- Held 2 in-person meetings to introduce the Capacity-Building Toolkit and solicit feedback
  - March 7, 2018
  - July 25, 2018
- Invited national organizations
  - ADA Centers, AUCD, NASUAD, NACDD, NCIL, NDRN, The ARC, Autism Society, Easter Seals, National Association for the Deaf
  - AARP, n4a, National Council on Aging, Alzheimer's Association, American Health Care Association/National Center for Assisted Living, LeadingAge, Argentum, Meals on Wheels America
  - FEMA/ODIC, National Corporation for Community Service, American Red Cross, International Association of Emergency Managers
- Virtual focus group
  - September 6, 2018
  - Invited Aging and Disability Networks representing multiple states
    - ✓ Areas Agencies on Aging
    - ✓ State Units on Aging
    - ✓ Centers for Independent Living
    - ✓ State Councils on Developmental Disabilities
    - ✓ Councils on Developmental Disabilities
    - ✓ University Centers for Excellence in Developmental Disabilities
    - ✓ Protection & Advocacy System
- NACCHO and ASTHO held calls with other members of the Aging and Disability Network unable to participate
- Multiple rounds of review by ASPR and ACL staff

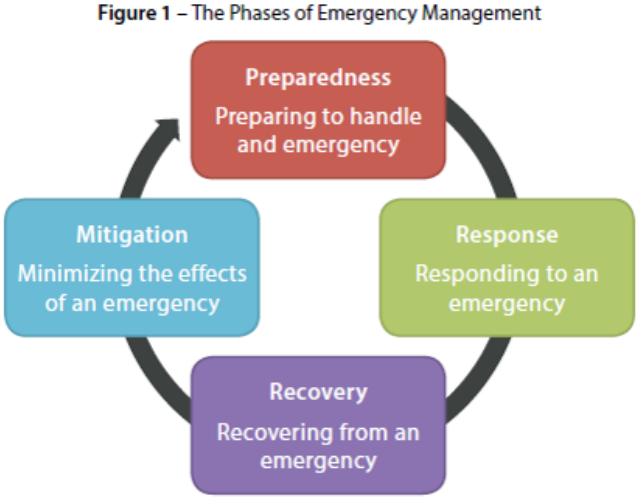
Purpose of the Capacity-Building Toolkit

Ensure equal access to our nation's emergency preparedness, response and recovery resources

- Provide information and resources for the aging and disability networks to become more engaged in emergency planning (CBO Readiness)
- Advance whole community planning and supporting consumers (Consumer Planning)
- Develop partnerships with emergency management and public health officials (Partnership)

Emergency Planning for Organizations

- Identify hazards
  - ✓ Conduct risk assessments
- Create an Emergency Operations Plan
- Understand the Incident Command System
- Understanding the Emergency Support Functions
- Participate in trainings and exercises
- Engage in consumer advocacy
  - ✓ Participation in exercises
  - ✓ Inclusion in emergency plans



Emergency Planning for Consumers

- Establish effective communication with consumers
  - ✓ Discuss emergency plans
  - ✓ Identify the support that may be needed in the event of an emergency
  - ✓ Discuss the emergency services that will likely be provided
- Support consumers with
  - ✓ Preparing emergency kits
  - ✓ Understanding safety checks
  - ✓ Navigating disaster assistance

CBO Partnering with Local Responders

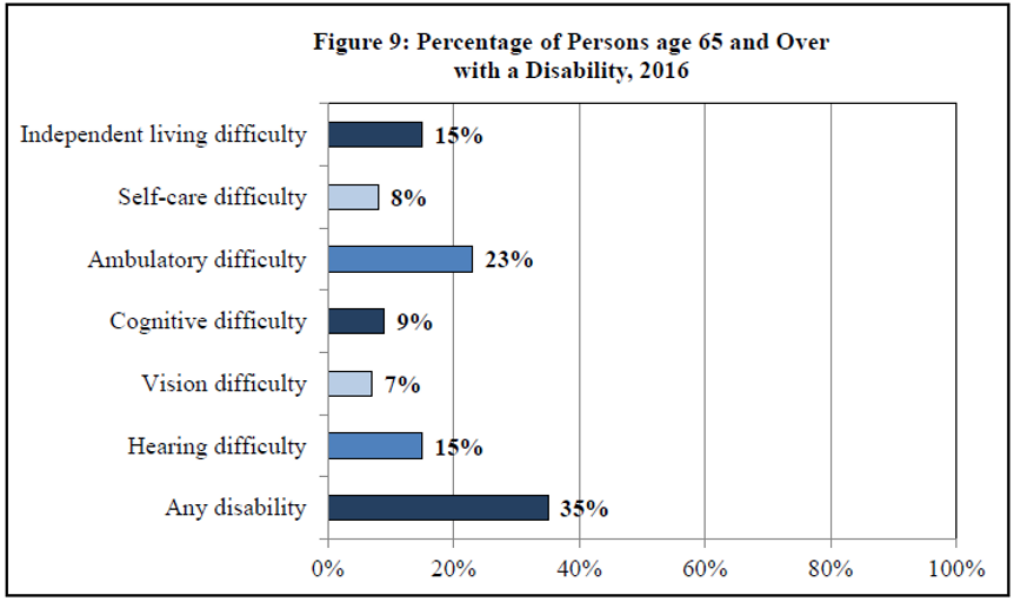
- Share situational awareness
- Role as emergency planning SME on access and functional needs
  - ✓ Sheltering in place/evacuations
  - ✓ Accessible transportation
  - ✓ Access to services and support
- Leverage CBO data in lieu of local registries

“Special Need Registries” are Problematic

- **Cost:** There is a significant cost in collecting, protecting, and organizing personal identifying information for developing and maintaining a registry
- **Maintenance:** Keeping the data up to date requires sophisticated resources and technical skills; it must be managed and maintained to ensure utility
- **Utility:** Many communities and counties provide and opt-in registry. To be useful, however, the data must be verified and kept up to date. Opt-in registries run the risk of being incomplete and out of date
- **Resources:** Risk of sending responders to registry locations that are out of date uses valuable time and resources
- **Resident Assumptions:** Residents who opt-in to a registry may falsely assume that someone will come for them and thus, may not take responsibility for their personal preparedness
- **Ineffective:** Many communities do not have the capability to effectively operationalize registry data or the capacity to disaggregate registry data to produce local situational awareness of their access and functional needs populations

Data & Tools

- Consumer data
  - ✓ CBO database
  - ✓ HHS emPOWER Program
- Demographic data
  - ✓ Census/American Community Survey
    - Age
    - Disability
    - Transportation
    - Living arrangements



*Percentage of persons age 65 and over with a disability, 2016. Census/SCS

Effective Communication

1. CBOs partner with local responders
2. Communication Outreach Information Network (COIN)
    - ✓ CBOs as trusted entities to distribute messages
3. Establish effective & accessible communication with consumers
    - ✓ Discuss disaster plans
    - ✓ Identify the support that may be needed in the event of a disaster
    - ✓ Discuss the disaster services that will likely be provided

Effective Communication for People with Disabilities

- **Hear the Warning**—Individuals must receive and understand messaging before they are able to respond; may experience challenges if communication needs are unmet
- **Understand the Warning**—Different people might have different understandings of what the warning means. Understanding depends on previous experience and knowledge of the hazard, & if personal understanding is insufficient or inaccurate, may opt to not follow emergency instructions
- **Develop Belief in the Risk**—Trust can depend on who issues the communication, how the message is delivered, & social effect (whether other people trust the message). Must have established trust in the disseminator of the alert or warning
- **Personalize the Risk**—Must believe that an alert was meant for them before they will respond. To verify alerts & warnings, people must have access to trusted sources of information
- **Decide on a Course of Action**—Personal factors influence individual response (social ties, pre-warning perceptions, & external factors including information source & method of dissemination). Everyday approaches for effective & accessible communication are more likely to be effective in an emergency

*National Council on Disabilities, Effective Communication for People with Disabilities: Before, During, and After Emergencies, Table of Communication Accessibility Considerations and Solutions

Evacuation & Transportation

- Promoting comprehensive evacuation planning
- Understanding transportation coordination in evacuation (ESF #1 Transportation)
  - ✓ Reviewing MOU/MOAs with transportation providers
- Including CBOs in state and local evacuation plan development, training, and exercises

***Four Elements of Evacuation Information**

1. Notification (What is the emergency?)
2. Way finding (Where is the way out?)
3. Use of the way (Can I get out by myself or do I need help?)
   - Self
   - Self with device or service animal
   - Self with assistance
4. Assistance (What kind of assistance might I need?)

*National Fire Protection Agency. (2016) Emergency Evacuation Guide for People with Disabilities

Sheltering and Accessibility

- Helping consumers prepare for emergency sheltering
- ADA compliance in sheltering
- Access and functional needs for level of care and shelter type

SWiFT Level	Explanation	Preparatory Steps
1	Cannot perform at least one basic ADL (activities of daily living: eating, bathing, dressing, toileting, walking, continence) without assistance	Evacuate early rather than late, depending on the circumstance. If possible, keep with family member, companion, or caregiver. Receives assistance in gathering all assistive devices, including eyeglasses, walkers, hearing aids, list of medications, names of doctor(s), family contact telephone numbers, and important papers, so they are accessible.
2	Trouble with instrumental activities of daily living (i.e. finances, benefits management, assessing resources)	Gather, with assistance if necessary, all assistive devices, including eyeglasses, walkers, hearing aids, list of medicines, names of doctor(s), family contact telephone numbers, and important papers so they are accessible.
3	Minimal assistance with ADL and instrumental activities of daily living	Advise individuals to have all assistive devices, including walkers, eyeglasses, hearing aids, list of medicines, names of doctor(s), family contact telephone numbers, and important papers together and accessible.

Baylor College of Medicine, Recommendations for the Best Practices in the Management of Elderly Disaster Victims, Seniors without Families Triage Tool (SWiFT) assessing ADLs

Legal Requirements

Disaster and Emergency Specific

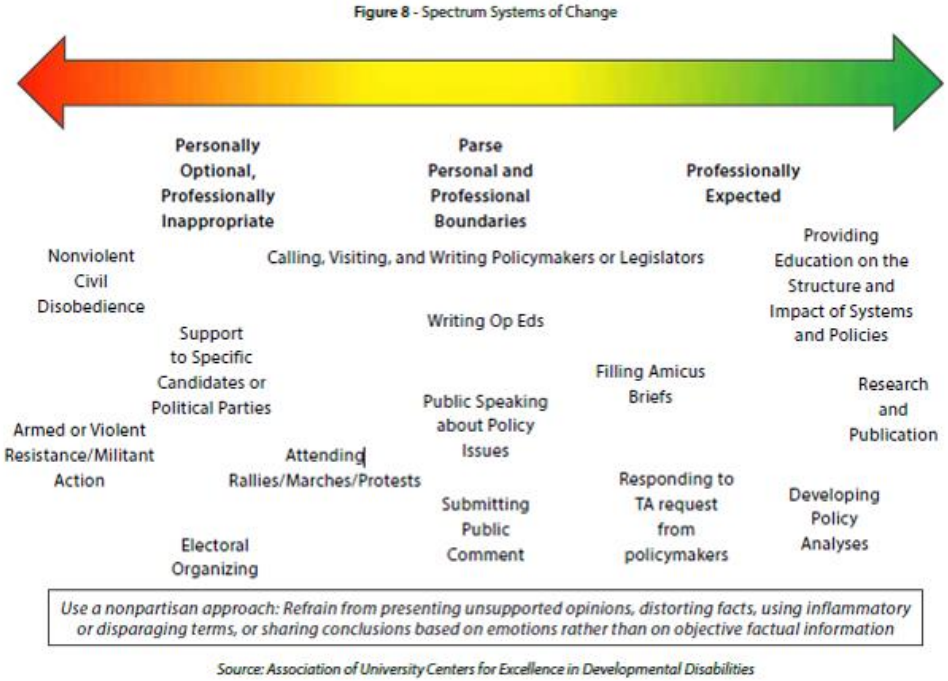
- Public Health Services Act of 1944
- Robert T. Stafford Disaster Relief and Emergency Assistance act of 1988
- Post-Katrina Emergency Reform Act of 2006
- Pets Evacuation and Transportation Standards Act of 2006
- Executive Order 13347: Individuals with Disabilities in Emergency Preparedness of 2004

Not Waived in Disasters or Emergencies

- Rehabilitation Act of 1973
- Privacy Act of 1974
- Age Discrimination Act of 1975
- Americans with Disabilities Act of 1990
- Health Insurance Portability and Accountability Act of 1996
- Developmentally Disabled Assistance and Bill or Rights of 2000
- Section 1557, Affordable Care Act of 2016

Legal Support & Advocacy

- Many ACL grantees provide legal support to consumers, for example:
  - National Center of Law and Elder Rights
  - ADA National Network
  - Protection & Advocacy Agencies
  - Senior Legal Hotlines
- Grantees of federal funds may have a role in promoting the rights of older adults and people with disabilities

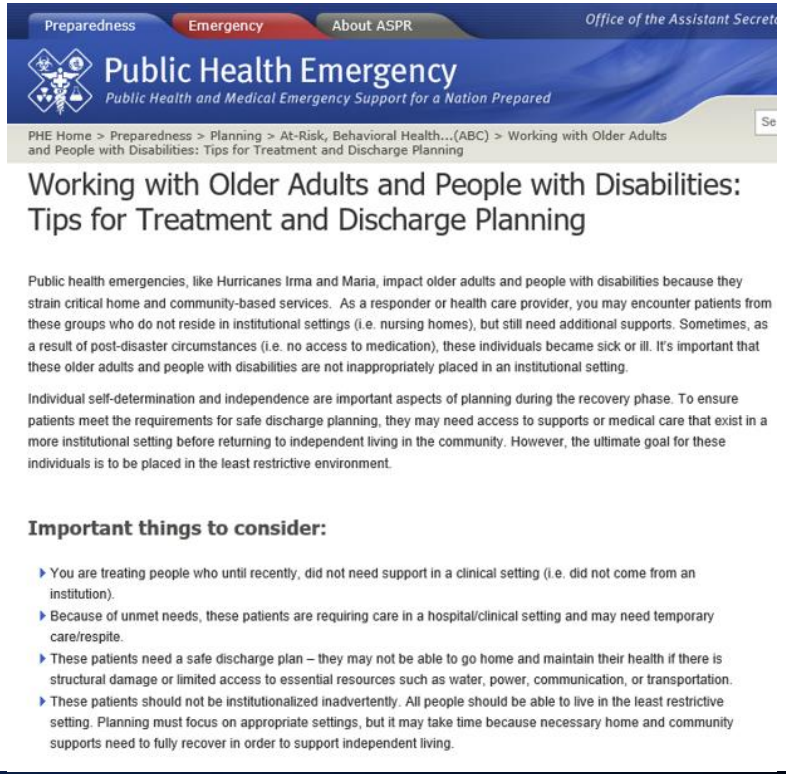


Role of CBO in Recovery

- CBO
  - ✓ Assess operational and financial impacts
  - ✓ Assess impacts to staff
  - ✓ Eligibility for FEMA Public Assistance or SBA disaster assistance loans
  - ✓ Develop lessons learned
- CBO & Local Responders
  - ✓ Provide lessons learned
  - ✓ Contribute to hot wash and after action report
  - ✓ Update Emergency Operations Plan to reflect lessons learned

Recovery—Supporting Consumers

- ✓ Return home or receive appropriate temporary housing (transition/discharge planning)
- ✓ Applying for FEMA Individual Assistance
- ✓ Assessing health and behavioral health needs
- ✓ Accessing services through the aging and disability networks



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Public Health Emergency

Public Health and Medical Emergency Support for a Nation Prepared

PHE Home > Preparedness > Planning > At-Risk, Behavioral Health...(ABC) > Working with Older Adults and People with Disabilities: Tips for Treatment and Discharge Planning

Working with Older Adults and People with Disabilities: Tips for Treatment and Discharge Planning

Public health emergencies, like Hurricanes Irma and Maria, impact older adults and people with disabilities because they strain critical home and community-based services. As a responder or health care provider, you may encounter patients from these groups who do not reside in institutional settings (i.e. nursing homes), but still need additional supports. Sometimes, as a result of post-disaster circumstances (i.e. no access to medication), these individuals became sick or ill. It's important that these older adults and people with disabilities are not inappropriately placed in an institutional setting.

Individual self-determination and independence are important aspects of planning during the recovery phase. To ensure patients meet the requirements for safe discharge planning, they may need access to supports or medical care that exist in a more institutional setting before returning to independent living in the community. However, the ultimate goal for these individuals is to be placed in the least restrictive environment.

Important things to consider:

- You are treating people who until recently, did not need support in a clinical setting (i.e. did not come from an institution).
- Because of unmet needs, these patients are requiring care in a hospital/clinical setting and may need temporary care/respite.
- These patients need a safe discharge plan – they may not be able to go home and maintain their health if there is structural damage or limited access to essential resources such as water, power, communication, or transportation.
- These patients should not be institutionalized inadvertently. All people should be able to live in the least restrictive setting. Planning must focus on appropriate settings, but it may take time because necessary home and community supports need to fully recover in order to support independent living.

Summary: CBOs New to Emergency Planning or Enhance Capabilities

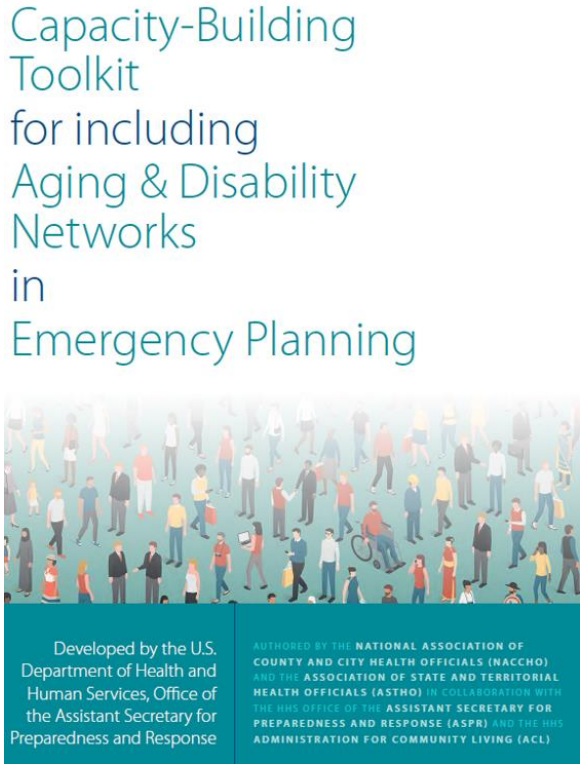
Capacity Building Toolkit for Including Aging & Disability Networks in Emergency Planning

- Highlights relevant resources and describes activities
  - ✓ Explains emergency planning to CBOs
  - ✓ Builds capabilities for supporting consumers
  - ✓ Introduces emergency managers and public health officials to CBO/aging and disability networks
- Each module
  - ✓ Resources in every module
  - ✓ Additional Resources and Tools
- Appendices
  - ✓ Templates
  - ✓ Worksheets
  - ✓ Checklists
  - ✓ Terms

Available Through NACCHO

[Capacity Building Toolkit for Including Aging & Disability Networks in Emergency Planning]

[www.phe.gov/abc]



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