The E.K. Shriver Center
Emergency Preparedness & Response Initiative

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E.K. Shriver Center, UMASS Medical School
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Research, education & service programs to improve the quality of life for children and adults with developmental and related disabilities:

- Research on biological and environmental influences on behavioral development
- Social science research
- Distance learning
- Graduate education
- Technology and information dissemination

Common Themes:
- Promote wellness & healthy lifestyle
- Promote safety & risk management
Emergency Preparedness & Response Initiative

- Health promotion: Preparedness is a health behavior; adequate preparedness and response prevents secondary health conditions
- Health equity: Increased vulnerability & disparate treatment → negative outcomes
- Civil rights: Equal access and opportunity (ADA)

Our Projects:
- Build resilience among people with disabilities
- Build capacity among public safety and public health responders (police, fire, EMS, public health, emergency managers/planners)
Emergency Preparedness & Response Initiative Projects
Online Survey: Emergency Preparedness of Families Impacted by Disability

**Hypothesis**: Families affected by disability/SHCN aren’t well prepared for emergencies

**Goal**: Develop intervention to increase family resilience

**Method**:
- Survey Monkey online survey to parents of children with disabilities/SHCN (0-21 years old) January - March, 2009
- Convenience sample; IRB exemption
- Final analysis: 314 respondent parents of children 1-21 from 35 states
- Disability = Developmental disability/delay, intellectual disability, and/or Autism Spectrum Disorder w/ or w/o another condition

*Funded by the University of Massachusetts Medical School and through a grant from the U.S. Administration on Developmental Disabilities*
Approx. 37% reported experiencing emergency or disaster

- Majority self-assessed a “medium” level of preparedness (mean=2.7)
- “Very prepared” took less than ½ recommended number of steps
Emergency Preparedness Training for Parents of Children with Disabilities/SHCN

- Pilot: In-person training
- Toolkit: Resource Notebook, Family Emergency Plan template (hard copy + flash drive), PowerPoint® handouts
- Development: Collaboration w/ parents & responders; geared to broad reading level
- Focus: “What if thinking and planning” & sharing “need to know” information
- Goal: For parents to leave the training with at least a portion of a written emergency plan
- Evaluation: Statistically significant gains in knowledge, self-efficacy and response efficacy; majority finished at least ¾ of their plans

Funded through a research award from the Deborah Munroe Noonan Memorial Research Fund, Bank of America, N.A., Trustee
Emergency Information Form

<table>
<thead>
<tr>
<th>Child’s Name</th>
<th>Nickname</th>
<th>Language Spoken/Understood</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth Date</td>
<td>Today’s Date</td>
<td>Completed By</td>
</tr>
<tr>
<td>Height</td>
<td>Weight</td>
<td>Hair/Eye Color</td>
</tr>
<tr>
<td>Gender</td>
<td>Blood Type</td>
<td>Identifying Marks</td>
</tr>
<tr>
<td>Child’s Address</td>
<td>Parent’s/Guardian’s Name and Address</td>
<td></td>
</tr>
<tr>
<td>Home Phone</td>
<td>Home Email</td>
<td>Work Phone</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Work Email</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mobile Phone</td>
</tr>
</tbody>
</table>

The most critical information to know about my child is:
1. 
2. 
3. 
4. 
5. 

Communication (critical issues):

Key personality traits: 

Key signs of normal function: 

Potentially life-threatening conditions:
Emergency Information Form Checklist

During an emergency or disaster my child is likely to need help or support in the following areas:

Communication, Reading, Writing, Thinking (speaking or understanding)

My child communicates by:

☐ speech  ☐ electronic communication device
☐ sign language  ☐ communication notebook
☐ vocalization  ☐ typing on the computer
☐ gesture  ☐ artificial larynx
☐ pointing to letters  ☐ writing
☐ pointing to words  ☐ other:
☐ pointing to pictures

My child’s communication is understandable

☐ all the time  ☐ only to those who know him or her well
☐ some of the time  ☐ not understandable

The best way for you to communicate with my child is:

[Blank space for answer]
Preparedness Training for Self-Advocates with ID/DD

- Design: Collaboration with a self-advocate who now leads the trainings. Built off a ME curriculum (SUFU).
- Focus: Likely participant experiences & taking key steps
- Trained 500 people with ID/DD
- Developed DVD
- Local ARC Emergency Preparedness Day
- Audience expanded to include people with head injury; provider agency staff; DDS staff; DDS Training Council; state DD Council

Funded by the University of Massachusetts Medical School and through a grant from the U.S. Administration on Developmental Disabilities
From Getting Ready for an Emergency: What can happen if you lose heat or electricity?
LEND Fellow Emergency Preparedness (EP) Day

- Annual full day training for federally funded graduate Leadership Education in Neurodevelopmental and related Disabilities (LEND) fellows
- Components: lecture; panel discussion; simulation
- Themes:
  - EP as public health issue
  - Personal preparedness as a health behavior
  - Potential vulnerabilities and strengths of disability community in emergencies
  - Individual & family preparedness “how to”
  - Provider agency preparedness
  - Civil rights & public policy: disparity/equity

Funded through a grant from the U.S. Administration on Developmental Disabilities
LEND Fellow Emergency/Disaster Simulation

1. Pick a role; divide into teams

2. Watch PPT w/ “TV broadcasts” about a chemical spill unfolding

3. Decision points: After team discussion, make decisions based on role and team
• **Project:** Developed 2 hour online course about emergencies/disasters and people with disabilities. Incorporates real life experiences.

• **Audience:** Health care personnel, EMS, long term care facility personnel, community health center personnel

• UMMS Center of Excellence for Emergency Preparedness and Training (CEEPET) project

**CEEPET is supported through a contract with the Emergency Preparedness Bureau at the Massachusetts Department of Public Health, with funding from the Assistant Secretary for Preparedness and Response (ASPR) Hospital Preparedness Program**
**Active Planning for Mass Care Sheltering and Evacuation of People with Disabilities**

- **Need:** Eliminate lack of communication between local response and disability communities; close gaps in emergency plans and planning.

- **Project:**
  1. Develop and implement in-person trainings for local emergency response personnel.
  2. Develop and implement Community Stakeholder Meetings for local emergency response personnel & disability community to share information and review local emergency plan for gaps.

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Active Planning Project

- Developed tools for local plan review: Workbook with needs assessment, gap analysis tool; setting priorities tool; closing the gap tool for use at Community Stakeholder Meeting

- Audience: Local emergency personnel & local disability community

- Design: Volunteer stakeholder collaboration
  - Review by local responders/managers/disability community members
  - Field test & feedback session
Hazmat Decontamination Drill Consultation

- US hospitals required to hold drills
- Decontamination process *not* designed for needs of people with disabilities/SHCN
- Shriver Center “victims” help responders practice; provide feedback about equal access & accommodations
- Link to related press and video re UMASS Memorial Hospital Drill

*Funded through a grant from the U.S. Administration on Developmental Disabilities*
NASDDDS Online Emergency Planning Tool

http://rtc.umn.edu/erp/main/

Shriver Center participation in this project funded through the Massachusetts Executive Office of Health and Human Services
Cross-Disability Collaboration

Massachusetts Task Force on Emergency Preparedness and People Requiring Additional Assistance

Available from the Massachusetts Office on Disability website:

http://www.mass.gov/anf/employment-equal-access-disability/oversight-agencies/mod/emergency-preparedness-1.html

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Emergency Preparedness and Response Initiative

Projects Currently Seeking Participants
PROJECT DEVELOPMENT

E.K. Shriver Center:
Susan Wolf-Fordham, J.D.
Nancy Shea, J.D., MPA
Patrick Gleason, M.A.
Charles D. Hamad, Ph.D.
David Stowe, MEM, consultant

Advisory Committee:
Mark Corr, Lexington Chief of Police
Keith Hoyle, Lexington Acting Fire Chief
Charlotte Rodgers, Lexington Director of Human Services
Victoria Buckley, Chair, Lexington Commission on Disability
Jennifer Williams, Co-Chair, Lexington Special Education Advisory Council; Member, Lexington Commission on Disability
Julie Miller, Lexington Community Representative
Responder Training

- 3-4 hour in-person training re: functional & access needs of people with disabilities & inclusive collaborative emergency planning
- Interactive training using scenarios from real life experiences
- Builds on existing response skills
- Appropriate for all experience levels
- Participating responders receive: Tips for First Responders card set; FEMA Orientation Manual; NOD Functional Needs guide; materials to share with the disability community
- Speak to us about CEUs & certificates of attendance
Training Topics

- Disaster experiences of people with disabilities
- Disaster needs of people with disabilities
- Disability demographics
- Disability awareness & etiquette
- Interacting with individuals with disabilities
  - Applying the OARS steps for successful interactions
  - People with mobility, vision, hearing, & cognitive disabilities, autism, mental illness
- Emergency communication message content & modalities
- Evacuation & transportation
- Mass care sheltering
- Hazardous material decontamination
- Inclusive emergency planning
  - Applying the C-MIST framework
  - Assessing your local emergency plan for gaps

Used with permission of Medical Reserve Corps 4A
Community Stakeholder Meeting

- 3-4 hour meeting in local community
- Response community & disability community members meet together to collaborate about gaps in local emergency plan
- Led by trained responders
- Facilitated by Shriver Center staff
- Goal: Complete the *Active Planning* workbook and create plan to close gaps
- Town receives gap analysis, list of priorities & closing gap plan
- Individualized for each participating town
- Disability community member participants receive: resources, useful handouts, items to start a household emergency preparedness kit
Active Planning Workbook, Tool #1

Where are we now?
Needs Assessment and Gap Analysis
Step 1
Tool: Where Are We Now?

F. Mass Care Sheltering

A. Shelter Setup

1. Shelter Capacity/Site Selection

- Our town’s shelter capacity calculation takes into account space issues relating to people with disabilities. For example, some people may have caregivers, service animals, mobility and other equipment, or may need accessible cots. The additional space needs should be included in the shelter space calculation.

- Our town’s emergency plan includes a process to evaluate potential shelter sites for physical accessibility and to address inaccessibility with remediation or by switching sites.

- Shelter site evaluation includes a review of:

<table>
<thead>
<tr>
<th>Parking areas</th>
<th>Check in areas/registration areas (accessible counter heights)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessible restrooms and showers (roll in showers/Hoyer lifts available)</td>
<td>Health and medical service areas</td>
</tr>
<tr>
<td>Sidewalk and exterior walkways</td>
<td>Sleeping areas (accessible cots)</td>
</tr>
<tr>
<td>Public telephones with TTY capacity</td>
<td>Signage (universal language)</td>
</tr>
<tr>
<td>Building entrances</td>
<td>Back-up power</td>
</tr>
<tr>
<td>Drinking fountains</td>
<td>Passenger drop off areas</td>
</tr>
<tr>
<td>Hallways and corridors, walkways</td>
<td>Refrigerator/other equipment with a good supply of ice</td>
</tr>
<tr>
<td>TVs (closed captioning)</td>
<td>Secure storage for medication w restricted access</td>
</tr>
<tr>
<td>Eating areas</td>
<td>Other:</td>
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2. Shelter Layout Plan

- Our town’s shelter layout plan takes into account the likely needs of people with disabilities (i.e. accessible cots placed near accessible restrooms; accessible cots placed adjacent to a wall when needed; privacy issues and need for quiet space).
Tool: Where Do We Want To Be?

2. Where Do We Want to Be? Setting Priorities

This tool will help your town determine what priorities to address related to gaps in your emergency plan.

1. Review part 1 of this Workbook and count the number of checked and unchecked boxes and record the information below:

   Count the checked and unchecked boxes in Section 1 above and tally them below.

   A. Identifying Local Needs _____ checked _____ unchecked boxes
   B. Local Emergency Planning Process _____ checked _____ unchecked boxes
   C. Public Emergency Preparedness Education _____ checked _____ unchecked boxes
   D. Emergency Communication _____ checked _____ unchecked boxes
   E. Transportation and Evacuation _____ checked _____ unchecked boxes
   F. Mass Care Sheltering _____ checked _____ unchecked boxes
   G. Hazardous Material Decontamination _____ checked _____ unchecked boxes
   H. Recovery _____ checked _____ unchecked boxes

2. Review the unchecked boxes, which will show your town gaps in its emergency plan. Note the sections with the most and fewest unchecked boxes.

   - Areas for quick and inexpensive solutions
   - Areas of greatest need
   - Setting priorities
### 3. How Do We Get There? Closing the Gap

This is the action plan for addressing the gaps identified in Section 2 above. Give each priority a title, briefly describe the gap, and then describe your strategy for closing the gaps.

**Our town’s plan to close the gaps in emergency planning for people with disabilities/access and functional needs:**

<table>
<thead>
<tr>
<th>Priority #</th>
<th>Brief description of the gap</th>
<th>Proposed strategy to close the gap</th>
<th>Responsible person &amp; contact info</th>
<th>Start/End Dates</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
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FREE to participating MA cities and towns

• Benefits to participating cities and towns
• Benefits to the disability community
• Benefits to responders (police, fire, EMS, public health, emergency managers, human services)
• Participating towns/cities must commit to BOTH parts of the project
Join the Active Planning Project

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