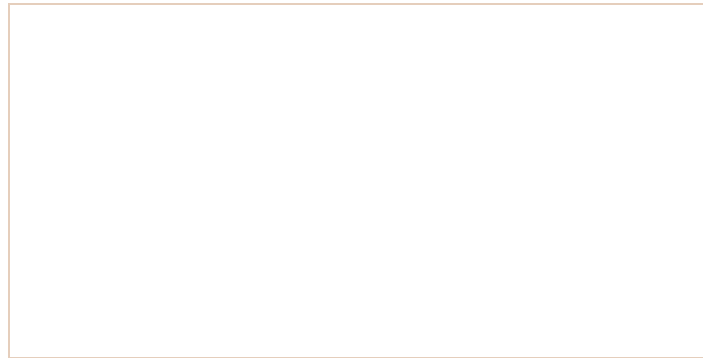


**EK Shriver
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The E.K. Shriver Center

Emergency Preparedness & Response Initiative



FEMA/Andrea
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Photograph ID:
33373

Sue Wolf-Fordham, J.D.
E.K. Shriver Center, UMASS Medical School
May 1, 2012





University of Massachusetts Medical School

Eunice Kennedy Shriver Center

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)

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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

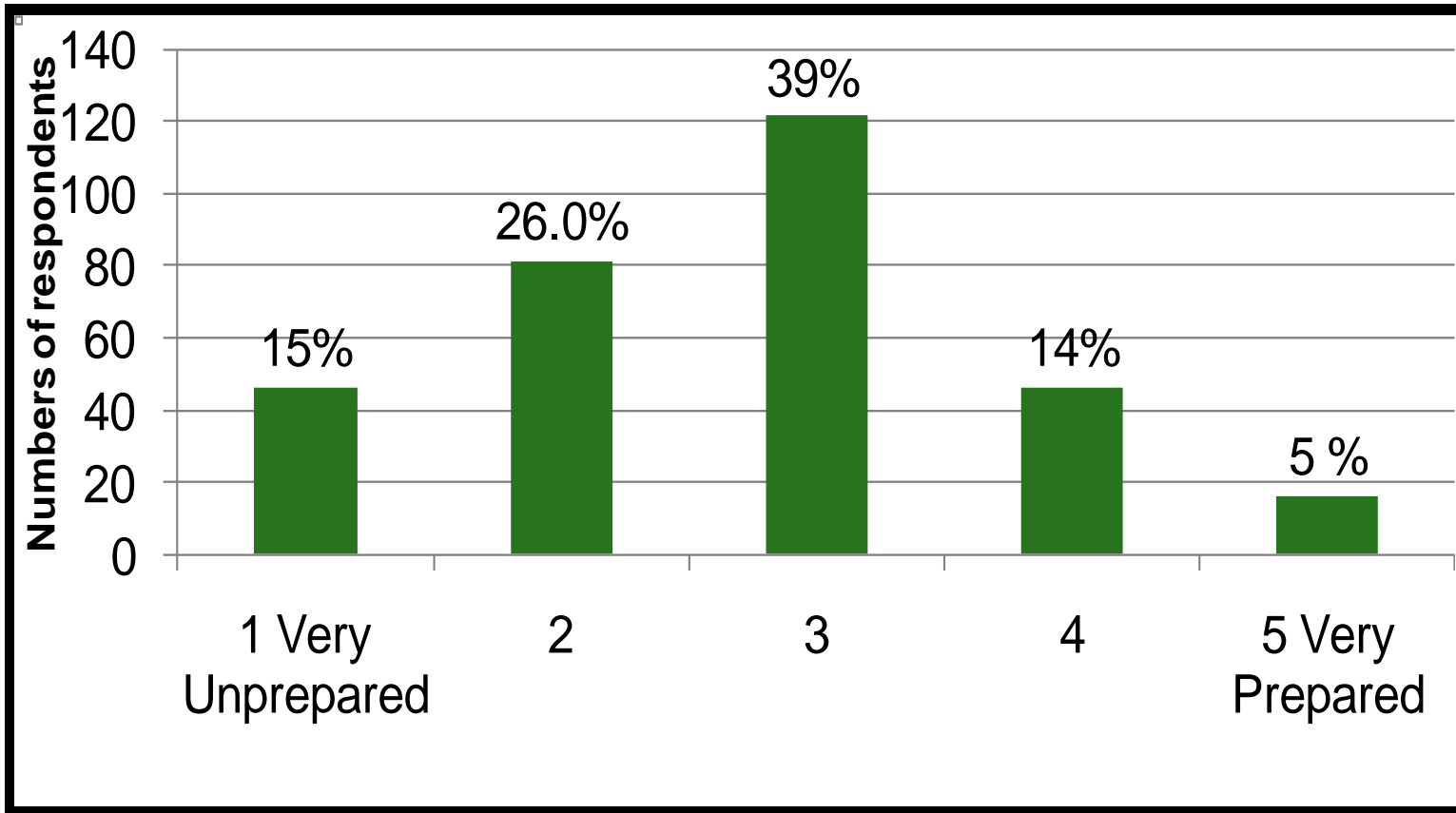
Goal: Develop intervention to increase family resilience

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

Online Survey

Self- Assessed Preparedness Level



- 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 (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 $\frac{3}{4}$ of their plans

template

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

Emergency Information Form

Fill in form with a pen or pencil



Emergency Information Form

Child's Name	Nickname	Language Spoken/Understood		
Birth Date	Today's Date	Completed By		
Height	Weight	Hair/Eye Color		
Gender	Blood Type	Identifying Marks		
Child's Address	Parent's/Guardian's Name and Address			
Home Phone	Home Email	Work Phone	Work Email	Mobile Phone

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 :

- | | |
|---|--|
| <input type="checkbox"/> speech | <input type="checkbox"/> electronic communication device |
| <input type="checkbox"/> sign language | <input type="checkbox"/> communication notebook |
| <input type="checkbox"/> vocalization | <input type="checkbox"/> typing on the computer |
| <input type="checkbox"/> gesture | <input type="checkbox"/> artificial larynx |
| <input type="checkbox"/> pointing to letters | <input type="checkbox"/> writing |
| <input type="checkbox"/> pointing to words | <input type="checkbox"/> other: <input type="text"/> |
| <input type="checkbox"/> pointing to pictures | |

My child's communication is understandable

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

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

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



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

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

CEEPET Online Course for Healthcare First Responders

- **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
<http://ceepet.org/accounts/110/homepage/>

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

Funded through a grant from FEMA through the MA Executive Office of Public Safety and Security. This document was prepared under a grant from FEMA's Grant Program's Directorate, U.S. Department of Homeland Security. Points of view expressed in this document are those of the author and do not necessarily represent the official position or policies of FEMA's Grant Programs Directorate or the U.S. Department of Homeland Security.

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

<http://www.umassmed.edu/news/education/2011/emergency-preparedness-drills.aspx>

NASDDDS Online Emergency Planning Tool

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

**Emergency Response Preparedness
Self-Assessment Instrument**

NASDDDS
National Association
of State Directors of
Developmental Disabilities Services

[Home](#) [Assessment](#) [Resource List](#) [About Project](#) [Contact us](#) [Site Map](#)

Home

The NASDDDS Emergency Response Preparedness Self Assessment Instrument was developed by the [National Association of State Directors](#) in collaboration with the [Research and Training Center \(RTC\)](#), Institute on Community Integration (ICI) at the University of Minnesota (UMN). Initiated following the Gulf Coast Hurricane disasters in 2005, the self assessment tool is designed to assist state developmental disabilities officials evaluate the extent to which their existing preparedness plans address the unique characteristics and needs of people with intellectual and developmental disabilities during periods of emergency or disaster.

[Using the Self-Assessment Instrument page](#)

[Login or Demo the Instrument.](#)

Questions/Feedback about this web site? E-mail the webmaster at: weste050@umn.edu.
© 2006 by The [National Association of State Directors of Developmental Disabilities Services \(NASDDDS\)](#)

**Emergency Response Preparedness
Self-Assessment Instrument**

NASDDDS
National Association
of State Directors of
Developmental Disabilities Services

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Assessment Home/Login

This assessment instrument is organized to evaluate preparedness in terms of:

- **Management Activities** (preparation, response and recovery); and
- **Operational Levels** (individual, service provider, local/municipal authorities, county, state and national agencies);
- **Content Areas** (collaboration, stakeholder involvement, communication, etc).

For further explanation of the instrument's organization and terms, [view our glossary](#).

Once you login, you will be able to choose the layout and section(s) of the assessment to view. We recommend that you complete the assessment in sections.

User Login

Username:

Password:

[Forgot your username or password?](#)

OR

[Demo the Assessment using a Guest Account](#)

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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- Timothy Moloney, MSEM
- John Rochford, M.S.
- Nancy Shea, J.D.
- David Stowe, MSEM
- Nathaniel Trull, Self-Advocate
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<http://www.umassmed.edu/shriver/service/emergency-preparedness-initiative.aspx>

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Emergency Preparedness and Response Initiative

***Projects Currently Seeking
Participants***



PROJECT DEVELOPMENT

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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

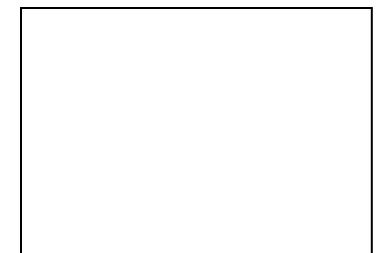
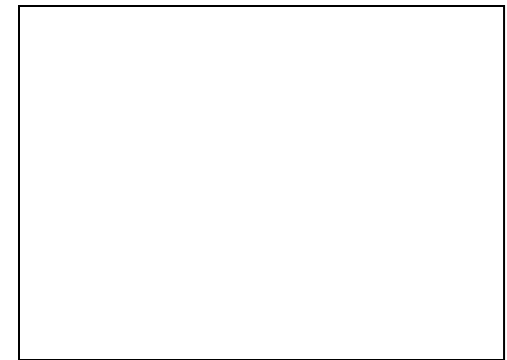
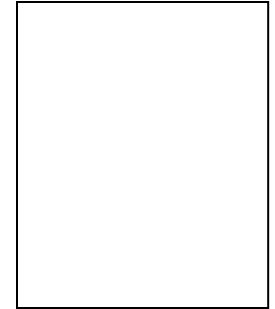
Jennifer Williams, Co-Chair, Lexington Special Education

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

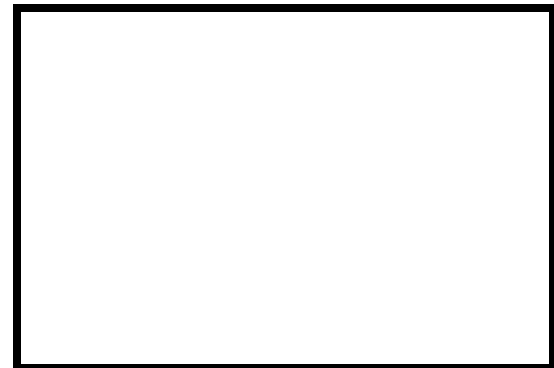


Training Topics

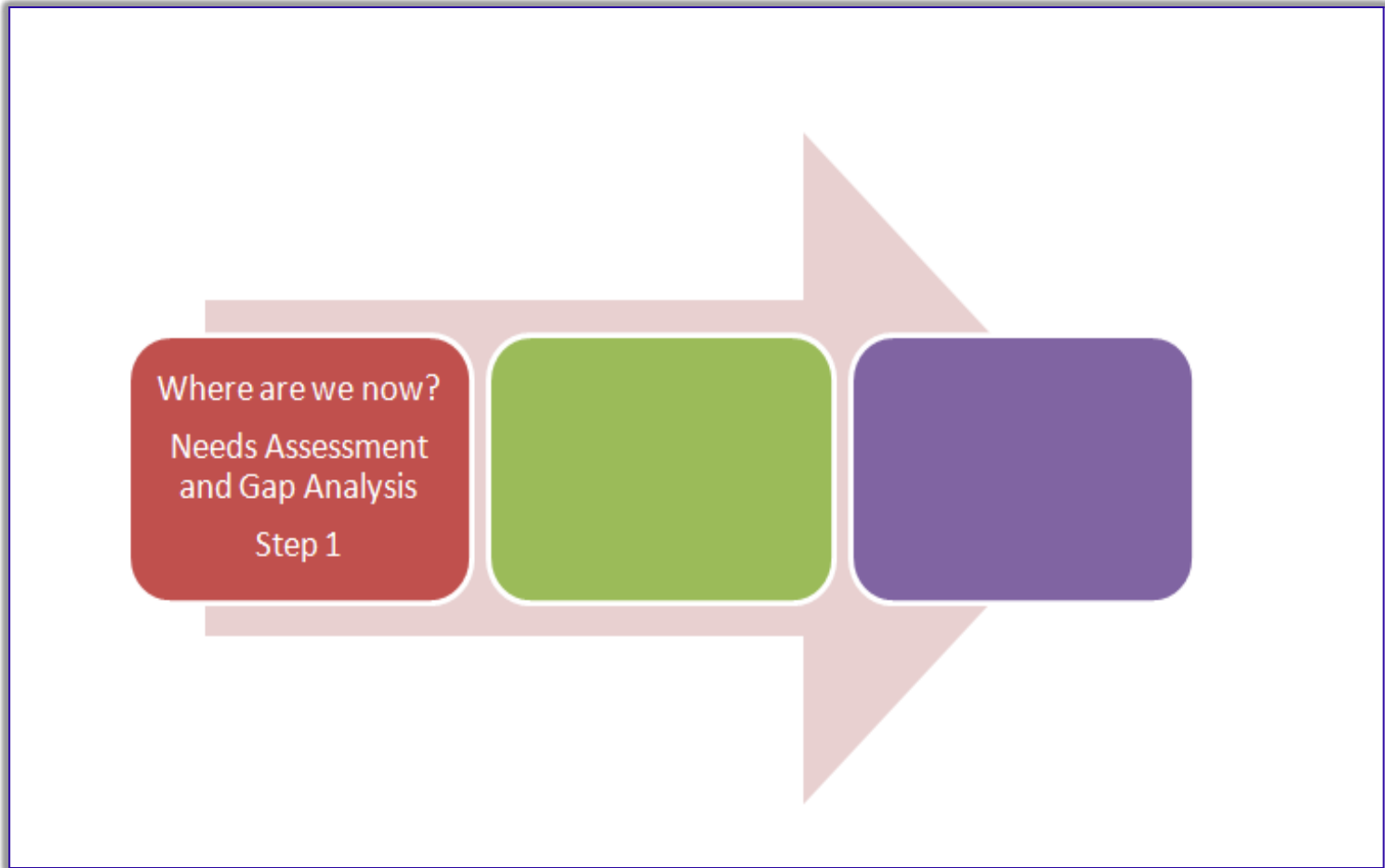
- ◆ Disaster experiences of people with disabilities
- ◆ Disaster needs of people with disabilities
- ◆ Disability demographics
- ◆ Disability awareness & etiquette
- ◆ Interacting with individuals with disabilities
 - ◆ Applying the OARS steps for successful interactions
 - ◆ People with mobility, vision, 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

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



Tool: Where Are We Now?

F. Mass Care Sheltering

A. Shelter Set Up

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:

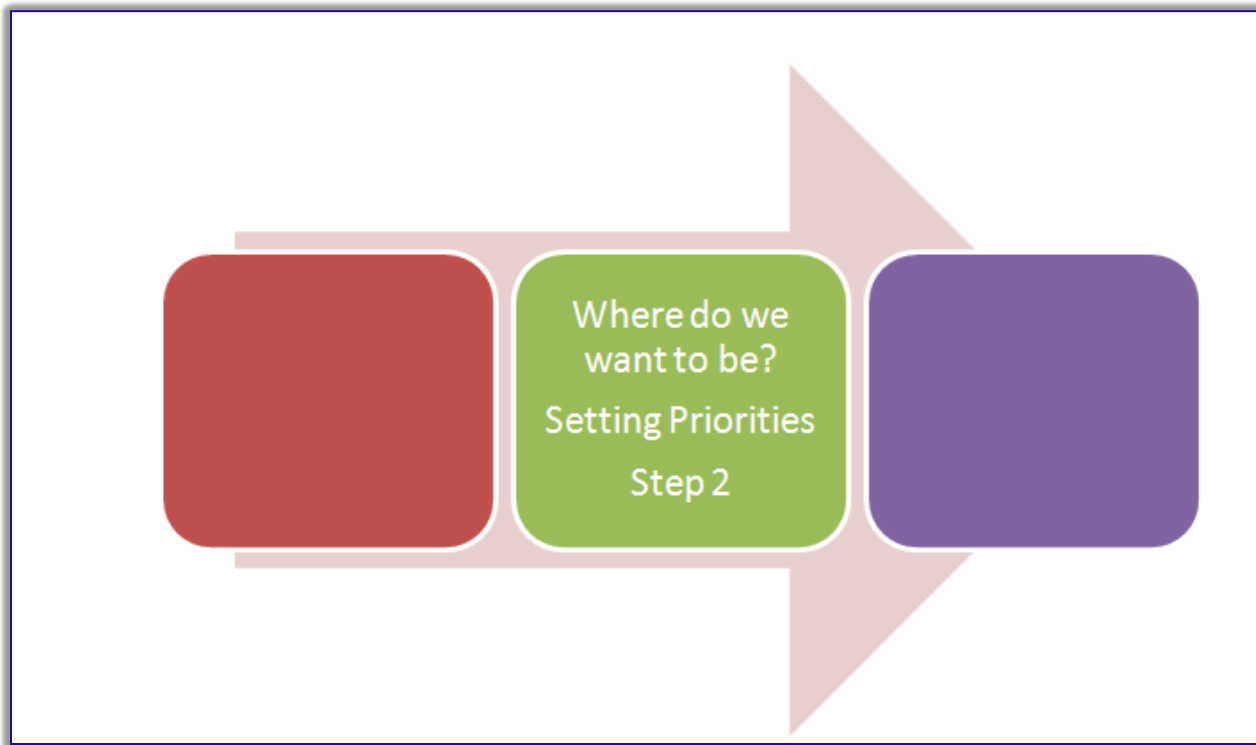


Parking areas	Check in areas/registration areas (accessible counter heights)
Accessible restrooms and showers (roll in showers/Hoyer lifts available)	Health and medical service areas
Sidewalk and exterior walkways	Sleeping areas (accessible cots)
Public telephones with TTY capacity	Signage (universal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

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).

Active Planning Workbook, Tool #2



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:

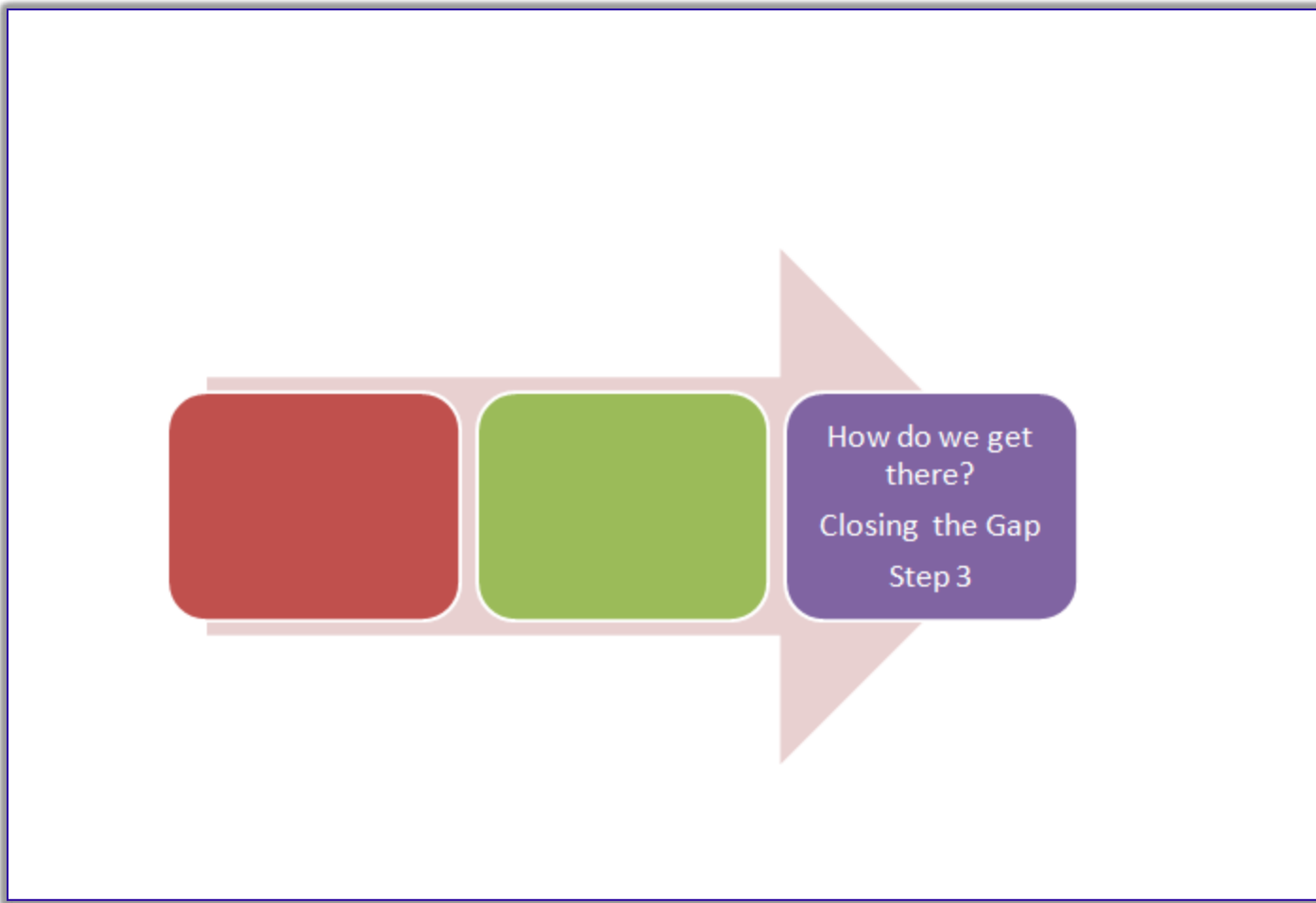
Count the checked and unchecked boxes in Section 1 above and tally them below.

- 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

Active Planning Workbook, Tool #3



Tool: How Do We Get There?

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:



Priority #	Brief description of the gap	Proposed strategy to close the gap	Responsible person & contact info	Start/End Dates
1.				
2.				
3.				

***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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