



NATIONAL EMERGENCY MANAGEMENT SUMMIT

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Special Populations:

Vulnerable, Silent and Compromised

**Disaster Planning for Citizens with Intellectual and
NeuroDevelopmental Disabilities**

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- **President American Academy of Developmental
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- **Editor-in-Chief Exceptional Parent Magazine**



Profile of the Individual with Intellectual & Developmental Disabilities

- Unique personality characteristics
- Syndrome specific characteristics
- Group heterogeneity



Profile of the Individual with Intellectual & Developmental Disabilities

COMMON BEHAVIORAL TRAITS

- Frustration Tolerance
- Impulsivity
- Self-Esteem
- Attention Sustainability
- Co-morbid Mood Disorders



Profile of the Individual with Intellectual & Developmental Disabilities

ADAPTIVE FUNCTIONING

- Communication
- Self-Care
- Home Living
- Social / Interpersonal Skills
- Community Resource Use



Profile of the Individual with Intellectual & Developmental Disabilities

ADAPTIVE FUNCTIONING

- Self-Direction
- Academic Skills
- Work
- Leisure Activities
- Health
- Safety



Profile of the Individual with Intellectual & Developmental Disabilities

ADAPTIVE BEHAVIOR

- Social
- Conceptual
- Practical



Anthropological Perspective of Pre-Disaster Risk and Vulnerability

- The Field of “Emergency Management”
- Cultural Influences of Vulnerability
- “Classquake”
- “Calculation of Vulnerability”
- “The Role of Flight”



Anthropological Perspective of Pre-Disaster Risk and Vulnerability

- Perpetuating Dependency
- Risk Assessment
- Various Coping Mechanisms
- “Embodiment”
- Expectations of Support
Infrastructure



Anthropological Perspective of Pre-Disaster Risk and Vulnerability

- Explaining Natural Disasters
- Symbolism
- Social Organization
- “Adaptive Flux”
- “Marginality”



Anthropological Perspective of Pre-Disaster Risk and Vulnerability

- Economic Upheaval
- Assembly and Seclusion
- Relocation Sites
- “Dependence”



Don't Leave Home Without It

- Polypharmacy
- Medical Issues
- Dual Diagnosis
- Communication Barriers
- Diets and Dysphagia



Don't Leave Home Without It

- Adaptive Equipment
- Communication Devices
- Assistive Technology
- Behavioral Issues
- Human Rights



Don't Leave Home Without It

- Seizure Disorders
- Ambulation
- Continuity of Care
- Sensory Processing
- Constancy of Environment



Don't Leave Home Without It

- "Chronobiology"
- "Self Determination"
- Contenance
- Confusion


University of Kansas Impact Study





Key Findings

- Pre-disaster Planning
- Pre and Post Disaster Communication and Information Sharing
- Pre and Post Disaster Coordination



Nobody Left Behind Research Major Findings

University of Kansas

- Limited Inclusion of PWD
- Low Level Understanding of the “Special Needs Community”
- Mobility Needs
- Inadequate Information about “People in Service Areas”



2007 University of Kansas Report

- Time that Displaced PWD's Stayed with Extended or Surrogate Families

2007 University of Kansas Report

GAPS IN PRE-DISASTER PLANNING

- Personal Preparedness Plans
- Limited Disaster Planning Skills in the Special Needs Community



2007 University of Kansas Report

GAPS IN PRE AND POST DISASTER INFORMATION SHARING AND COMMUNICATION

- Knowledgeable Sources Untapped
- Whereabouts of PWD Unknown
- Government Talking to Government



2007 University of Kansas Report

GAPS IN PRE AND POST DISASTER COORDINATION

- Disconnect between “Special Needs Community” and Emergency Mgmt. Agencies
- Devaluation of Special Needs Community by Emergency Mgmt. Agencies
- Mass Care Shelters Refused PWD
- Restoring the “Civic Fabric”



2007 University of Kansas Report

Recommendations

- Leadership Role Initiative for Special Needs Community
- Defining the Needs of PWD
- The Garbage Pail Classification of “Vulnerable Populations”



2007 University of Kansas Report

RECOMMENDATIONS

- Need for Systematic Training and Education in Disasters in the Special Needs Community (SNC)
- Availability of Evidence Based Research Findings for SNC
- Creation of a “Play Book”



2007 University of Kansas Report

RECOMMENDATIONS

- Designation of a Disability Contact when Emergency Operations are Activated
- “Functional and Medical Support Sheltering”
- Community Based Registries of People Needing Assistance



2007 University of Kansas Report

RECOMMENDATIONS

- Community Based Registries of Resources for PWD

RFID Implantable Chip



Roadblocks to Human Use of RFID

Dr. Rick Rader holds a microchip that could be implanted beneath a patient's skin for medical identification. The tiny chip, about the size of a grain of rice, is visible in the middle of the circle.

STAFF PHOTO BY KATHLEEN GREENSON

Chips spark ethics concerns

Orange Grove clients would be in first group studied for ID implants

By EMILY BERRY
STAFF WRITER

Medical ethics experts are questioning a proposal to implant medical identification microchips in the arms of developmentally disabled clients at Orange Grove Center.

"That's pretty disturbing and kind of surprising in that anyone would allow that to occur," said Dr. Stuart Finder, a director at the Center for Biomedical Ethics and Society at Vanderbilt

WHAT'S NEXT

Dr. Richard Seelig, vice president of medical applications at VeriChip Corp., will meet with the Orange Grove Human Rights Committee at noon today.

University Medical Center.

"Typically, the idea of using vulnerable people — children, disabled people, pregnant

women, prisoners, a whole variety of categories — we normally say that's not a good idea," Dr. Finder said.

Dr. Rick Rader, director of the Morton J. Kent Habilitation Center at Orange Grove Center, is advocating cooperation in a study with the maker of the VeriMed implantable device. He arranged meetings Thursday and today for one of the company's physicians with leaders at Orange Grove and Erlanger hospital.

Dr. Rader said VeriChip Corp., the Delray Beach, Fla., company that manufactures the device, has agreed to provide free implants for as many as 100 Orange Grove clients. The clients would be the subjects in the first group study of the application of the device, which normally costs \$200, he said.

Dr. Rader and other Orange Grove medical committee mem-

See IMPLANTS, Page A9



National Organization on Disability

THE SNAKE PROJECT

- The Numbers Game
- Defining Special Needs
- Levels of Shelters

National Organization on Disability

THE SNAKE PROJECT RECOMMENDATIONS

- Employ The “Pearls”
- Replace Durable Medical Equipment (DME)
- Maintain Families and Community Placement
- Ask! Ask! Ask!



National Organization on Disability

THE SNAKE PROJECT RECOMMENDATIONS

- Federal Financing for Medical Necessary Services
- Supplemental Government Funding
- Philanthropic Organizations
- Availability of Accessible Information

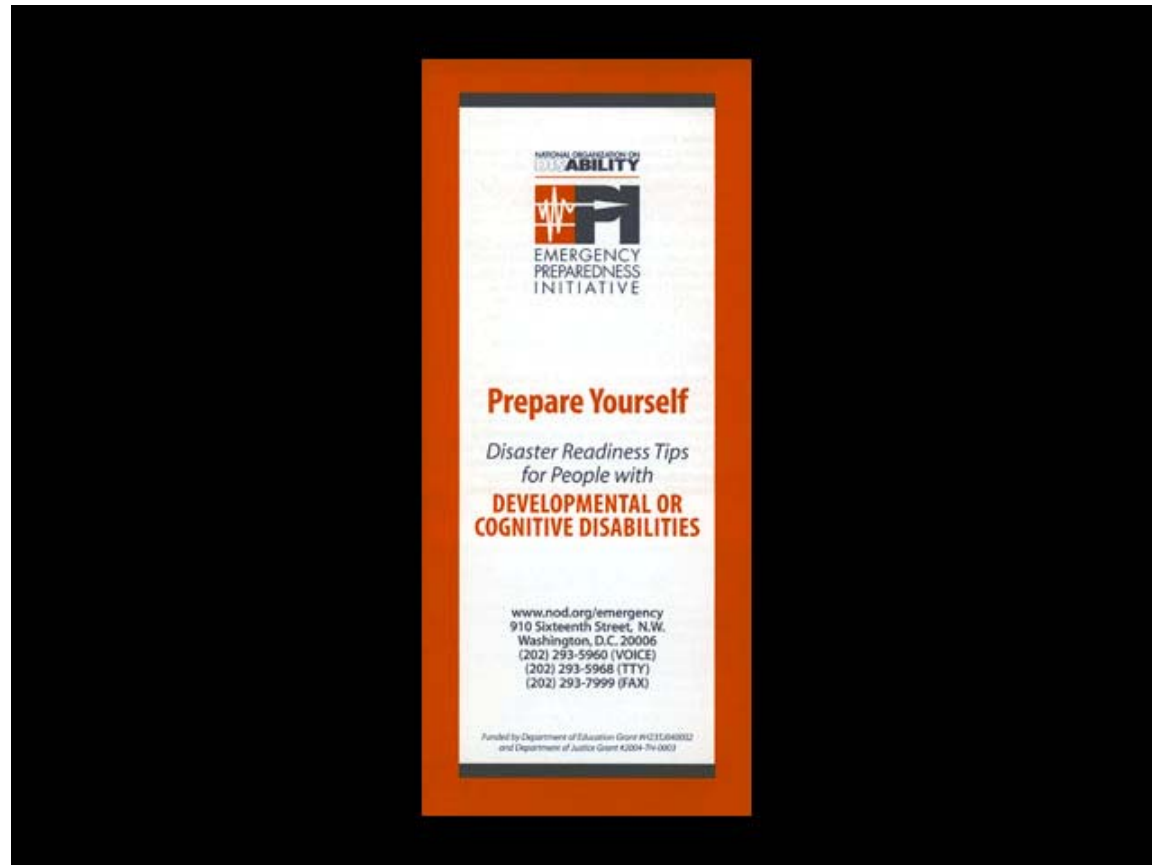


National Organization on Disability

THE SNAKE PROJECT RECOMMENDATIONS

- Service Coordination
- Cross Training

National Organization on Disability



Senate Bill to Assist PWD in Disasters Fails

109TH CONGRESS
1ST SESSION

S. _____

To address the needs of individuals with disabilities in emergency planning requirements and relief efforts in the event of a major disaster, to increase the accessibility of replacement housing built with Federal funds following Hurricane Katrina and other major disasters, and for other purposes.

IN THE SENATE OF THE UNITED STATES

Mr. HASKIN introduced the following bill, which was read twice and referred to the Committee on

A BILL

To address the needs of individuals with disabilities in emergency planning requirements and relief efforts in the event of a major disaster, to increase the accessibility of replacement housing built with Federal funds following Hurricane Katrina and other major disasters, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the "Emergency Prepared-
5 ness and Response for Individuals With Disabilities Act
6 of 2005".



National Organization on Disability

THE SNAKE PROJECT TAKE HOME MESSAGE

“We, as a nation, can do more to improve the outcomes for people with disabilities and the aging population the next time disaster strikes – and there will be a next time.”