

# Developing a training handbook for emergency personnel and caregivers on the topic of how to support persons with mental disabilities in emergencies and disasters

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# Aim and research plan

- Objectives
  - Find out about specific reactions and needs of people with mental disabilities in emergencies and disasters.
  - Find out about additional training needs of emergency personnel and caregivers

# Methods

1. **Desk research** looking for guidelines on mentally disabled persons in emergencies/disasters
2. **Focus group discussions** on experienced challenges with experts from caregiving and emergency organisations.
3. **In depth interviews** on specific reactions, needs and coping strategies of mentally disabled persons in emergencies based on case examples.
4. **Pilot training** with experts from both emergency and caregiving organisations.

Analysis was done using qualitative content analysis.

# Step one: Desk research

- Keywords mentally disabled, intellectual impairment, mental retardation, autism, in combination with disaster, emergency
- 65 guidelines and handbooks, 12 practice examples and 45 tools were found
- The mapping of these guidelines, handbooks, practice examples and tools show that whereas information is available about interaction and support of people with disabilities in disasters, there is hardly any specific guidance on persons with mental disabilities (16).
  - Two action sheets have been developed on the specific situation of people with mental disabilities in emergencies and disasters (one in German, one in English) that can be found on the website: <http://eunad-info.eu/home.html>

## Step two: Focus group discussions

- 8 experts from 3 caregiving organisations (providing workplace and care for people with mental disabilities, adults and children) and one emergency organisation (ambulance service Austrian Red Cross)
- Focus group discussions on
  - Practice examples and experience
  - Training needs for caregivers and emergency personnel

# Perceived challenges

Emergency managers	Caregivers
<ul style="list-style-type: none"> <li>• Lack of experience with mentally disabled persons in the personnel</li> <li>• Difficulty differentiating between “normal” behaviour and symptoms, communication problems</li> </ul>	<ul style="list-style-type: none"> <li>• Fear to make mistakes and be held responsible</li> </ul>
<ul style="list-style-type: none"> <li>• Evacuation: difficulties in accessing information about persons with mental disability and lack of pre disaster networking cooperation with organisations caring for people with mental disabilities</li> </ul>	<ul style="list-style-type: none"> <li>• Excessive/manifold demands during response phase (informing police, emergency workers, firefighters; enabling contact with mentally disabled person)</li> </ul>
<ul style="list-style-type: none"> <li>• Contact with mentally disabled person is highly dependent on good interaction with the caregivers</li> </ul>	<ul style="list-style-type: none"> <li>• Double role (affected and caregiver)</li> </ul>
<ul style="list-style-type: none"> <li>• Caregivers often do not have enough knowledge about demands of emergency situation</li> </ul>	<ul style="list-style-type: none"> <li>• Perceived chaos and lack of knowledge about emergency situations feelings of helplessness and being overwhelmed</li> </ul>
	<ul style="list-style-type: none"> <li>• Feelings of empathy, responsibility and guilt causes stress and endangers appropriate action</li> </ul>

# Perceived training needs

- Skills (emergency exercises in caregiving organisations, exercises on communication with mentally disabled persons for emergency personnel)
- Knowledge (mental disability, specific reactions and needs)
- Checklists (emergency plans, emergency kits etc.)

# Step three: In depth interviews

<i>Type of Expert</i>	<i>Case examples</i>	<i>Number</i>	<i>Age</i>		<i>Gender</i>		<i>Organisation</i>
			<i>20-40</i>	<i>40-60</i>	<i>female</i>	<i>male</i>	
Caregivers	7	6	2	4	3	3	Innsbrucker soziale Dienste; Lebenshilfe, home for the elderly
Management of disability facilities	5	5		5	1	4	Heilpädagogische Familien; Lebenshilfe
Emergency personnel	5	3		3	2	1	Austrian Red Cross
Emergency management	3	2		2		2	Austrian Red Cross
Total	20	16	2	13	5	10	4

# Case examples

Emergency personnel	Caregiving organisation
<ul style="list-style-type: none"><li>• Death of a relative</li><li>• Death of a caregiver</li><li>• Medical emergency</li><li>• Delivering a death message</li><li>• Support through viewing of dead body</li><li>• Evacuation</li><li>• Rescue during disaster</li></ul>	<ul style="list-style-type: none"><li>• Death of a relative</li><li>• Death of a client in a disability facility</li><li>• Violence</li><li>• Loss of persons of trust</li><li>• Medical emergencies</li></ul>

# Main Results: reactions and needs

- Stress reactions and needs in emergency situations are the same in people with mental disabilities as in non-disabled persons but
- Reactions may be stronger, more nonverbally expressed and with a later onset.
- Dissociation and regression as well as aggression seem to occur more often. Dissociation is often not recognized as the differentiation from disability related behaviour is often not easy.
- Grief reactions are not as continuous as with non-disabled persons and a lack of understanding and mourning rituals endangers recovery especially when no information is given.
- Using social support and adaptation to new situation seems more difficult for the target group.
- A regular daily schedule, routines and rituals and a continuity in caregivers seem to be essential.
- Knowing the client, good cooperation and communication between caregivers, emergency personnel and relatives are the most important factors in emergencies and disasters.

## Step four: Pilot training

- A pilot training was developed containing the following parts
  - A PowerPoint presentation on specific reactions and needs of people with mental disabilities
  - A case example to be used for exercise and case discussion
  - A preliminary checklist to be used as a framework for a discussion on how to develop a checklist
- The training took place at the University of Innsbruck on January 20, 2017.
- 18 Participants from 5 caregiver and 1 emergency organisation took part, they had at least ten years of experience.

# Results

## Knowledge part of the training

- Discussing PowerPoint input, we saw that **more focus must be put on the differentiation between three groups of disabled people:** persons with minor and medium level intellectual impairment, people with autism spectrum disorders, and people with dementia. These seem to be the biggest groups in the facilities and therefore the primary target groups.
- The general contents needed were **trauma, grief and dissociation,** information on the above mentioned groups as well as a part on **reactions and needs as well as coping** of people with mental disabilities in general and specific information on the three groups.

# Results

## Skills part

- The **use of case examples** and **the exchange between the organisations** were most fruitful
- Discussion of the case example showed the need for an exchange between caregivers and emergency personnel. Either group did not know enough about the procedures and needs of the other group. They found it very informative to exchange their views.
- **Joint trainings and exercises** seem to be of utmost importance

# Results

## Checklist construction

- Discussion of checklist materials clearly showed that it is not possible to develop one set of checklists for all types of events and organisations
- **Each organisation has to develop their own checklists based on their chosen event types and based on their organisation type**
- We have to provide framework for this

# References

- Ballan, M. S., & Sormanti, M. (2006). Trauma, Grief and the Social Model: Practice Guidelines for Working with Adults with Intellectual Disabilities in the Wake of Disasters. *Review of Disability Studies*, 2(3). Available at <http://www.rds.hawaii.edu/ojs/index.php/journal/article/view/339>.
- Center for Independence of the Disabled in New York. (2004). *Lessons Learned from the World Trade Center: Emergency Preparedness for People with Disabilities in New York*. Available at [http://www2.ku.edu/~rrtcpbs/resources/pdf/lessons\\_learned\\_from\\_the\\_world\\_trade\\_center\\_disaster.pdf](http://www2.ku.edu/~rrtcpbs/resources/pdf/lessons_learned_from_the_world_trade_center_disaster.pdf)
- Fraser, A. B. (2007). *Emergency Evacuation Planning Guide For People with Disabilities*. National Fire Protection Association (NFPA). Available at <https://www.nfpa.org/~media/Files/Safety%20information/Forconsumers/Disabilities/evacuationguidePDF.pdf>.
- Irblich, D. & Blumenschein, A. (2011). Traumatisierung geistig behinderter Menschen und pädagogische Handlungsmöglichkeiten. In: *Trauma und Gewalt. Forschung und Praxisfelder*. 5. Jg., 1/11, 74-93
- Irblich, D. (2006a). Traumafolgestörungen bei Menschen mit geistiger Behinderung. In: *Klauß, Theo (Hg.): Geistige Behinderung- Psychologische Perspektiven*, Heidelberg: Universitätsverlag Winter, 121- 137
- Irblich, D. (2006b). Posttraumatische Belastungsstörungen bei Menschen mit geistiger Behinderung. In: *Geistige Behinderung. Fachzeitschrift der Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung e.V.* 45. Jg., 1/06, 112-123