

Empowering personal disaster preparedness and self-help of people with disabilities

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About this study and its background - demand

One main task of national societies and of Europe should be:

- Development of personal disaster preparedness and self-help of people with disabilities and impairments.

Fundamental basis for this:

- **Convention on the Rights of Persons with Disabilities** of the UN.

It is necessary not only “to ensure the protection and safety of persons with disabilities in situations of risk” (Article 11) but “that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” (Article 12 (2)).

These demands of the convention are not yet realized.

Still people with disabilities are widely regarded as objects of the process of disaster preparedness and not as subjects, able to act on their own and to prepare themselves.

About this study and its background - targets

- Increasing disaster protection gap in part of the regions in Europe.
- According to the German Civil Defense and Disaster Relief Law (ZSKG) municipalities are responsible to develop, support and manage personal disaster preparedness and self-help of the population.

From the above mentioned reasons the German Federal Office of Civil Protection and Disaster Assistance (BBK) initiated and funded the meanwhile completed project we are talking about.

Aims of the project have been

- finding approaches for **development of personal disaster preparedness and self-help of persons with disabilities and impairments** and their family members
- including Europe-wide research in 2013 and 2014 to find **good practice** in this regard
- **guideline for municipalities in Germany** to support development of personal disaster preparedness.

Personal emergency preparedness

Personal emergency preparedness covers self-protection and self-help.

- ***Self-protection*** is the sum of individual measures to avoid, provide for and master events. Self-protection covers particularly measures to protect the close living and working area and to avoid or decrease damages to lives and health. The protective capacity corresponds to the *resilience* of persons (mastering and reaction potential, retention of ability to act on one's own after damaging events). Self-protection requires the acquisition of *abilities and knowledge*.
- ***Self-help*** (as part of self-protection) is the sum of individual measures for mastering of events. Self-help covers all measures from the beginning of damaging events especially until the arrival of relief units (isolation phase). Learning of abilities is required before the event (e.g. first aid, dealing with fire extinguishers, interpretation of warnings).

Impairment, disability and empowering

About a *quarter of the population* in Germany has an impairment or a disability. The situation in other European nations is quite similar.

- The term *disability* refers to persons who are officially registered as disabled persons.
- The term *impairment* is used when severe functional reduction lasts longer than six month.
- *Empowering* is the process of self authorization, leading to a condition of empowerment.

The ability to protect and help oneself means that persons with impairments or disabilities **know, what to do** in an emergency situation. Furthermore they are **empowered to help others** who may need protection or first aid.

Knowledge about self-protection can save life and hinder deterioration of health and property.

Various kinds of support are necessary to reach this goal as well as an environment which does not disrupt but encourages this process.

Expert-oriented research in Europe (good practice)

A Europe-wide expert-oriented research in 2013 and 2014 targeted to overview the situation in Europe and to find examples of good practice concerning developing of personal disaster preparedness of persons with disabilities.

Research has been done especially acquiring knowledge from members of the European Disaster, Conflict and Social Crisis Research Network (DCSCRN) and from several organisations of persons with disabilities and relief organisations.

Nations included in the expert-oriented research have been Germany, France, United Kingdom, Switzerland, Austria, Italy, Greece, Spain, Portugal, Sweden, Norway, Denmark and Finland.

Result: The topic is ignored largely in European countries. There are some exceptions on organisational and local level in the field of first aid and fire protection education. Different from the situation in Europe there are initiatives – even among European organisations – to develop and enhance personal disaster preparedness and self-help of people with disabilities in so called developing countries and in the United States.

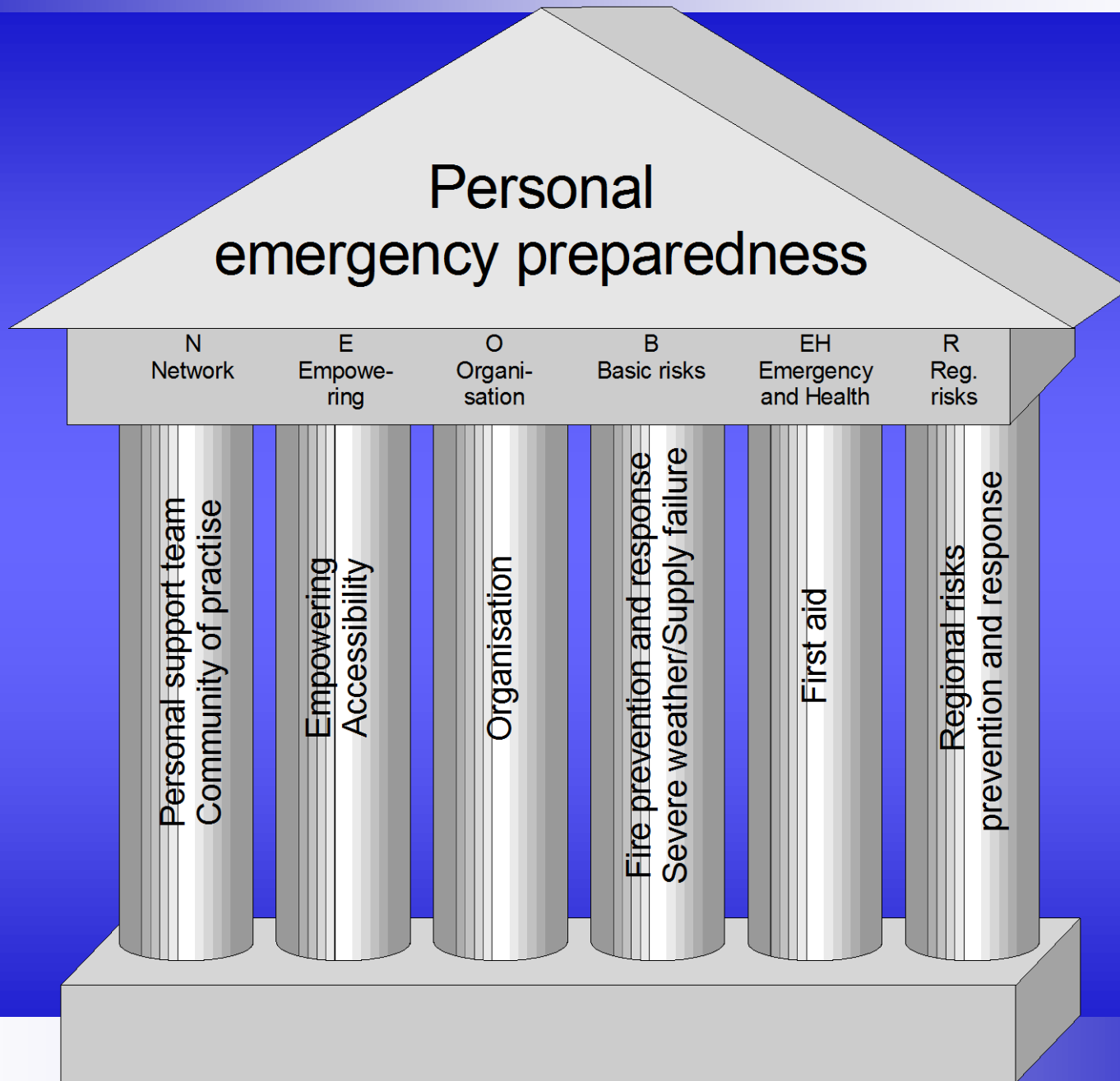
Why is personal disaster preparedness and self-help important for people with impairment or disability?

- a) They can bring themselves in during planning and putting into action of personal disaster preparedness measures. In that process they win self-confidence and knowledge and enlarge their **ability to act** (empowerment).
- b) They don't lose time during the **isolation phase** (lasting from the onset of an event until arrival of rescue services) and have the chance to save life(s), health and property.
- c) They win general competences (e.g. by learning fire protection and first aid).
- d) In an emergency they better can assess their own situation and act on their own or instruct persons about the best way to support them.
- e) By developing a preparedness plan in a participatory way (e.g. in Communities of Practice – CoPs or in personal support teams), they belong to a network and their particular needs get socially visible.
- f) Resilience increases and vulnerability lessens.

Models to develop personal emergency preparedness of persons with disabilities or impairments

In the study and guideline two models have been developed. Both can be used by the administration of municipalities, relief organisations or others to initiate and promote personal disaster preparedness of persons and networks in their catchment area and they are immediately utilizable for people with disability or impairment and their family members.

- a) NEOBEHR – gives orientation at the beginning and during development of personal disaster preparedness and self-help.
- b) KE-MUST – is useful to reach a systematic understanding of functional needs of persons with disabilities and impairments in emergency situations. Moreover KE-MUST helps persons with disabilities or impairments to think through their own functional needs during developing of their own preparedness.
The model has been included in the Toolkit of Sagramola and Alexander, which has been introduced yesterday.



NEOBEHR – a model to develop personal disaster preparedness

The model (Geenen & Strangmeier 2014) consists of six columns:

N – Network

E – Empowering

O – Organisation

B – Basic risks

EH – Emergency and Health

R – Regional risks

Column 1 – Network [I]

Three modes of developing personal emergency preparedness:

- Individual mode
- Personal support-team
- Community of Practice (CoP)

A combination of the three modes.

Column 1 – Network [II]

1. The individual mode: Everybody is planning and learning on his own; only supported by one-way-communication (e. g. mass media, training material).
2. Personal support-team: it is organised around a person with disability or impairment. The team supports this person during the process of developing personal emergency preparedness.

Column 1 – Network [III]

3. Community of Practice (CoP): It is a mode of *situated participatory learning in a horizontal organised community* (Sarmiento & Olsen 2012) originally developed by Lave and Wenger (1991).
 - Aim of the Community of Practice is to improve personal emergency preparedness of all persons involved in the community.
 - They bring in their point of view, their knowledge and abilities and learn from perspectives, knowledge and meaning and priorities of the others and change themselves in the meantime.

Column 2 – Empowering

- *Empowering* is the process of self authorization, leading to a condition of empowerment.
- To reach this goal various kinds of support are necessary as well as an environment which does not disrupt but encourages this process.
- Support to reduce or to lift all kinds of barriers (barrier-freedom).

Column 3 – Organisation [I]

- The development of personal disaster preparedness affords some knowledge about organisation structures.
- Important telephone numbers (e. g. fire department, medical emergency and rescue service, pharmacy after hours service, poisoning emergencies)
- How to release an emergency or fire report (Where did it happen? Where is the fire? ...)
- Where and when fire protection information and first aid training are offered?
- Stockpiling of drinking water, food, medicaments and other important things.

Column 3 – Organisation [II]

- Energy stockpiling – in the case of an emergency with lasting power failure (e. g. flashlight, batteries, lighters, battery-powered radio).
- Emergency pack (with ID card/passport, important documents, addresses of relatives, friends, organisations, persons to be contacted during an emergency or disaster, clothing and hygienic articles ...).
- Developing of a personal checklist for emergencies.

Column 4 – Basic risks

Personal emergency preparedness means to be informed about basic risks. Some kinds of catastrophes may occur everywhere.

To these risks belong

- fire,
- severe weather,
- supply failure (power failure, disrupted or reduced water supply).

Column 5 – Emergency and Health

Personal emergency preparedness includes knowledge and equipment.

- First aid training or refreshment.
- Storage of necessary medicines (first aid box, medicaments to be taken on a regular basis).
- Other items (as pain relievers, fever thermometer, skin disinfectants).
- In the case of disability necessary additional equipment.
- Addresses of attending doctors, physiotherapists and so on.
- Description of health situation of family members, including allergies, medicaments to be taken on a regular basis and so on.

Column 6 – Regional risks

For personal emergency and disaster preparedness it is necessary to learn something about regional risks. Regional risks cover a large spectrum of catastrophe triggers.

Therefore only a few examples are given to illustrate this column.

- Flooding.
- Earthquake, volcanic eruption, landslide, mudflow.
- Chemical, biological, radiological or nuclear (CBRN) hazards.

KE-MUST – Tool to analyse functional needs of persons with disabilities or impairments as base for personal disaster preparedness and self-help

For purposes of preparation and reaction to emergencies the concept KE-MUST takes into account *functional needs* in the following areas:

- Communication
- Empowerment
- Medicine
- Independence / Barrier-freedom
- Supervision
- Transport

Source: enriched model of Kailes & Enders 2007 (C-MIST).

C – Communication

Inclusion of persons who

- have reduced or no ability to speak spoken language, to read, to see or to hear,
- are restricted in learning and/or understanding.

During an emergency or disaster it is possible, that persons with communication needs are not able

- to hear verbal announcements,
- to understand the message.
- to see direction indications of emergency exits or emergency services.

E – Empowerment

- Raise of self effectiveness
- Improvement of self-confidence
- Ability to help others
- Acquisition of important competences in personal disaster preparedness and self-help and thus increase of resilience
- Reduction of vulnerability.

M – Medical needs

are related to persons who need support in

- activities of daily life – bathing, eating, etc.,
- treatment of chronic, deadly proceeding, contagious health situations,
- composition of medicine und dose-delivery, intravenous therapy, giving infusions,
- dialysis, oxygen, suction,
- treatment of wounds, catheter, ostomy.

During an emergency or disaster:

- People may be separated from family and friends.
- During disasters early recognition of functional needs and the appropriate intervention may help to prevent a deterioration of health (whose recovery is connected to high costs) and helps avoid a reduction of functional independence.

U – (functional) Independence

is related to persons, who

- use supportive accessories and/or equipment, to act independent in everyday life, as
 - mobility aids – e.g. wheelchairs, crutches,
 - communication aids – e.g. hearing aids, computers
 - medical equipment – oxygen, syringes
 - guide dogs,
- need medicine to act independently.

During an emergency or disaster:

- Individuals may be separated from their supportive accessories, their equipment or their guide dogs.
- Persons with impairment or disability should be evacuated with their supportive equipment and their guide dogs, if at all possible.
- In an emergency shelter a person should stay together with her assisting animal.

S – Supervision needs

are related to persons suffering from

- dementia, Alzheimer,
- depression,
- schizophrenia,
- gateway trauma, intensive fear, PTSD,
- disorientation in strange surroundings,
- brain injury,
- development impairment or
- serious emotional illness or impairment or difficulty to learn and to understand.

Additionally unescorted children have supervision needs.

T – Transportation needs

are related to persons, who cannot move independently with a vehicle because of

- kind of impairment or disability,
- complaints related to age,
- temporary injuries,
- poverty,
- addiction,
- missing disposal possibility or
- legal restriction.

Guidelines for municipalities in Germany to support development of personal disaster preparedness of persons with disability

In the study examples of good practice are explained.

In the guideline suggestions are made

- how to initiate development of personal disaster preparedness and self-help in the regional population (especially supportive networks and CoPs),
- how trainings should be conceived,
- what should be taken into account with regard to barrier-freedom and the particular functional needs of persons with disabilities,
- which kinds of information should be provided by the municipality and
- which improvements will be gained in municipalities when personal disaster preparedness and self-help among persons with disability or impairment are developed.

1. **Personal disaster preparedness** and **self-help** of persons with disabilities or impairments lower vulnerability in any case.
2. They contribute to empowerment.
3. Necessary are appropriate ways to develop them, for example in a Community of Practice (CoP) or a support team. Persons with impairment or disability become part of a horizontal oriented network with exchange and rising understanding of each other.
4. The model NEOBEHR and the tool KE-MUST support orientation during development of personal disaster preparedness.
5. Personal disaster preparedness of persons with disabilities and of supportive persons can save life, health and property in everyday emergencies and in disasters. Rescue teams and fire brigades are not always and everywhere just in time on the spot.
6. European nations and their municipalities have to recognize the necessity to develop personal disaster preparedness and self-help of persons with disabilities or impairments and to develop and put into action suitable measures.

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**Thank you very much for your attention
and your interest!**

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