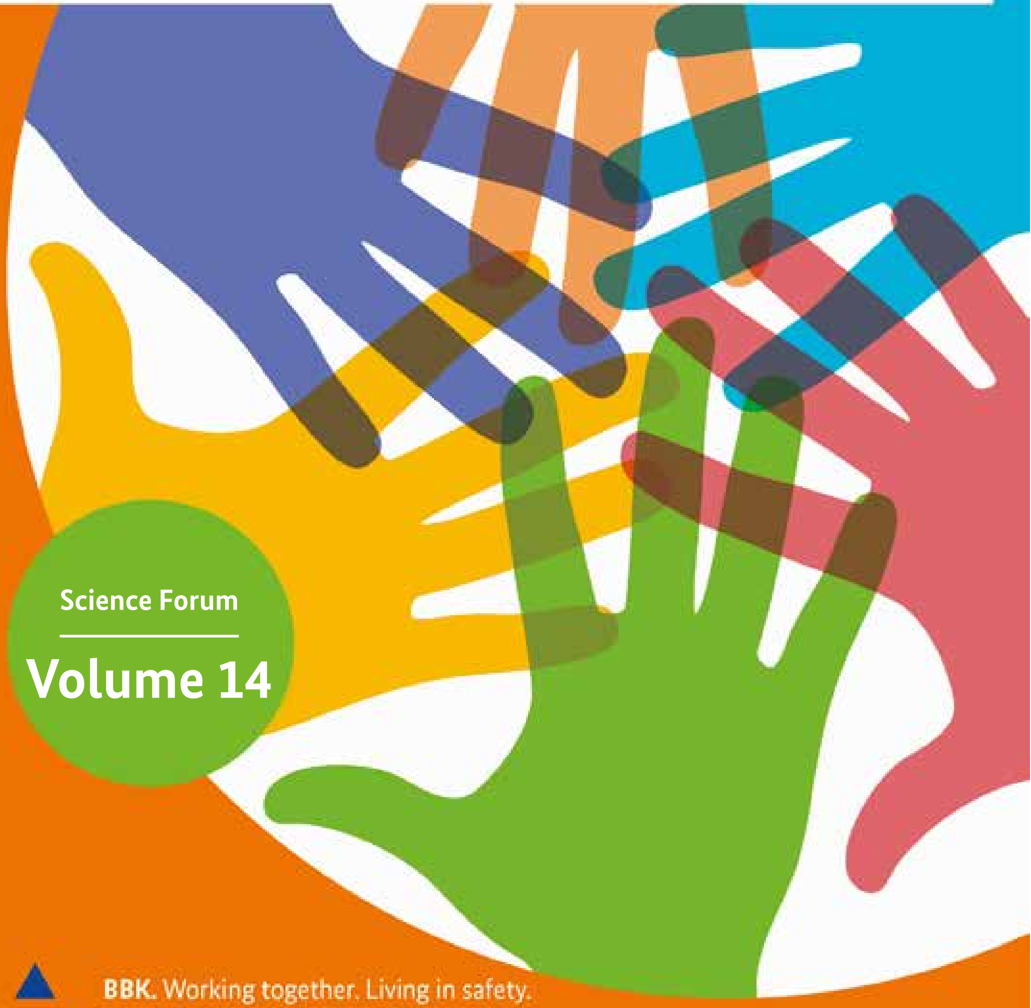
Federal Office
of Civil Protection and
Disaster Assistance

EUNAD
HELPING THE
DISABLED
IN DISASTERS

Assisting People with Disabilities in Case of Disaster

European Network for Psychosocial Crisis Management



Science Forum

Volume 14

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Federal Office
of Civil Protection and
Disaster Assistance

Assisting People with Disabilities in Case of Disaster

European Network for Psychosocial Crisis Management

Recommendations for Preparedness, Response and Recovery

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Co-financed by the European Commission
Grant Agreement Nº ECHO/SUB/2012/640917
Grant Agreement Nº ECHO/SUB/2015/718665/ PREP17

BBK. Working together. Living in safety.

Published by
Federal Office of Civil Protection
and Disaster Assistance
P.O. Box 18 67, D-53008 Bonn, Germany
Phone +49 (0)228 99 550-0
Fax +49 (0)228 99 550-1620
www.bbk.bund.de

Produced by
Druck- und Verlagshaus Zarbock GmbH & Co. KG
D-60386 Frankfurt am Main, Germany

Lectorate and Translation by
Kern AG, Sprachendienste, Bonn, Germany

Image credits
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ISBN-13: 978-3-939347-85-9

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Norwegian Centre for Violence and Traumatic Stress Studies
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Preface

Dear readers,

Psychosocial issues and tasks are by now a key fixture in the field of modern civil protection. Providing psychosocial assistance for people who have had to experience emergency situations, serious accidents, terrorist attacks or catastrophes is an integral part of crisis management and civil protection in Germany and its neighbouring European countries. Emergency response personnel are now specially trained with regard the psychosocial challenges involved in their line of work, and are provided with professional support to process the things that they experience during their deployment if required.

The quality of national and European psychosocial crisis management is ensured through basic research, the evaluation of deployments and training, as well as interdisciplinary and international cooperation and networking. Thus, the German

Federal Office of Civil Protection and Disaster Assistance (BBK), which is part of the Federal Ministry of the Interior (BMI), has organised numerous research projects focusing on the sociological issues of civil protection since 2000; either at German universities or carried out by the BBK itself. The BBK has worked together with partners from various specialist authorities, fire services, police forces, aid organisations, the Federal Agency for Technical Relief, churches, associations, societies, insurance companies and other organisations to evaluate scientific findings in the field of psychosocial crisis management, and has used these findings to develop quality standards that are in line with international guidelines and that have now been passed as binding within Germany.

Project work and collaboration with European partners represents a further key component of the BBK's quality assurance work in the field of psychosocial crisis management. Thanks to funding from the European Commission, Directorate European Civil Protection and Humanitarian Aid Operations – DG ECHO, the BBK has been able to run several projects in the field of social science.

The BBK's two most recent European projects – the second of which was also coordinated by the BBK and the results of which are now available and presented in the subsequent chapters – focused on the availability of psychosocial care and treatment for people with disabilities in the event of serious accidents, attacks or catastrophes.

The "European Network for Psychosocial Crisis Management – Assisting Disabled in Case of Disaster (EUNAD, 2013–2014)" project focused on people with sensory impairment. The follow-up project, entitled "European Network for Psychosocial Crisis Management – Assisting Disabled in Case of Disaster – Implementation (EUNAD IP, 2016–2017)", also dealt with the psychosocial crisis management available to people with physical and mental disabilities and looked at the development of pedagogical self-help toolkits for people with disabilities.

Research, training and workshops represented the milestones of the EUNAD projects. The research is based on a multi-method approach; training activities were carried out with different target audiences, and national and international workshops were held to provide a space for experts to share their knowledge. The "voices" of the disabled and their associations were integrated into all of these steps.

Both EUNAD projects picked up on the demand of the UN Convention on the Rights of Persons with Disabilities (2009) to guarantee the protection, safety and appropriate treatment of people with disabilities in situations of risk, including armed conflicts, humanitarian emergencies and natural disasters (article 11).

The present recommendations on inclusive psychosocial crisis management are on the one hand based on scientific studies on the situation facing people with sensory, physical and mental disabilities in emergency situations, their specific risk and protective factors, the consequences of the stress factors, and their needs. On the other hand, these recommendations have been developed and evaluated as part of an intense professional discussion with experts from the field of civil protection and, in particular, from the field of psychosocial crisis management as well as representatives from organisations representing people with disabilities.

The recommendations are based on the time course of traumatic stress response. This means we distinguish between preparedness, response, and recovery. Specifically we focus on the acute assistance provided in the first hours and days after the event, and medium- to long-term measures. The recommendations include "best practices" and incorporate national and European guidelines where available.

All of the recommendations are intended to clarify the needs of people with disabilities, to sensitise professionals and to stimulate the implementation of appropriate practical support. These steps are all necessary to make the notion of inclusive disaster management a reality.

The recommendations are aimed at professionals working in the field of psychosocial crisis management, including in acute, medium- and long-term assistance, risk and crisis communication; at emergency response personnel and at the authorities and organisations with security remits, as well as at those with political responsibility, and should be incorporated into the relevant training programmes.

But they also address people with disabilities and their carers, so that their potential for help and self-help can be better incorporated into disaster management.

These recommendations on inclusive psychosocial crisis management could not have been drawn up without technical expertise, a willingness to cooperate, mutual respect and openness, and a constructive sharing of knowledge and commitment to the cause.

I would like to thank all those involved from the partner organisations – the University of Innsbruck (Austria); Charles University, Prague (Czech Republic); Centre for Psychotraumatology Alexianer Krefeld GmbH (Germany); Norwegian Centre for Violence and Traumatic Stress Studies, Oslo (Norway); University of Southern Denmark, Odense (Denmark) – and all of the other organisations that collaborated on this project for their outstanding cooperation.

Together with my colleagues Claudia Schedlich, Frederike Albers and Volker Harks, as well as all of my colleagues at the BBK and partner organisations who were involved, I hope that you find these recommendations inspiring and that this volume provides you with new ideas and suggestions regarding your work in the field of crisis management.

Yours

Dr Jutta Helmerichs
Head of Psychosocial Crisis Management
Federal Office of Civil Protection and
Disaster Assistance

Bonn, December 2017

Convention on the rights of persons with disabilities

The EUNAD initiative targets the implementation and preparation of EU human rights-related assistance programs for people with disabilities who are survivors of disasters. In this context the statements of the UN Disability Rights Convention are crucial.

Preamble

The States Parties to the present Convention have agreed as follows:

Article 1

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Article 11

Situations of risk and humanitarian emergencies

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

Reference

https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

1

Introduction to EUNAD & EUNAD IP

Claudia Schedlich, Frederike Albers, Gisela Zurek

Over the past decade there has been a rise in numbers of large-scale disasters worldwide including in Europe. Complex natural and technical disasters as well as other man-made major incidents like terrorist attacks have increased both in frequency and intensity. Psychosocial crisis management (PCM) constitutes an essential component of overall crisis management for major incidents in the acute response phase and especially in mid-term and long-term support to improve individual and community recovery and resilience. PCM encompasses the implementation of adequate supply structures in preparation for large-scale incidents, the development of a comprehensive overview of the psychosocial situation, and the preparation and implementation of acute, mid-term and long-term psychosocial support provision.

The EUNAD (2013–2014) and EUNAD IP (2016–2017) projects are funded by the European Commission, Directorate Humanitarian Aid and Civil Protection-DG ECHO (Grant Agreement Nº ECHO/SUB/2012/640917 and Grant Agreement Nº ECHO/SUB/2015/718665/ PREP17). Following the statements of the UN Disability Rights Convention, the EUNAD initiative aimed to continue preparation and implementation of EU human rights-related assistance programs for disabled survivors of disasters. Concepts of psychosocial crisis management for people with disabilities were developed, evaluated and communicated. This was conducted on the basis of existing guidelines and the results of former EU projects, e.g. EUTOPA and EUTOPA IP (IMPACT Guidelines for Early Intervention and for uniformed services, Target Group Intervention Program (TGIP) for large-scale damage situations, more information at: www.eunad-info.eu). The beneficiaries and the cooperating and supporting authorities in the EUNAD initiative ensured a high standard of empirical evidence as well as a link to civil protection and operational authorities.

Partners in the EUNAD initiative are:

German Federal Office of Civil Protection and Disaster Assistance (BBK) (Coordinator EUNAD IP)
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www.bbk.bund.de

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www.uibk.ac.at/psychologie

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Prague, Czech Republic
www.ff.cuni.cz

Centre for Psychotraumatology Alexianer Krefeld GmbH (Coordinator EUNAD)
Krefeld, Germany
www.alexianer-krefeld.de

Norwegian Centre for Violence and Traumatic Stress Studies
Oslo, Norway

University of Southern Denmark
Odense, Denmark
www.sdu.dk/psykotrauma

Cooperating Partners and advisory board members in the EUNAD initiative are:

Group de Support Psychologique,
Luxemburg, Luxemburg, Charles Brück

Impact-National knowledge and advice centre for psychosocial care concerning critical incidents – Partner in Arq Psychotrauma Expert Group, Diemen, The Netherlands, Michel Dückers

Israel Trauma Coalition. Response and Preparedness, Jerusalem, Israel, Talia Levanon

Sociedad Española de Psicotraumatología y Estrés Traumatico (SEPET-D), Madrid, Spain, Francisco Orengo

Julius-Maximilians-University, Faculty of Human Sciences, Institute for Special Education, Chair of Special Education IV – Education for People with Developmental and Intellectual Disabilities, Würzburg, Germany, Thomas Spaett, Florian Rubenberger, Moritz Kastner

Cooperating Partners in the EUNAD initiative are:

Federal Association for special education, Würzburg, Germany

The Association of German Professional Psychologists; project group: emergency psychology for people with intellectual disabilities, Berlin, Germany

University of Cologne, Unit of Education and Rehabilitation for people with intellectual disabilities and severe impairment, Cologne, Germany

University of Cologne, Unit of Education and Didactics for people with hearing impairment, Cologne, Germany

German association of the deaf, Berlin, Germany

German Association of the blind and partially sighted, Berlin, Germany

Red Cross Austria, Innsbruck, Austria

Ministry of the Interior of the Czech Republic, Prague, Czech Republic

Police Presidium of the Czech Republic, Prague, Czech Republic

DG Fire and Rescue Service of the Czech Republic, Prague, Czech Republic

Standing Commitee on Crisis, Disaster and Trauma psychology EFPA, Brussels, Belgium

Section on Crisis, Disaster and Trauma Psychology, Prague, Czech Republic

The Czech Union of the Deaf, Prague, Czech Republic

Czech club of hard of hearing, ASNEP, Prague, Czech Republic

Centre for Childern with Hearing Impairment Tamtam, o.p.s, Prague, Czech Republic

National Council of People with Disabilities of the Czech Republic, Prague, Czech Republic

Nautis, the National Institute for Autism, Prague, Czech Republic

Social services center Tloskov, Tloskov, Czech Republic

Emergency medical service of the South Bohemian Region, section psychology, České Budějovice, Czech Republic

The youth organization of the Blind and partially sighted, Oslo, Norway

Norwegian Association of the Blind and partially sighted, Oslo, Norway

STATPED – National educational service, Holmestrand, Norway

The National federation for combined vision and hearing loss, Oslo, Norway

The Norwegian association of youth with disabilities, Oslo, Norway

The Norwegian center for hearing and mental health, Olso, Norway

The Danish Association of the Physically Disabled (DHF), Copenhagen, Denmark

Odense University Hospital, Odense, Denmark

The Special Hospital for Polio and Accident Victims, Odense, Denmark

European Union of the Deaf, Brussels, Belgium

European Blind Union, Paris, France

The main objective of the EUNAD initiative is to develop guidelines to integrate people with sensory, physical and mental disabilities in crisis management programs. To achieve this objective, EUNAD projects are subdivided into the following tasks: Evaluation, Research, Workshops, Recommendations, Training and Toolkits:

- *Evaluation:* Establishing networks with associations for people with disabilities; literature analysis of research about people with disabilities in psychotraumatology; analysis of European projects on inclusive disaster management.

- *Research:* Organisations and professionals working in disaster preparedness and response have insufficient knowledge particularly about trauma exposure, specific reactions and coping mechanisms, and the needs and demands of people with disabilities in disaster settings. Qualitative and quantitative studies on people with disabilities in general psychotraumatology and their psychosocial situation close this knowledge gap.

- *Workshops:* Extending the European network for psychosocial crisis management by including associations for people with disabilities in local workshops in each participating country and international workshops. National and international workshops ensure an intensive expert exchange, the evaluation of EUNAD recommendations and the dissemination of EUNAD results.

- *EUNAD Recommendations and EUNAD expert group:* Recommendations on psychosocial support of people with disabilities and PCM during and after disasters; building a EUNAD expert group that may serve as a precursor to a CECIS module development. Results from all tasks will be integrated into the EUNAD recommendations that serve as a basic framework agreement for the EUNAD expert group.

- *Training:* A substantial gap exists in psychosocial emergency care for people with disabilities in terms of secondary and tertiary prevention. This reveals the need for specific training and education for various occupational groups on psychosocial crisis management for people with disabilities. An essential part of the EUNAD initiative is to offer training activities for different vocational groups and the development of a training manual. Potential trainees are officials responsible for disability management, civil protection authorities, uniformed services, social workers and mental health professionals. Outstanding experts involved in the training activities will be one source of members for the EUNAD expert group.

- *Toolkits for schools and facilities for people with disabilities:* At the end of the first EUNAD project there was a strong call not only to focus on the improvement of skills among helpers but also to emphasize the strengthening of self-help competences among individuals with disabilities. EUNAD IP develops and evaluates educational toolkits for children and young people with disabilities in order to strengthen their self-help competences and to improve their preparedness in disaster settings.

2

Target Group Intervention Program

Robert Bering, Barbara Juen, Claudia Schedlich, Gisela Zurek

EUNAD and EUNAD-IP belong to the family of European-funded EUTOPA projects that have emerged against the background of the marked increase in natural disasters and major losses caused by technical failure or terrorism (e.g. natural disasters: www.emdat.com) over recent decades. Major losses mean that many people need care: those who were directly or indirectly affected, as well as their families, victims, bereaved persons, witnesses, the affected community and relief units. Aside from the medical treatment of those injured, the necessity of acute, mid-term and long-term care has been increasingly recognized and advanced in recent years. The need to incorporate psychosocial emergency care of those affected from the start is uncontested among experts. This topic is also finding increasing recognition in all European countries.

To mention a few examples, the 9/11 terrorist attacks in New York, the terrorist attacks in Madrid 2003, London 2004, in Turkey, Belgium, France and Germany 2016, or in Turkey, Great Britain and Spain 2017, flood disasters and the tsunami 2004/2005 in Indonesia and Japan (2011) have demanded immediate response as well as mid- and long-term strategies. Each event develops its own dynamic and requires a great deal of commitment, creativity, flexibility, and resilience from helpers. “The heterogeneity of traumatic events and their aftermath defies any specific guidelines, and there is a need for flexibility of interventions and adaptations to specific circumstances.” (Hobfoll et al., 2007, 284)

In the actual case of a disaster, mid- and long-term stress reactions must be expected in victims, witnesses, relatives and the bereaved, and rescue workers. In this case it is the collective challenge to all professional helpers to ameliorate suffering, support victims and assist them in returning to their normal lives. If we want to sensibly integrate psychosocial crisis intervention programs in emergency preparedness, response and recovery, we are dependent on minimum standards that take into account the course of stress disorders. The main question is: according to current research, which crisis intervention measures have proved useful in acute, mid- and long-term aftercare in curtailing the risk of post-disaster stress disorders?

Uncertainty regarding effectiveness and goal orientation are evident in the conception and conduct of crisis intervention measures in acute, mid- and long-term aftercare (cf. Bering, 2011; Bering et al., 2006). “No evidence-based consensus has been reached to date with regard to effective interventions for use in the acute and the mid-term post mass trauma phases.” (Hobfoll et al., 2007, 284). To cover this topic, we would like to introduce the disaster management cycle and describe the basic strategies of the Target Group Intervention Program. Moreover, we link this knowledge to the need for inclusive disaster management for groups with special needs.

2.1 Disaster phases and inclusive disaster risk reduction

2.1.1 Phases of action

How to define a disaster? A disaster is characterized by three key features: (1) a sudden beginning, (2) the collective experience of being affected by the disaster, and (3) a collectively great degree of threat and destruction. After a disaster

- a large number of people are affected directly and indirectly,
- a large number of people need medical treatment and psychosocial support,
- there are great physical, social and mental challenges,
- regional emergency medical services – including emergency psychosocial capacities – do not suffice,
- various occupational groups are involved and need to be coordinated (e.g. fire brigade, rescue services, police, military, emergency medical services, psychosocial acute help, physicians, psychologists and psychotherapists, political policy-makers),
- central leadership and organizational structures for acute, mid- and long-term care are necessary,
- the required assistance is highly complex,
- capacities for mid- and long-term care are usually overstrained; resources may have been destroyed,
- security in one's own surroundings may no longer exist; entire areas or regions are affected,
- trust in public officials is put to the test and easily upset.

However, we have two options in disaster management. First, we can be prepared; second, we can respond. In the Hyogo framework, (2005–2015) building resilience of nations and communities has been the priority (see https://www.unisdr.org/we/coordinate/hfa) in disaster preparedness. In this context the term *action* indicates that crisis management is not just about reaction/response and recovery, but that state-of-the-art crisis management should also largely happen before a (possible) event (see Othman & Beydoun 2013). Disasters do not happen in a social vacuum; they are embedded in time and space (Barton, 2005). When they happen they interfere with a living, dynamic psycho-social system. Therefore, a chronological view on crises sooner or later turns into a reflexive perspective (see Alexander, 2005), along the lines of *after a crisis is before a crisis*. The form of this reflexive perspective usually is one of a – or better the – "Disaster Management Cycle" (see e.g. Challen et al., 2012).

Among many other institutions and organisations, the US Federal Emergency Management Agency (FEMA) uses and promotes a four-stage cycle. This cycle of disaster risk reaction includes (1) mitigation (2) preparedness (3) response, and (4) recovery. Terminology and some details differ, depending on organisations, countries or other users/promoters, but the main thoughts are sufficiently summarised in the scheme below.

Figure 1: Adapted from Twigg, (2004)
Source: stg.allindiary.org/documents/2014/03/disaster-cycle.pdf

1. “Mitigation is the effort to reduce loss of life and property by lessening the impact of disasters. Mitigation is taking action now – before the next disaster – to reduce human and financial consequences later (analysing risk, reducing risk, insuring against risk).” (FEMA) Mitigation includes efforts to prevent or decrease the effects of man-made or natural disasters by the assessment of threats to a community. These assessments include the likelihood of an attack or disaster taking place. We suggest adding the long-term effects of disasters on communities or parts of communities regarding their enhanced or reduced resilience.

2. Preparedness includes planning, resource allocation, and training of individuals. This phase also includes disaster response exercises which help people practise what to do if a disaster occurs.

3. Response includes public donations, incident management, coordination, search and rescue operations, damage assessments, handling of fatalities, etc.

4. Recovery involves cleaning, reinstitution of public services, rebuilding of public infrastructure, and all that is necessary to help restore civic life, including disaster assistance and crisis counselling.

2.1.2 Disaster risk reduction and inclusion

In the recent Sendai framework (2015–2030) the focus is laid upon disaster risk reduction. Priorities for action are: understanding disaster risk, strengthening disaster risk governance, investing in disaster risk reduction for resilience, and investing in disaster preparedness and to build back better in the recovery and rehabilitation phase (see http://www.unisdr.org/we/coordinate/sendai-framework).

Regarding mental health and disability, the Sendai framework expert group recommends the prioritizing of mental health and disability

(http://pubdocs.worldbank.org/en/619761454942779225/Mental-Health-Well-being-Disability-A-New-Global-Priority.pdf[1]):

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[1] United Nations: Mental Health, Well-being and Disability: A New Global Priority. Key United Nations Resolutions and Documents. 2015

1. Ensuring that disaster risk reduction (DRR) policies and programs always include mental wellbeing and disability as a priority. The international community needs to include mental wellbeing and disability as a priority theme in all DRR frameworks. Humans are emotional beings; their mental health and psychosocial wellbeing play key roles in resilience, recovery and reconstruction. Integration of mental health and psychosocial wellbeing and the rights of persons with mental or intellectual disabilities makes DRR more effective, resilient and robust.

2. Adding targets for and indicators of mental health and psychosocial wellbeing in DRR. The Hyogo Framework for Action 2 should include mental health and psychosocial wellbeing as transformative new targets and as indicators to represent subjective well-being towards optimizing resilience of people and society.

3. Including persons with mental or intellectual disabilities in DRR: Disability-inclusive DRR should always ensure the inclusion of persons with mental or intellectual disabilities. Persons with mental or intellectual disabilities need to be included in disability frameworks and movements; they cannot be excluded from the benefits created by the progress made in DRR.

4. Developing guidelines on mental well-being and disability in DRR: Practical global guidelines on mental wellbeing and disability in DRR should be developed in the United Nations system.

5. Including mental well-being and disability in all efforts related to peace and security, development and human rights: mental well-being and disability need to be mainstreamed in existing work to advance peace and security, development and human rights, including the upcoming Post-2015 Development Agenda, to optimize resilience in response to disasters.

6. Establishing a multi-stakeholder working group on mental wellbeing and disability in the United Nations system: A multi-stakeholder focus group on mental wellbeing and disability should be established as part of the stakeholder group for DRR and sustainable development in the United Nations system.

In the context of assisting people with disabilities in case of disaster we must differentiate between disabilities caused by stress response syndromes and disabilities caused by hearing, visual, motor or mental impairment prior to the disaster. In the first case we deal with secondary prevention of physic disorders; in the second we address the issue of inclusive disaster management and the special needs of people with disabilities.

2.2 Target Group Intervention Program measures

The Target Group Intervention Program (TGIP) was designed for secondary prevention of chronic stress response syndromes in the response and recovery phases. The idea of TGIP is to identify those who are at risk of developing psychic disorders and to conduct a range of measures including psychological first aid, psychosocial acute and mid-term support and if necessary, therapy and rehabilitation. This might be necessary if survivors are at risk of developing stress response syndromes with long-lasting mental disabilities.

TGIP focuses on individual mid- and long-term aftercare measures and aims to connect to early intervention concepts as seamlessly as possible. We investigate which measures are efficient at which point of the potentially traumatic process during and after a disaster. It is beyond dispute that people in an existentially threatening and impairing situation need support. One goal of efficient psychosocial aftercare measures must therefore be the minimization of stress response syndromes due to traumatic stress. How can we conduct successful secondary prevention? In the past, the main aim and research focused on prevention of posttraumatic stress disorder (PTSD). Today's state of knowledge, however, is that the impact of stress after a potentially traumatic experience is clearly more complex, so that an empirical focus on PTSD does not do justice to the scope of stress reactions. Acute stress reaction (ICD: F 43.0), adjustment disorder (ICD: F 43.2), and posttraumatic stress disorder (PTSD – ICD-10: F 43.1) are some of the psychological impairments, along with comorbid disorders in cases of long-term progress (e.g. depression, anxiety disorders or somatization disorders as well as addictions). However, our approach in EUTOPA and EUTOPA-IP addressed the question of how the functioning of those affected is impaired; we consider how to include the needs of survivors with visual, hearing, motor and intellectual disabilities.

We distinguish between acute response and mid- and long-term intervention. To achieve a risk group-related response, we have developed the TGIP, a secondary preventive concept of individual psychosocial aftercare. Its purpose is to prevent the development of mid- and long-term stress disorders following critical incidents. Planning an intervention strategy in the scope of TGI in cases of major losses is geared to the procedures of TGI with victims of violence (Fischer et al., 1999) and soldiers of the German armed forces (Bering et al., 2003) and is adjusted to the logistic and structural conditions of major losses. The fundamental differences between the concept of TGI and other early intervention concepts are:

1. a screening instrument developed for the sole purpose of early detection of persons at risk (Cologne Risk Index – CRI)

2. the distinction between risk-independent and risk-dependent intervention measures

Early detection of risk factors that promote the development of stress disorders plays a key role in this concept. To assess the risk, an appropriate questionnaire, i.e. a checklist, is used that enables prognostic inferences about the coping progress. After assessing each risk profile, individually customized interventions can be suggested and initiated.

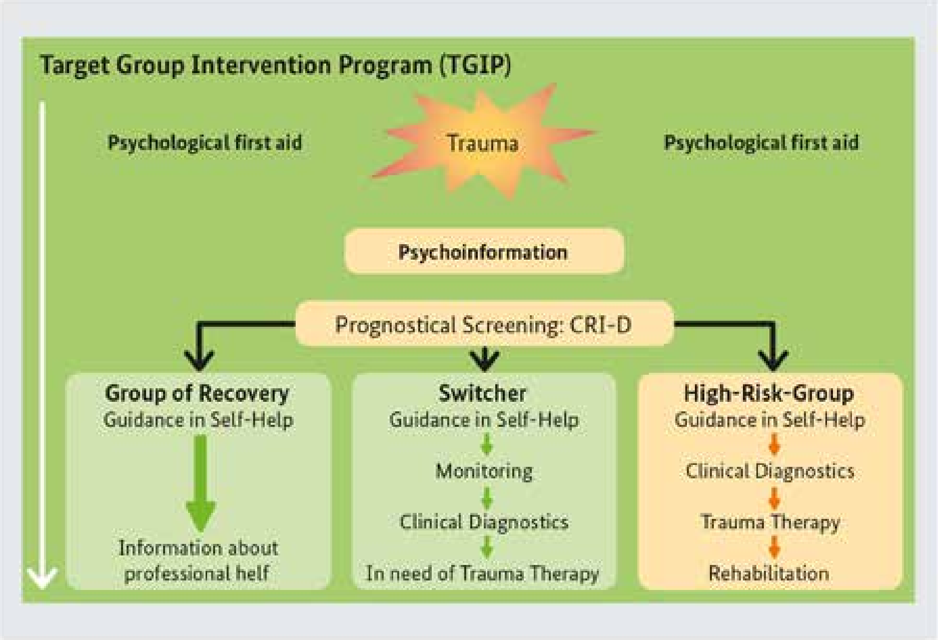


Figure 2: Standard flow chart of target group intervention

Figure 2 shows that TGIP distinguishes between measures that are offered regardless of the individual risk profile of the persons concerned and measures that are customized to the individual risk profile (Schedlich et al., 2003). We assume that the early detection of at-risk persons using the CRI and the customisation of intervention measures enable economical planning that can guarantee the ideal support of even large numbers of affected persons when staffing levels are low. It is emphasised that the reaction to extremely stressful experiences should not be viewed as pathological or as the pre-stage to pathology. Many people temporarily suffer from normal stress reactions and mainly need support in re-establishing resources and returning to normality, not traditional diagnostic procedures or clinical treatment (Hobfoll et al., 2007).

The basis of planning interventions for individual psychosocial aftercare is

1. orientation on the time criterion, to the process model of traumatic stress

2. orientation on the risk profile of affected persons, risk evaluation using the CRI (cf. Bering et al., 2008)

The phase boundary is difficult to pinpoint in many disaster situations and in the event of large numbers of injured persons because of the continuous violence, sustained shock and lack of aid. Furthermore, it is often difficult to create a clear boundary between an acute situation and a post-situation period; as a result, acute measures may overlap with intermediate-term aftercare.

The risk profile for developing a stress disorder can only be assessed within the course of the process. This poses the question of which promising intervention measure should be conducted at which point in time. The question also arises as to which interventions are appropriate for the different groups. To find answers to these questions, the axis of time in fig. 2 has been divided into the acute phase (A), the transition phase (B) and the impact phase (C). In addition, the standard modules of target group intervention (see fig. 2) have been divided into risk-dependent and risk-independent modules of target group intervention (see fig. 3).

In case of major losses and disasters, there are three condition criteria that influence the planning of an intervention in each case and that are distinctive to TGI:

1. At what point during the traumatic process does the intervention come into action?

2. Under what network conditions is TGI implemented?

3. How many people are affected by a critical incident?

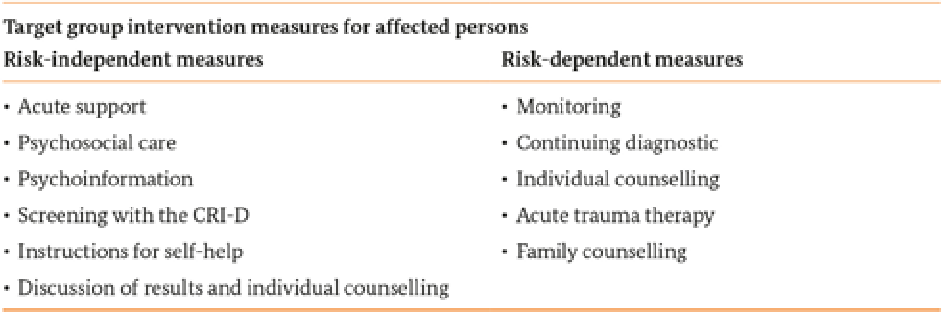
The number of affected persons and the availability of professional helpers are pivotal to the setting (individual or group setting) and the extent of help possibilities. The objective is to offer adequate help to as many affected persons as possible to prevent long-term disorders, while making ideal use of staff capacities. The psychosocial aftercare for relief workers must also be optimised to prevent psychological after-effects and sustain work capability. It is necessary and sensible to provide a target group-oriented intervention strategy so that affected persons as well as relief units are neither over- nor under-accommodated with supportive measures.

The type of intervention is dependent upon the course of the process. Acute care is central to phase A. Phase B describes the length of time between shock and early impact. Psychoinformation and screening with the Cologne Risk Index are key measures in phase B. Phase C leads into the graduated planning of intervention for the self-recovery, switch and risk groups.

The acute care of affected persons through primary safeguarding and psychological first aid are among the risk-independent measures (phase A). Only after the shock phase has subsided can psychoeducative information geared towards the CRI, among other things, be implemented. Discussion of the results and brief counselling conclude the passage into the early impact phase (B).

Monitoring, continuative diagnostics, individual counselling, family counselling and acute trauma therapy are among the risk-independent intervention modules. These interventions are allocated to phase C on the time base. Thus, the helper orients their choice of intervention by the time base and the victim's risk profile. This means that we must disassociate ourselves from the somatological paradigm of emergency medicine, to enable accessible diagnostics (psychological triage) at the place of the incident and in immediate hospital treatment respectively. While the training of emergency physicians and paramedics aims to enable them to recognize and administer life-saving interventions at the place of the incident, if possible, therapists and first aiders must be able to survey the complete course of process and prevent the chronification of a stress disorder during a psychosocial crisis intervention program. The somatic paradigm of emergency medicine thus cannot be translated one-to-one to crisis intervention programs. In the following we will specify the intervention modules of the target group intervention program in order to characterize it more precisely. Interventions during the acute traumatic situation, the impact phase and in the traumatic process adhere to the guideline: as much as necessary, as little as possible.

In planning an intervention, it is important to distinguish between basic prevention measures for all persons affected and tiered measures that depend on the individual risk profile. In content the emphases vary depending on the point in time of the intervention, i.e. whether interventions are offered in the context of the acute situation, the impact phase or the traumatic process. The planning of the intervention in the TGI context is described in the following chronological order, whereby we distinguish between risk-dependent and risk-independent measures.



Target group intervention measures for affected persons	
Risk-independent measures	**Risk-dependent measures**
• Acute support	• Monitoring
• Psychosocial care	• Continuing diagnostic
• Psychoinformation	• Individual counselling
• Screening with the CRI-D	• Acute trauma therapy
• Instructions for self-help	• Family counselling
• Discussion of results and individual counselling	

Figure 3: Target group intervention measures for affected persons

Before tiered, risk-dependent interventions become effective, basic psychologically relevant measures, aside from medical treatment, must be implemented within the scope of secondary prevention. These measures include acute care of those affected by providing primary safety and psychological first aid. Psychoeducation and screening with the CRI, discussion of the results, brief counselling and instructions for self-help should not be implemented before the initial shock phase has worn off.

2.2.1 Risk-independent measures in TGI

Acute care

In the acute situation and immediately thereafter, the following measures are part of the primary care of those affected, independently of their risk profile:

- Medical treatment
- Safeguarding and protection for those affected
- Ensuring that all primary needs (thirst, hunger, warmth, hygiene) are met

- Distancing from the place where the event happened
- Information about the event (cause, extent)
- Information on the whereabouts of family members
- enabling contact with other family members
- grief support
- information about continuative help
- offers to talk

Medical care is always a priority when dealing with major losses. Acute psychological care, however, is a key part of care and affects the way victims deal positively with what they have experienced. The priorities are building relative safety and primary care as well as clear information. Another paramount concern during this stage is the recreation of social connections (Hobfoll et al., 2007). Information is an existential human need – to know whether loved ones are unharmed and well. Transparency and to an extent knowing the reasons for courses of action (medical measures, necessary separation of families during medical treatment, shelter possibilities, contacts) are helpful in order to counteract the loss of control. Questions that those affected have about the situation are not ignored but answered to the best knowledge and correctly, since the victims have a pronounced desire to know as much as possible at this time. Information must be presented in a brief and clear manner since the intake capacity is extremely limited in the shock situation.

Transparency and calming attention are internalised positively in this situation (Bengel, 2007; Lasogga & Gasch, 2000). Further measures, such as psychoeducation and in-depth instructions for self-help etc. are not indicated at this early stage and do not promise lasting preventive effects.

Psychosocial support measures in the latency phase and after (phase B and C)

Following the acute situation, those affected often have requirements regarding the safeguarding of their daily lives and material resources, as well as safeguarding the social network, depending on the situational context. The main concerns here are providing appropriate counselling and support opportunities (e.g. regarding financial support, legal clarification, finding missing persons), help with dealing with public authorities and giving those affected information about these opportunities. Depending on the level of damage to the person's life context, this support may be necessary over a long period (months to years). Victims of terrorist attacks, for example, frequently need long-term support with legal actions against the terrorists. In extreme cases these legal actions can go on for decades, like after the bombing in Bologna in 1981. Disputes over monetary compensation, e.g. after technical disasters, are also often linked to long preliminary proceedings.

Funeral services and commemoration services also need to be organized and supported. Affected persons may eventually need support in creating a memorial.

Ensuring that the above-mentioned support is provided as seamlessly as possible is one of the goals of psychosocial aftercare after disasters.

The psychological aftercare measures mentioned in the following text focus on individual secondary preventive support in dealing with traumatic experiences and the reduction of stress disorders, as well as the prevention of long-term stress disorders.

After the initial shock reaction has subsided, initial psychoeducative, informative measures can be implemented. If psychoinformation is not possible at that stage, e.g. due to deployment issues or for medical or personnel reasons, it can be also offered at any later point in the course of the traumatic process. More specific descriptions of the content and implementation of psychoeducational measures can be found in volume III (cp. Zurek et al., 2008).

After psychoinformation, screening with the CRI-D is implemented in order to gain a differentiated assessment of the individual risk profile. Depending on the result of the CRI assessment, those affected are assigned to the self-recovery, switchers or risk groups. The assignment of affected persons to the risk groups depends on the level of points in the risk index and is the basis for target-oriented, continuative intervention. The results of the assessment are **always** and **only** disclosed in individual contact. A differentiated description of the CRI for use in case of a disaster can be found in Bering et al. (2008).

2.2.2 Conclusion

What does TGIP mean for our topic of disability management in crisis intervention programs? We conclude that risk factor management for people with disabilities is challenging and data on specific risk factors are not available. However, we point out that time course models, a flexible approach and the relation of disaster response and preparedness affect our research strategies and basic recommendations (Bering et al., 2015, Gerwinn et al., 2016). Our booklet is a first step towards an inclusive TGIP. However, we have no tools to verify different levels of risk in our groups with special needs. Our book summarizes literature surveys (Chapter 3), experiences in practice (Chapter 4) and research in the field of disability management (Chapters 5–8). Finally, we have formulated key recommendations (Chapter 9). According to the UN Convention on Rights for Persons with Disabilities, strategies for inclusive disaster management must be defined.

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3

Analysis of literature and guidelines: summary

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Research analysis shows that there are substantial differences around the world in the vulnerability and resources of individuals with disabilities in the wake of a disaster or an emergency. In industrialized societies the inclusion of people with disabilities is gaining importance in disaster and emergency management concepts. Nevertheless, the needs of individuals with disabilities in a disaster or an emergency are largely not met at the moment (Ha, 2016). In less developed countries efforts are also being made to address the needs and requirements of people with disabilities. People with special needs often face greater barriers in case of emergency or disaster than people without disabilities (Paudel et al., 2016). People with pre-existing disabilities are more likely to develop co-morbidities after a disaster (Reinhardt et al., 2011). Research also shows that individuals with special needs recover more slowly and less well from disasters. Although their needs after a disaster are similar to those of people without disabilities, their recovery may be more complicated and they require additional support (Stough, Sharp, Decker & Wilker, 2010). Disasters or emergencies may have negative long-term psychological effects on people with impairments. Findings indicate that individuals with disabilities resulting from a disaster have an increased risk of mental health problems and PTSD (post-traumatic stress disorder) symptoms after a disaster (Zhou et al., 2015). To sum up, we can say that despite previous efforts, disaster and emergency response is still not disability-inclusive. The literature on the needs of people with disabilities is limited. Further research is necessary to provide better knowledge and awareness of the requirements of people with disabilities in the event of a disaster or emergency. This could result in their vulnerability being reduced and their resources being strengthened.

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3.1

Analysis of national and European projects focusing on psychosocial support for disabled citizens in critical incidents and disaster situations

Claudia Schedlich, Gisela Zurek

Over the last 15 years, the European Commission (EC) has funded various projects aiming to develop and optimize quality standards and multidisciplinary guidelines (MG) in psychosocial crisis management (PCM) as well as to foster networking of the institutions and professionals involved. Beside general guidelines on PCM, some projects focus on different aspects:

- the needs and demands of specific sections of the population, e.g. children, migrants, older citizens
- PCM in cases of terrorist attacks
- focusing on professionals; the target groups are e.g. uniformed services and hospital staff

- PTSD, early intervention, mid- and long term psychosocial aftercare
- the development of victims' associations
- building up networks

Projects and Guidelines (European and international)

Psychosocial Crisis Management in general

- Psychosocial Support in Situations of Mass Emergency European Policy Paper (2001); Ministry of Health, Belgium and European Experts
- EU Exchange of Experts in Civil Protection (since 2002) under the head of the German Federal Agency for Technical Relief (THW)
- Working Together to Support Individuals in an Emergency or Disaster (2002–2004); British Red Cross (www.gov.uk/government/publications/working-together-to-support-individuals-in-an-emergency-or-disaster-british-red-cross-report)
- Informed. Prepared. Together – IPT (2008–2009) under the coordination of the European Red Cross, (www.redcross.org.uk/About-us/Media-centre/Press-releases/2009/July/Informed-Prepared-Together-Red-Cross-and-EU-promote-community-resilience-to-crisis)
- NATO & OTAN: Psychosocial care for people affected by disasters and major incidents: A Model for Designing, Delivering and Managing Psychosocial Services for People Involved in Major Incidents, Conflict, Disasters and Terrorism: Draft Nonbinding Guidance (2008), (http://www.coe.int/t/dg4/majorhazards/ressources/virtuallibrary/materials/Others/NATO_Guidance_Psychosocial_Care_for_People_Affected_by_Disasters_and_Major_Incidents.pdf; www.coe.int/t/dg4/majorhazards/ressources/virtuallibrary/materials/UK/Principles_for_Disaster_and_Major_Incident_Psychosocial_Care_Final.pdf)
- ISAC Guidelines on Mental Health and Psychosocial Support in Emergency Settings (2007)

- Psychological Support for survivors of disaster (2008)

- Building Resilience Amongst Communities in Europe (embrace) – project under the coordination of the Université catholique de Louvan (UCL) Belgium, and the University of Northumbria at Newcastle (UoN), United Kingdom (2011–2015), (http://www.embrace-eu.org/)

- Operationalizing Psychosocial Support in Disasters (OPSIC), EU FP 7 Project (2013–2016) under the coordination of the IFRC reference center for psychosocial support (http://cordis.europa.eu/project/rcn/108235_en.html)

Psychosocial Crisis Management in cases of terrorist attacks

- Citizens and Resilience (2005–2007); Stichting Impact, the Netherlands, (www.impact-kenniscentrum.nl)

- Sharing European Resources for Victims of Terrorism – EURESTE (2005-2006 and since 2007); Red Cross, Belgium, (www.eureste.org)

- Developing Standards for Victims of Terrorism (2006–2008); Intervict University, Catholic University

- Victim Support; Forum for Restorative Justice, The Netherlands

- Prevention of longlasting Disorders for Victims of Terrorist Attacks – PLOT (2005–2007); University of Cologne, Centre for Psychotraumatology, City of Cologne, Germany, (www.plot-info.eu)

Development of victims associations

- V-Net I and V-Net II: Network for victims of terrorism initiated by the Asociación de Ayuda a las Victimas del 11 M, Madrid/ Spain

- SURVIVORS – Joint Response to Loss and Survival in Terrorism (2007–2009); City of Cologne, Germany; City of Bologne, Italy; Asociación 11M – Affectados Terrorismo, Madrid/Spain; Westminster Council, Social Services, London/UK

- European Network for Affected by Terrorism – ENAT

Professionals, e.g. uniformed services or hospital staff

- Reinforce Rescuers' Resilience by Empowering a well-being Dimension – RED (2007–2009); Italian Red Cross, Regional Commitee of Piemont, Red Cross-France, Universities of Turin and Pavia, Regione Autonoma delle Valle d'Aosta, Fonda Formación Euskadi, Impact, (www.cri.piemonte.it/progetti/red)

- Improve the Preparedness to give Psychological Help in Events of Crisis – IPPHC (2007–2009); Ministry of Heath, Hospital Camillo Forlanini, Italy, European Experts, (https://webgate.ec.europa.eu/chafea_pdb/health/projects/2006212)

- Psychosocial support for civil protection forces coping with CBRN – CBRN Incidents and PSS (2011–2013); German Federal Agency for Technical Relief (THW), Federal Office of Civil protection and Disaster Assistance (BBK), Centre for Psychotraumatology, Germany; Impact, The Netherlands; Direcctión General de Protección Civil y Emergencias Ministerio del Interior Gobierno de España, Spain, (http://www.bbk.bund.de)

Building up a network

- European Network for Traumatic Stress – TENTS and TENTS-IP (since 2007); The Netherlands, Germany, Portugal, United Kingdom, Finland, Sweden, Norway, Turkey, Spain, Croatia, (https://www.estss.org/index.php?s=TENTS)

Specific aspects, e.g. PTSD, early intervention, mid- and long term psychosocial aftercare, specific target groups

- Nice-Guidelines: Posttraumatic Stress disorder (PTSD). The management of PTSD in adults and children in primary and secondary care (2005)

- The Tents Guidelines for psychosocial care following disasters and major incidents (2008)

- Dutch Guidelines – Psychosocial Support for Uniformed Rescue Workers (2010)

- European Guideline for Target group Oriented Psychosocial Aftercare in Cases of Disaster – EUTOPA and EUTOPA-IP (2007–2011), (www.eutopa-info.eu)
- Multidisciplinary Guideline for early psychosocial interventions after disasters, terrorism and other shocking events (2007)
- Enhancing disaster management preparedness for the older population in the EU (PrepAGE) (2014–2016) under the coordination of the Austrian Red Cross, (www.prepage.eu)

From these international and European projects and guidelines we summarize the following remarks:

- The different projects advance psychosocial activities in the European countries involved. They enhance national, European and international networking.
- The interconnectedness of relevant professional groups, institutions and political authorities can only occur on a national level.
- The guidelines developed can be used as a basis to implement PCM in the European member states.
- The individual projects don’t advance an overall European process and conceptual framework for PCM. There is still no integrative and consensual process.
- The EU-funded projects on psychosocial support and psychosocial crisis management (PCM) offer recommendations on early intervention. A framework for mid- and long term interventions is not well integrated.
- A common terminology on measures and interventions of psychosocial crisis management has yet to be generated. In addition, measures of mid- and long-term psychosocial aftercare have to be integrated in the MG of the EC.

Following the overview and these remarks, we would like to outline our main question:

> To what extent are the demands and needs of people with disabilities considered?

The main question in analysing the guidelines and project results is whether they focus on the specific needs of people with disabilities in preparedness, in the acute phase or in the mid- and long-term aftercare in larger incidents.

The World Health Organization (WHO) estimates that between 7 and 10 percent of the world's population live with disabilities. People with disabilities are often literally and programmatically "invisible" in different assistance programs. In Europe in 2015 an estimated 17.5% of the population are older than 65 and 4.7% older than 80 years old. The prevalence of physical, hearing, visual and cognitive impairment increases exponentially with age.

Most of the surveys of guidelines cited in this report show a lack of specialized concepts for practical care, health care and psychosocial support and counselling services for people with disabilities in disaster situations. In the field surveys there were only few specialized doctors, no specialist therapy and a lack of specialized medicines and treatments. Moreover, there were generally no referrals to specialist services.

Therefore, it is necessary to take into account the statements on vulnerability:

- Populations at risk include people who have substantial pre-existing healthcare problems and needs, e.g. people who have impairments.

- Evidence shows that people in these groups are more vulnerable than the general population to suffering the welfare, psychosocial and mental health effects of disasters.

- Impaired individuals are particularly vulnerable during the preparedness and response phases to disasters.

- Factors that mediate or moderate children's recovery after critical incidents include disabilities.

3.1.1 What should we do? Demands

A disaster plan should also consider and plan for the needs of special groups, such as those with sensory, cognitive or physical impairments, those who are mentally ill, and frail elderly people. This requires planning and rehearsal, and the use of tools such as targeted mapping of local populations so that special groups may be accommodated within universal major incident plans. The key in responding to special populations lies predominantly in being aware of them and their particular needs. It is important to provide information to the affected population on the emergency, relief efforts and their legal rights.

The wide occurrence of special populations – including people with disabilities and elderly people – emphasizes the importance of:

- planning and coordination to meet the needs of special populations,
- understanding the cultural, ethnic and socio-economic factors involved in working with special populations,
- training professionals from diverse fields: community workers, uniformed services and healthcare staff,
- promoting public health activities and prevention measures,
- taking active steps to promote coping within communities,
- being aware of cultural expression, rituals and ceremonies,
- designing services of adequate duration,
- planning adequate rehabilitation services,
- collecting, verifying and disseminating information with respect to the persons involved in the event.

3.1.2 Results and Outlook

We conclude that there are specific questions that lead to further aspects regarding the special requirements of people with disabilities in large-scale damage situations:

- Do people with disabilities have special needs in large-scale damage situations?
- Are there specific risk factors for the development of trauma-related disorders?
- Are there specific resilience factors in the community of people with disabilities?
- Which groups have no access to media due to disability (e.g. people with visual or hearing impairments)?
- What methods may need to be developed for dissemination of information to reach out to such people?

Further research is required in this field. It would be a big step forward if international and European projects were aware of the specific needs and demands of people with disabilities. This would optimize the implementation and preparation of EU human rights-related assistance programs for disabled survivors of disasters based on the UN Convention on the Rights of Persons with Disabilities.

4

Survey of psychosocial emergency care and uniformed services on their experiences with people with disabilities

Claudia Schedlich, Gisela Zurek

As part of the EUNAD project (2013–2014) the Federal Office of Civil Protection and Disaster Assistance, section Psychosocial Crisis Management, conducted a survey to answer the following questions:

- To what extent do suppliers of psychosocial acute help come into contact with people with visual and hearing impairment and other impairments in their missions?
- To what extent are the special needs of people with sensory impairment and other disabilities part of these suppliers' education?
- How well prepared do they feel to fulfil these tasks?
- What needs and demands do they see for future actions?

One main supplier of psychosocial acute help in Germany is the predominantly voluntary emergency pastoral care. A questionnaire was developed and dispatched to almost all emergency priests in Germany through their co-ordinators in the federal states.

The sample

71 questionnaires were evaluated altogether. The overall return rate was 15%.

- 69% of the respondents were male, 31% female.
- 51% worked in a uniformed service organization, 49% did not.
- 92% worked in psychosocial acute help, 8% did not.
- 51% of the respondents acted in a double function, as a psychosocial acute helper and as a member of a uniformed service organization.
- 74% of the respondents had worked for a period longer than 10 years.
- 32% worked in a major city, 29% in a medium sized city, 14% in a small town, and 24% in rural areas (1% did not specify).

Experiences in missions with people with sensory impairment

About 70% of the respondents indicated that when on missions, they have never had contact with people with visual and hearing impairments or people with multiple disabilities.

- 32% of the respondents have had contact with people with blindness and visual impairments when on missions, 67% have not (1% did not specify).
- 30% of the respondents have had contact with deaf and hard-of-hearing people when on missions, 69% have not (1% did not specify).
- 22% of the respondents have had contact with people with multiple disabilities when on missions, 76% have not (2% did not specify).
- 36% of the respondents reported domestic emergencies with people with disabilities, 16% evacuation, 14% road accidents, 11% fire, 10% violence, and 13% other.

These results suggest that mission situations with people with disabilities are rare and not part of everyday routine. This might explain why the topic is underrepresented in the relevant curricula.

Training

Almost all respondents (96%) have completed continuing education in psychosocial acute help. However only one quarter of respondents covered the topic “People with sensory impairment” during their education. 76% reported less detailed or no information about deaf and hard-of-hearing people, 77% reported less detailed or no information about people with visual impairments and blindness.

- 96% of the respondents have had comprehensive education in psychosocial acute help, 4% have not.

- 25% reported that the topic “people with sensory disabilities” was a topic during their education, 25% did not (2% did not specify).

- On the question of how well their education prepared them to deal with deaf and hard-of-hearing people, 47% answered “less prepared”, 29% “not at all”, 18% “well prepared”, 6% “very well prepared”.

- On the question of how well their education prepared them to deal with people with visual impairments and blindness, 59% answered “less prepared”, 18% “not at all”, 17% “well prepared”, 6% did not specify.

- On the question of how well their education prepared them to deal with people with multiple disabilities, 59% answered “less prepared”, 23% “not at all”, 12% “well prepared”, 6% “very well prepared”.

Exercises

Only 3%–12% of the respondents have experienced exercises that included people with a hearing impairment, visual impairment or multiple disabilities.

- On the question if actors were involved in exercises representing deaf and hard-of-hearing people, 96% answered “no”, 3% “yes” (1% did not specify).

- On the question if actors were involved in exercises representing people with blindness and visual impairments, 87% answered “no”, 12% “yes” (1% did not specify).

- On the question if actors were involved in exercises representing people with multiple disabilities, 88% answered “no”, 10% “yes” (2% did not specify).

The findings show that in exercises, which represent a crucial educational element, people with disabilities were significantly underrepresented.

Subjective experience of preparedness

About half of respondents indicated that they do not feel well prepared in dealing with people with impairments. Only 3% to 4% indicated that they feel very well prepared.

- On the question if they feel prepared for contact with deaf and hard-of-hearing people, 46% reported feeling “less prepared”, 27% “not prepared”, 23% “well prepared”, and 4% “very well prepared”.

- On the question if they feel prepared for contact with people with blindness and visual impairments, 48% reported feeling “less prepared”, 18% “not prepared”, 31% “well prepared”, and 3% “very well prepared”.

- On the question if they feel prepared for contact with people with multiple disabilities, 52% reported feeling “less prepared”, 31% “not prepared”, 14% “well prepared”, and 3% “very well prepared”.

Open questions

At the end of the questionnaire, respondents were asked to identify the particular challenges entailed in dealing with deaf/hard-of-hearing people and those with visual impairments/blindness when on missions, and to suggest what content in particular should be included in their training or further training.

Respondents identified the following main challenges when dealing with blind or visually impaired people:

- Helpers should basically be made aware of the particular situation of these people and their specific needs.

- More comprehensive information dissemination is necessary. Information e.g. on the situation and environmental conditions, planned measures, and necessary decisions must be continuously communicated. This information must be clearly and comprehensibly formulated and must take into account the fact that the people concerned are not able to verify visual information.

- It is important to listen carefully and to find out precisely what the people with disabilities need.

- The additional time required (for comprehensive communication of information, transport etc.) and the requirement for more staff and more oversight were mentioned as special requirements for these missions.

Respondents identified the following challenges above all when dealing with deaf/hard-of-hearing (D/HH) people:

- Helpers should basically be made aware of the particular situation of these people and their specific needs.

- The core challenge on missions dealing with D/HH people is the communication barrier. In order to enable the best possible communication with D/HH people, it is considered necessary to implement alternatives to verbal communication methods in advance and to practise the use of these. Written information material and pictograms should be developed in advance.

- Verbal and written communication in simple, clear sentences must be practised. This also applies to appropriately louder speaking for hard-of-hearing people.

- Possible access to sign language interpreters should be known in advance.

- The additional time required (for comprehensive communication of information, transport etc.) and the requirement for more staff and more oversight were mentioned as special requirements for these missions.

Respondents assessed the inclusion of this topic area in training and further training as necessary. They criticised the fact that so far, little attention has been paid to it in the field of missions and civil protection. The following content should be particularly taken into account in training and further training:

- Basic knowledge about different forms of impairment, their causes, levels of impairment and effects

- Promoting increased awareness and understanding for this target group and overcoming inhibitions

- Basic competence in communication with deaf people, basic knowledge of sign language

- Giving blind and visually impaired people as sense of orientation
- Legal principles
- Principles according to Hobfoll et al. (2007), communicating safety, calming, self-efficacy, connectedness, and hope, adapted for people with disabilities.

In terms of didactic methodology, respondents proposed that:

- People with disabilities should be included as instructors at training activities
- Training activities should be developed in collaboration with associations for people with disabilities
- Practical exercises should be a core element of training activities, e.g. giving orientation and communication.

Conclusion

In the light of the results from the survey and from the interviews with teachers of uniformed services and professionals in mid- and long term psychosocial support (psychosocial acute helpers, social workers, psychotherapists), it becomes apparent that the needs and demands of people with disabilities are severely underrepresented in the relevant training programs.

Accordingly, an essential demand of all respondents and the EUNAD initiative is to integrate this content into the existing curricula for e. g. uniformed services, psychosocial acute helpers, social workers, psychotherapists, medical doctors, and to include it in regular training courses and exercises.

5

Hearing impairments

Robert Bering, Philipp Benz, Florentine Gerwinn,
Lena Richter, Jennifer Söhn

Ask Elklit, Tina Jeppesen, Angelina Isabella Mellentin, Lotte Skøt

The EUNAD projects aim to improve the EU human rights-related assistance programmes for the disabled survivors of disasters. This part refers to deaf and hard-of-hearing (D/HH) individuals.

All people are vulnerable when disaster occurs, but D/HH individuals are particularly vulnerable because of their inability/limited ability to hear sounds which affects their ability to obtain and share information. When exposed to a traumatic experience all individuals have a right to post-disaster medical and psychosocial services; therefore D/HH individuals should also have a right to them. The Convention on the Rights of Persons with Disabilities (CRPD, 2006) provides the full range of rights for persons with disabilities, including during situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters. Many European countries have signed and approved the CRPD. This means that State Parties and public authorities have an undeniable responsibility to ensure that first response, healthcare and trauma-informed aftercare services are adapted to meet the specific needs of people with disabilities, including D/HH individuals. Despite the responsibility for the CRPD, the specific needs of D/HH individuals are often excluded from services across Europe. This is probably due to the lack of research evidence available and services that are poorly informed about what should be done for D/HH individuals in the event of disasters.

D/HH individuals constitute a significant minority group in countries of the European Union where 20% of the population is estimated to have some form of hearing loss. For example in Germany, the biggest country in the EU, there are an estimated 80,000 deaf people and another 16 million people with some form of hearing loss. An important fact is that around 140,000 of them need an interpreter for sign language (Wirth, 2010; Hintermaier, 2007).

The preferred communication methods for D/HH individuals vary greatly depending on the degree of hearing loss and cultural orientation. Communication methods include different sign languages or Sign Supported Communication, Mouth-Hand-System, hand alphabet (typically used to spell out names, places or other words that do not have a particular sign), lip-reading and spoken and written language in the mother tongue. A percentage of the D/HH individuals have chosen to identify with the Deaf community which is a cultural and linguistic minority group centred on using sign language as their communication method. Sign languages are fundamentally different from the spoken language in the country where they are used, and are recognized as an independent language (Wirth, 2010; Hintermaier, 2007).

In relation to the main subject of this international project, there are only a limited number of international studies that have researched the issue regarding one or more of the post-disaster services (e. g. Øhre, 2017; Øhre et al., 2015; Engelmann, 2013; Barnett, 2002). All these studies found that there was a lack of deaf awareness among the professionals working for the different services. Deaf awareness means having an understanding of: (a) the difficulties faced by D/HH individuals when attempting to communicate with hearing individuals, and (b) how to minimize these communication difficulties. Studies from the USA, Norway and England that examined the general healthcare experiences of D/HH individuals and the difficulties experienced by deaf individuals when accessing primary healthcare and accident and emergency services found that the majority of D/HH individuals faced communication difficulties when attempting to retrieve information from health staff either directly and/or through relatives/sign language interpreters. Another finding was the difficulty for D/HH individuals in finding a sign language interpreter, especially in emergency situations. Furthermore, two of the studies reported that poor communication can lead to dangerous misunderstandings about treatment and compromise the health of D/HH individuals. Two studies about the experience of D/HH individuals with accessing trauma-informed after-care services from the USA reported a lack of services targeting D/HH individuals, which resulted in difficulties in finding clinicians/therapists that could meet their specific communication needs (Wirth, 2010; Hintermaier in M.,Tsirigotis, C., 2008).

It is often necessary for deaf individuals to have a sign language interpreter to assist with communication, but they are rarely available. In small areas with fewer interpreters, deaf individuals often end up having to use the same interpreter for more than one situation. This is problematic because some deaf individuals report feeling uncomfortable sharing intimate trauma experiences with an interpreter they would have to use in other situations.

All-deaf support groups in mental health settings are rarely available because D/HH individuals are a minority group. The studies mentioned show the important communication difficulties that D/HH individuals face when accessing services, and most of the studies provide suggestions and recommendations for how services can be improved. The findings however, cannot be generalized to fit the experiences of D/HH individuals all over Europe, and therefore there is an urgent need for studies investigating the experiences of D/HH individuals when accessing services after trauma or disaster.

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5.1 Research results

5.1.1 Danish study

Ask Elklit, Tina Jeppesen, Angelina Isabella Mellentin, Lotte Skøt

The goal of this Danish study was to gain information about the experience of D/HH individuals when accessing first response, healthcare and trauma-informed aftercare services after experiences of disasters, and which improvements they suggest to these services. As disasters are relatively uncommon in Denmark, the range of D/HH individuals recruited was expanded to include individuals who had experienced other crisis situations. The participants were nine D/HH individuals that reported having experienced at least one disaster or crisis situation. Six of the participants identified themselves as deaf (D) and three as hard-of-hearing (HH). The participants filled out a list with traumatic events they or someone they knew had experienced. On average the participants had been exposed to 3.3 potentially traumatic events. Afterwards the individuals participated in a semi-structured interview. Because of the low number of participants who had experienced a disaster, they were asked hypothetical questions regarding recommendations for professionals in the event of a disaster.

The difficulties the participants met during interactions with first response and healthcare services could be divided into four major themes:

1. Lack of deaf awareness among first responders and/or healthcare professionals.

2. Problems gaining access to interpreter services at the hospital.

3. Healthcare professionals who relied on family members to translate information to the D/HH patients.

4. Healthcare professionals who were unwilling to adjust their speech or try different forms of communication.

Experiences

One major complaint of all participants was that the first response and/or healthcare professionals had a general lack of deaf awareness and lacked experience in dealing with D/HH individuals; they were therefore unprepared to meet their communication needs.

In Denmark, hospitals are required to provide and fund interpreter services for D/HH individuals. Despite this, all the participants who use DSL as a communication method experienced problems in gaining access to a sign language interpreter at the hospital. One of the participants stated that he had been refused a sign language interpreter on several different occasions at the emergency room due to disputes about who should pay. These problems in gaining access to an interpreter can create extra stress for D/HH individuals who are already in a crisis. Being a D/HH relative to a patient in the hospital, and not a patient themselves, makes the interpreter situation even more difficult, as in this type of situation the hospital is not required to pay for a sign language interpreter.

When healthcare professionals turn to relatives to communicate with the D/HH individuals, other problems can emerge. Among other things the patients' feeling of dependency can rise and there is a chance that relatives may inadvertently leave out important details from the healthcare professionals. Furthermore, it is an extra responsibility for the relative in an already emotional situation, and when healthcare professionals rely on hearing relatives to communicate with the D/HH patients, more problems arise when the hearing relatives are not available. Due to busy work schedules, hospital personnel are often not willing to adjust their speech or try other forms of communication. These things might result in the D/HH patient not receiving the information they need.

In Denmark, there are no all-D/HH support groups for victims of trauma and their relatives; the D/HH individuals must settle for trying to find a hearing support group, which can lead to rejection as one of the participants experienced because of the difficulties related to sign language interpretation.

The participants also expressed concerns regarding the limited number of crisis psychologists who are trained to service the specific needs of the D/HH population. Participants whose primary language was DSL reported preferring to work with a crisis psychologist who is proficient in DSL. However, when seeking a psychologist, the D/HH individuals who rely on DSL to communicate often ended up having to choose a hearing crisis psychologist who understands trauma but does not use DSL. Deaf individuals do not necessarily want to work with a deaf psychologist due to issues of trust and confidentiality. One participant explained that in principle everybody in the deaf community knows everybody else, so there is a chance that one may meet one's psychologist at a party, for example, and even though the psychologist has a duty of confidentiality, it feels wrong.

For some D/HH individuals, the use of interpreter services is often necessary during sessions with a crisis psychologist. The National Interpreter's Authority has a budget for psychological crisis treatment, and there is no limit to the number of interpreting hours a D/HH person can get. The responsibility of booking a sign language interpreter lies with the D/HH individual, not the psychologist. The use of an interpreter can cause some challenges. One participant described working with an interpreter as a strange experience because it disrupted the flow in the conversation and his ability to communicate directly with the psychologist. Other problems reported included a lack of chemistry with the interpreter and a fear of being misinterpreted.

Another problem that can arise when D/HH individuals have to use a sign language interpreter is that the likelihood of having to use the same interpreter for more than one venue is high. One participant reported that he didn't want to use an interpreter from the centre he usually books from because he used the same centre when he needed a sign language interpreter for work-related situations and he always had in the back of his mind that the interpreter knew something personal about him. Participants whose primary method of communication was speech reported preferring to work with a hearing crisis psychologist who has knowledge of deafness/hearing loss. One HH participant described not experiencing any problems regarding communication because the psychologist made sure that they sat directly opposite her when talking; another HH participant had the opposite experience because the psychologist sat away from the light when talking, resulting in the participant having to use all her energy on trying to hear what the psychologist was saying.

Recommendations

The participants provided extensive suggestions for improvements in the provision of services for D/HH individuals who have experienced disasters/crises. They would like to see more sign language interpreters made available, so that D/HH individuals have a better chance of getting one at the scene of an emergency as well as in crisis situations at hospital. Some participants also felt it was important that funding be made available to finance sign language interpreters for D/HH individuals who are relatives of hospital patients. With regard to trauma-informed aftercare services, participants would like to see them expanded to include all-D/

HH support groups for trauma victims and their relatives as well as more crisis psychologists who are trained to service the specific needs of the D/HH population

The participants reported that they felt that it was important that the different professionals (first responders, healthcare professionals in hospital settings, crisis psychologists) who are likely to encounter individuals with experiences of disasters and crises acquire more knowledge about the varying communication needs of D/HH individuals. Furthermore, they would like the knowledge of how to service the needs of D/HH individuals to be incorporated into the training of first responders and for brochures on deafness and hearing loss to be distributed to different workplaces (e.g. hospitals, doctor's surgeries, psychology clinics).

Conclusions

The Danish study is the first of its kind to investigate the experiences of D/HH individuals with accessing first response, healthcare and trauma-informed aftercare services in Denmark following experiences of disasters and crises. It was obvious to the participants that the professionals had had limited or no contact with D/HH individuals in connection with their work, and therefore lacked the necessary knowledge about how to communicate with them.

To sum up, the problems the participants met were: (a) problems gaining access to a sign language interpreter at hospital, (b) healthcare professionals who were unwilling to adjust their speech or try other forms of communication or who relied on hearing relatives to pass on information, (c) a lack of all-D/HH support groups, (d) problems finding a crisis psychologist with expertise in a specific area who could also use sign language, (e) problems finding a sign language interpreter for the sessions with the psychologist that the participants were not using in other situations (e.g. work related) and with whom they felt comfortable.

Overall, the present study illustrates significant gaps in the provision of services for D/HH individuals in the event of disasters and crises. The difficulties reported by participants in accessing services are all centred on communication barriers. When communication barriers are present it is highly likely that D/HH individuals won't receive all the information they require. There are certain things that can be done to limit information deprivation and other problematic outcomes for D/HH individuals. Our participants provided us with extensive suggestions for improvements to service provision, including a list of practical recommendations for first responders, healthcare professionals (hospital settings) and crisis psychologists. Summarized, the recommendations for first responders are: Create and maintain good eye contact, stay calm, use gestures (e.g. yes, no, come), point to body parts and speak slowly, write things down, use cards with pictures/gestures or phones/tablets with the sign language alphabet or that can translate speech into text and vice versa. Learn basic sign language phrases (e. g. "Are you okay"), book an acute sign language interpreter and if this is not possible, arrange a video conversation with an interpreter. For healthcare professionals, the recommendations are: book a sign language interpreter. Written notes are only appropriate for brief interactions, not for more complicated discussions. Look directly at the patient, speak slowly and clearly and make sure there is enough light. Be aware if the person's hearing aid has been removed or switched off and use for example phones/tablets with the sign language alphabet or that can translate speech into text and vice versa, avoid communication through relatives and ensure patients receive all relevant information. For crisis psychologists, the summarized recommendations are: Sit directly opposite the client and avoid looking at the sign language interpreter when speaking and listening. Speak slowly and clearly and sit in a good light. Be aware of the chemistry between client and interpreter and be aware of the importance of using the same language interpreter for each session.

5.1.2 Special needs and challenges in the medical rehabilitation of deaf or hard-of-hearing individuals

Jennifer Söhn, Philipp Benz, Lena Richter, Robert Bering

Research aim/Background

Within the framework of the EUNAD IP project, the Centre of Psychotraumatology (CoP) of the Alexianer Krefeld GmbH did a mainly qualitative-based study that aimed to identify challenges, requirements and coping skills in rehabilitation treatments for hearing impaired individuals. An additional goal was to develop procedural proposals for psychosocial aftercare following different disasters orientated on the specific situation of deaf or hard-of-hearing (D/HH) individuals.

Methods

The study is based on 11 guide supported and structured interviews with D/HH individuals at the time of their medical rehabilitation at the CoP. The interviews analyses were oriented on Mayring's qualitative content analysis. Additionally, therapy and reflection sessions with an interpreter and systemic consultant were included as were the results of the psychometric questionnaires (PDEQ, TAXON, FLZ, SCL-90, PSSI, BDI, PTSS-10). The results were analysed with SPSS.

Results

All 11 deaf and hard-of-hearing participants in the research sample grew up with hearing parents; nine of them had parents who could not speak sign language, and two had parents with basic skills. All 11 participants reported disturbed communication and loss of information. The participants stated that verbal messages had often not been understood within the family and reported feelings of social exclusion and isolation. Seven participants reported experiences of physical violence, eight reported experiences of psychological violence and five reported experiences of sexual violence. Violence was experienced in the families of all participants; this was mostly described as a result of the lack of communication possibilities. In rehabilitation nine participants showed difficulties in reacting in a sensitive manner, especially in taking on the perspective of other individuals and reflecting their needs. These findings lead to the hypothesis that problems in everyday communication with the above-mentioned consequences could be regarded as a risk factor for posttraumatic stress disorders. In the context of treatment at the CoP it became clear that diagnostic testing needs to be optimized because despite interpreting, the psychometric questionnaires were only partly comprehensible for the deaf/hard-of-hearing participants. For example, it was unclear if dissociations occur among the participants because the descriptive concepts are not represented linguistically in sign language. All participants had difficulties answering the questions so that some parts of the questionnaires could not be evaluated. This was especially the case for the “Peritraumatic Dissociative Experiences Questionnaire” (PDEQ) and the “TAXON”. For the purpose of usable and meaningful diagnostics, psychometric instruments should be culturally adapted for deaf and hard-of-hearing people. In the context of the therapy sessions it became clear that stabilisation techniques with visual, haptic and motor methods and exercises were preferred. Attendance interpreters were also preferred in the meetings, while Verba Voice was viewed critically in most cases. In the end, further professionalization of treatment measures in these areas seems necessary to further optimize the rehabilitation of D/HH people.

5.2 Recommendations for Deaf and Hard-of-Hearing People

The recommendations refer to emergency care and psychotherapy for deaf and hard-of-hearing (D/HH) people. They contain instructions for action and statements intended to serve the general interaction with affected persons in crisis situations. In addition, recommended psychotherapy methods are identified that proved to have a significant influence on treatment success. Recommendations are subdivided under the headings “General recommendations”, “Emergency preparedness”, “Emergency response” and “Psychosocial aftercare”.

The following recommendations are based on the results of two mainly qualitative studies. The studies were carried out within the framework of the EUNAD project. The University of Southern Denmark and the Center of Psychotraumatology of the Alexianer Krefeld GmbH were the implementing institutions.

5.2.1 General recommendations

- **Deaf and hard-of-hearing (D/HH) individuals react just like hearing individuals during times of crisis.**

- Cooperation, networking, communication, exchange with associations of D/HH people (**"Nothing about us without us"**) is essential.

- D/HH people mostly see themselves as part of a **"linguistic and cultural minority group",** not as disabled.

- D/HH people are a **heterogeneous group** according to their communication skills. Some are unable to understand or read spoken language. Accordingly, there might be a need to simplify spoken/written language. Some are able to communicate in sign language or signed language (sound accompanying signs). Communication skills depend on the time of becoming deaf or hard of hearing (pre-, peri-, postlingual adaption), severity of hearing loss, other diseases/disabilities, age, socialization and education. Universal design means taking all possible kinds of communication skills into account.

- Use and adapt **existing structures and services,** try to find **universal designs.** Services should be offered **all over the country** and should not be centralized.

- **Sensitization of population** (possible zero-responders) **and professionals** about deafness/hearing impairment. Sensitization via:

  - school education,

  - information material (e. g. via flyer: as an example, the German government distributed about 20,000 flyers including information about communication with D/HH people; via the internet & media),

  - training activities.

  Sensitization should include:

  - personal experience (e. g. in Israel, fire fighters are required to work for 30 hours with people with disabilities),

  - cultural, ethnic and socio-economic factors,

  - communication skills & possibilities to communicate (e.g. difficulties of lip-reading, max. 30% of what is spoken can be apprehended),
  - rights of D/HH people,
  - learning basics about/in sign language.

- To ensure communication with deaf people who speak sign language, the **possibility of calling interpreters in an emergency without going through a lot of bureaucracy** should be implemented. Financial issues for communication with interpreters should be solved.

- Develop **information material about acute, mid- and long-term services for D/HH people after disasters.** Produce different versions according to communication skills (written design, videos, media, internet, blogs etc.).

- **Communication advice:**
  - Speak slowly and clearly, do not shout (as many hard-of-hearing people show symptoms of hypo- and hyperacusia at the same time).
  - Use basic signs, gestures or cards etc. that symbolize cohesion, help, security etc.
  - Ask what the D/HH person has understood or ask him/her to repeat your communicated information to make sure he/she did understand your message.

- **Be careful:** The way humour is used in deaf culture differs from the way it is used in hearing culture. Humour can lead to misunderstandings.

5.2.2 Emergency preparedness

- **Information** (e.g. about existing dangers, the present situation and development after disaster) should be communicated in a variety of ways:
  - TV, media, Internet, SMS, Apps, etc. (in written text, spoken language, sign language)

- Assemble a **network of interpreters** trained in specific fields such as medicine or welfare (translating via video vs. in person) to be called upon during times of emergency.

- Create **information material** for D/HH people in cooperation with deaf and hard-of-hearing associations (in written text, spoken language, sign language) including:

    - rights of D/HH people,

    - recommendation to have all necessary equipment (e.g. cell phone, hearing aid with spare battery, etc.) with you,

    - information about inclusive alert- and emergency-call-systems,

    - stress reaction after disaster,

    - general advice on how to cope with stress reactions,

    - services and particularly how to access services (address & contact details).

- D/HH individuals should be **educated in disaster preparedness, first aid, etc.** (e.g. via deaf and hard-of-hearing associations).

- **Collect a voluntary database** of people with disabilities for easier contact, crisis communication and warning.

- **Use multi-sensory attention alert systems** (e.g. sound, vibration and flashlight) **and emergency call systems** (e.g. telephone, SMS, FAX, apps, skype, internet, e-mail).

- Develop possibilities of communication that work without electricity in case electricity does not work during a disaster (e.g. writing with pencil on paper, prepare pictures where D/HH people can show where it hurts, laminated sign language alphabet etc.).

- Create **inclusive standards** for evacuation and emergency routines for employers/schools/communities/public-traffic systems/ public places etc. In particular, D/HH individuals should take part in disaster drills and simulations.

5.2.3 Emergency response

5.2.3.1 Psychological first aid

- **Try not to separate D/HH individuals** from each other or their relatives/friends as these people promote their feeling of security and their chance to communicate and receive information.

- **When evacuating D/HH individuals let them take their compensatory equipment with them if possible.** (e.g. notebook, hearing aid, mobile phone).

- **Specific communication advice:**

  - Ask for preferred means of communication (e.g. spoken language, written language, sign language).

  - Call sign language interpreters if D/HH individuals prefer sign language. If you cannot arrange direct interpretation use remote sign language interpretation.

  - Maintain eye-contact and observe their facial expressions and reactions.

  - Make sure there is enough light so they can see your face and what is going on around them.

- Use signal symbols (e.g. logos, orange vest, and blanket) in chaotic situations so that they can orientate visually.

- Do not wear helmets etc. outside the danger zone to give deaf and hard-of-hearing individuals the chance to lip-read or see facial expressions.

- Be aware that deaf and hard-of-hearing individuals are most vulnerable in the dark or while asleep when they cannot compensate their hearing loss with the visual sense.

5.2.3.2 Psychosocial aftercare

- Psychiatric centres should be able to treat D/HH individuals in general not only at one place per country. (Example for best practice: PsySurdus – an online psychiatric service for the deaf including listening webcam, chat and e-mail. Communication is based on French Sign Language (LSF) – Link: http://www.sos-surdus.fr/.

- Make the preferred means of communication possible. Sign language interpreters should automatically be provided and should be organized in advance – this should not be the responsibility of the deaf and hard-of-hearing individual.

- **Specific communication advice:**

  - Make use of possible technical devices/materials that can assist communication.

  - When using sign language interpreters, sit directly opposite the client and avoid looking at the sign language interpreter while speaking and listening.

- D/HH individuals have the same needs as hearing individuals in the therapy situation e.g. closeness, empathy, humour etc.

- **Psychopathology:** D/HH individuals suffer from same psychiatric disorders as hearing individuals but there is evidence for generally increased incidence of psychiatric problems in this population. Incidence of PTSD has not been fully analysed so far. More research is needed. Hard-of-hearing people or people who suffer an increasing loss of hearing often report of hyper- and hypoacusia at the same time. This phenomenon is very similar to hyper-arousal syndrome of traumatized people. Personnel should find out if a person is affected by this syndrome.

- **Therapy and Sign Language:** Trauma treatment is difficult if it has to be done via a sign language interpreter; eye contact is extremely important during therapy, but this is lost if one uses an interpreter. The preferred option is for therapists who speak sign language. If therapists are not able to speak sign language it is preferable to use same interpreter if multiple sessions are needed. Physically present interpreters are preferred rather than interpretation via “Verba Voice”. Sign language interpreters should remain neutral and should be unknown to the D/HH individual.

- D/HH individuals are used to being guided by hearing individuals; they also expect that in the context of therapy. The content and procedure of therapy and the role of the therapist as person who helps and supports the patient to help himself must be explained.

- Visual material to support the therapeutic interventions can be useful.

- Stabilization techniques which make use of bilateral stimulation and body movement are preferable over techniques that make use of imagination.

- Technical terms like “skill” or “trigger” must be paraphrased and explained. It can be useful to agree with the patient on a gesture for these terms.

- Provide **contact information for support groups for D/HH individuals** (e.g. crisis groups, bereavement groups).

- Information about important meetings/sessions should be provided in written form.

Visual impairments

6

Trond Heir, Marianne Hansen, Audun Brunes

Visual impairment is defined as a decreased ability to see (Colenbrander, 2009). About 40 million Europeans have a diagnosis of visual impairment, including 32 million with low vision and 8 million with blindness (Pascolini & Mariotti, 2012). The numbers are expected to increase due to an aging population, greater frequency of systemic diseases, and more immigration from war-torn countries (World Health Organization, 2014). Visual impairment can occur at any point in life and has different causes, such as injuries, infections, systemic diseases, inherent conditions, and congenital anomalies.

Vision is a key sensory modality for obtaining rapid and precise information about the surrounding environment. Visual impairment may thus lead to increased susceptibility for risks and hazards in daily life. Visual impairment may also be an obstacle to gaining necessary and sufficient information in an emergency situation. For some individuals, this may challenge the ability to take care of their own safety and security. A qualitative study that was part of the European Network for Psychosocial Crisis Management (EUNAD) revealed that visually impaired people's daily lives included a range of hazards and potential threats (Saur et al., 2016). Fear of daily accidents was more pronounced than fear of disasters. Some participants reported avoidance of help-seeking in unsafe situations due to the shame associated with not being able to cope. Withdrawal and social isolation were important issues.

However, little research has been done to examine the occurrence of post-traumatic reactions in individuals with visual impairments and whether they are more at risk of mental health adversities than their sighted peers (Shaar et al., 2013). As a sequel to the first EUNAD study, we wanted to gain more knowledge about type and frequency of traumatic events among individuals with visual impairments, and what impact various types of adverse life events may have on mental health. We also wanted to know more about mental health in visually impaired people in general, and what factors are important for good health.

6.1 Research results

6.1.1 Results from a population study of visually impaired individuals

Trond Heir, Marianne Hansen, Audun Brunes

Telephone interviews of people with visual impairment were conducted in Norway between February and May 2017. Researchers from EUNAD-IP collaborated with the Norwegian Association of the Blind and Partially Sighted in preparing an interview guide and information for participants. The organization comprises about 10,000 members. Participants were randomly selected among organization members with low vision and blindness within four age groups: 18–35 years, 35–50 years, 51–65 years, and 66 years and older. Phone calls to potential respondents were made until each age group included 150–200 participants. The final number of participants was 736.

The interview guide included various scales and instruments to obtain information about the participants' visual impairment, their use of assistive devices, experiences with disasters and other events involving a threat to life or integrity, as well as matters of loneliness, coping and mental health. We used the diagnostic guidelines of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) to categorize whether respondents fulfilled the criteria of posttraumatic stress disorder (PTSD) or depression (American Psychiatric Association, 2013).

Trauma exposure

The participants were asked about their experiences with adverse life events specified from a list of 18 potentially traumatic events. About 80% of the participants reported one or more adverse life-events experienced during their lives, men and women to a similar degree. The most commonly reported adverse events were illness or injury causing vision loss (36%), life-threatening illness or injury (35%), and transportation accidents (32%). Fewer people had experienced natural disasters (12%), or fire or explosions (20%).

There were some differences in the nature of the adverse events experienced by men and women. Men were exposed to illness or injury causing vision loss to a greater extent than women. Women were more often exposed to sexual assault and other unwanted or uncomfortable sexual experiences than men.

Posttraumatic stress disorder

Posttraumatic stress disorder (PTSD) is a mental disorder that may develop after exposure to exceptionally threatening or horrifying events. PTSD can occur after a single traumatic event or from prolonged exposure to trauma.

If reporting more than one event, respondents identified their worst event, i.e. the event that currently bothered them the most. Respondents were asked whether the event involved accidental or violent death or danger to life, serious injury, or sexual violence. They had to give a positive answer to fulfil the threat-criterion of PTSD.

The criteria for current PTSD were fulfilled by 12% of the participants. The prevalence was higher in women (14%) than in men (9%), and higher in younger age groups than in the older. Illness or injury causing vision loss was the most common event causing PTSD in men. For women, sexual assault, physical assault, and vision loss were the most common events causing PTSD. The prevalence of PTSD was considerably higher than in the general population of Western countries, suggesting that blind and visually impaired people represent a high-risk population. Disasters or large-scale accidents appear to be a minor cause of adverse mental health in this population, as we found only one case of current PTSD (0.3%) among people who reported that a natural disaster, fire or explosion was their worst event. On the other hand, our findings indicate major challenges related to the mental health consequences of injury or illness causing vision loss, and physical and sexual assaults.

Depression

Prevalence rates of major depression were 9% in men and 12% in women, and higher in younger age groups than in the older. The prevalence rates of major depression were higher in our study population than in the general population, suggesting a minority at high risk for reduced mental health.

This was even clearer when we examined the prevalence of dysthymia, a chronic depression that entails a person being depressed on most days for the last two years. Prevalence rates of dysthymia were 16% in men and 23% in women, compared to the 1–3% prevalence rate in the general population.

Two factors were strongly associated with depression and dysthymia: first and foremost the perception of loneliness, and secondly the experience of being the victim of bullying. Both may be causal factors in the development of depression, and since both occurred relatively frequently in this data material, they deserve to be elaborated on.

Loneliness

The interview-guide included three questions about loneliness, i.e. how often the responder felt lack of companionship, felt left out, or felt isolated from others. Often feeling lack of companionship was reported by 21% of the responders, and some of the time by 39%. Often feeling left out was reported by 12%, and often feeling isolated from others by 13%. There were no differences across gender or age groups. The highest levels of loneliness were reported by individuals who had other functional disabilities in addition to their visual impairment and by people who had experienced being victims of bullying.

Bullying

The interview also included three questions about bullying; whether the respondent had ever been a victim of bullying, whether it had happened during the last 6 months, and whether bullying was related to the visual impairment. Bullying experienced at any point in life was reported by 42% of the respondents, and bullying during last 6 months by 8%. Of those who experienced bullying, 65% reported that the bullying had been mainly (53%) or partly (12%) related to their visual impairment. There were no differences between men and women. Younger people had experienced more bullying than the elderly. Individuals with other functional disabilities in addition to visual impairment had been exposed to more bullying than others.

Referral to psychologist

During the first part of the data collection (n = 315), we discovered that there was a need for psychological follow-up for some participants. Therefore, the remaining participants (n = 421) were offered psychological assistance. Of the 421 who received the offer, 45 (11%) wanted a consultation with a psychologist. Desire for psychological help was associated with loneliness and previous exposure to traumatic events.

A recurring theme of the consultations was minority stress and the struggle to handle stigma that was internalized in many cases. Other important themes were feelings of marginalization and that people had their basic rights violated. Some described living with visual impairment as entailing a feeling of captivity and anxiety, whereas others expressed difficulty sleeping due to fears of nightly intruders.

Use of assistive devices and personal assistance

Respondents used assistive devices and personal assistance to varying degrees; 35% used a white cane, 13% a guide dog, 12% used GPS, 52% took advantage of personal transport, and 28% of a companion. Of those who reported that they did not use a white cane, 15% thought they would be more mobile if they used one. It is worth noting that they had higher levels of loneliness and depression than other respondents. Similarly, a considerable proportion of non-users thought they would be more mobile if they used a guide dog (16%), GPS (29%), personal transport (36%) or a companion (34%). In general, these individuals experienced more loneliness and depression than others.

The same was true for the feeling of safety. Among non-users there were many who believed that they would be safer if they used a white cane (28%), guide dog (25%), GPS (26%), personal transport (33%) or a companion (40%). Higher levels of loneliness and depression were also commonly present among these.

Lack of use was not necessarily a matter of access. For example, half or those who thought they would be more mobile or safer if they used personal transport reported that they had easy access to such transport without making use of it. Similarly, a majority of those who thought they would be more mobile or safer if they used a white cane reported that they had access to using it if they wanted. It appears that inadequate use of assistive devices and personal assistance may result in loneliness and depression, but the reverse causality may also apply.

Implications and recommendations

The current research project clearly shows that people with visual impairment are at risk for reduced mental health. A significant proportion develops mental health problems such as PTSD and depression. The most common causes of PTSD in both males and females were injury or illness causing vision loss, and additionally for women, physical and sexual assaults.

The mental strain caused by vision loss appears to be of high impact. The vision loss can occur abruptly, but may also develop gradually over a long period, with the associated stress of not knowing how the loss of vision will progress. The elevated risk of mental health adversities in individuals with visual impairments needs to be recognized and appropriate preventative actions taken – e.g. providing information to at-risk visually impaired individuals and offering them mental health examinations and follow-up by mental health care professionals. Furthermore, it is important the ophthalmologists and others who face people with vision loss have a low threshold for referral.

The relatively frequent reports of physical and sexual assaults on visually impaired women suggest a group at high risk of serious abuse and subsequent psychological reactions. This finding emphasizes the need for preventive measures as well as professional assistance when such events occur.

Disasters and large-scale accidents appear to be a minor cause of mental health adversities in visually impaired people. Rather, people with visual impairment have a greater susceptibility to a variety of hazards and potential threats in daily life, resulting in a higher risk of stress reactions, withdrawal and social isolation. This calls for emphasis on safety procedures in everyday life and universal design in public spaces.

At an individual level, disasters and large-scale accidents require the same approaches used in everyday accidents. The consequences for the individual rarely depend on whether there are few or many people who are affected at the same time. Psychosocial first aid and aftercare for visually impaired people should include focusing on predictability and adequate information to prepare for coping and self-efficacy. Professionals should be aware of the need for independence and self-reliance.

The research findings show that visually impaired people are at higher risk of loneliness and depressive disorders. Loneliness and depression can be consequences of social withdrawal or inadequate social integration. Coping in social contexts can be more challenging with visual impairment, and people with visual impairment may be more easily left out and isolated from others. Social integration should therefore be a main objective in promoting living conditions for people with visual impairment, regardless of when in life vision loss occurs.

The research findings also show that visually impaired people are at high risk of being bullied, and that bullying may be a possible cause of loneliness and depression. People with other disabilities in addition to visual impairment were at an even higher risk. It is well known that being different in one way or another makes you more vulnerable to sanctions and exclusions. Bullying is often subtle and not always easy to address. Bullying may include intimidation or mimicking the disability, or more subtle forms of exclusion. For example, exclusion and alienation might result from people speaking to others instead of directly to the visually impaired person; from underestimating a visually impaired individual due to prejudices; or from leaving them out of social events. In many ways, subtle forms of bullying are like a glass ceiling effect: an invisible, subtle barrier that prevents some individuals from developing and participating in society on equal terms.

Visually impaired and blind individuals should have the same access to mental health services as the rest of the population. Our survey highlights an unmet need for psychological treatment in this minority group which could have several explanations. First, there is a lack of knowledge among health personnel about the mental health adversities associated with visual impairment. Second, people with visual impairment may have a higher threshold before they seek help compared to individuals without impairments. And third, visually impaired individuals might be reluctant to seek help due to a desire for self-reliance and to avoid being a "victim". Increased awareness of mental health adversities and facilitation of health care services for people with visual impairment should be addressed by health care authorities and user organizations in collaboration.

Some do not use assistive devices such as a white cane, guide dog or GPS, or personal transport or assistance although they had access to them, and also believed that using them would make them safer and more mobile. It is worth noting that reluctance to use assistive devices or personal assistance is associated with more loneliness. There are thus good reasons to encourage visually impaired people to use assistive devices and personal assistance in cases where this can increase mobility and safety. Sometimes it might be a matter of overcoming fear of being labelled, or fear of being a burden. Awareness about this is useful both for the individual user and for the attitudes of the general population.

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6.2 Recommendations for the blind and visually impaired people

The following recommendations are based on the findings of a qualitative study carried out in the first EUNAD project (2013–2014) and the population study carried out in the EUNAD-IP project (2016–2017).

The recommendations refer to exposures to, prevention and coping with traumatic events, as well as promotion of psychological health and wellbeing.

Recommendations are subdivided under the headings “General recommendations”, “Emergency preparedness”, “Emergency response” and “Psychosocial aftercare”.

The Norwegian Centre for Violence and Traumatic Stress Studies was the implementing institution.

6.2.1 General recommendations

- **“Nothing about us without co-operating with us”** is essential. Contact and cooperation with user organizations to ensure user participation are essential and should be the foundation for developing recommendations for this group.

- Establish appropriate measures to ensure access, on an equal basis with others, to the physical environment, to information and communications, including information and communications technologies and systems, and to other facilities and services open to or provided for the public.

- Individuals with visual impairment constitute a heterogeneous group. The ability to orientate by vision varies. Being visually impaired varies from mild vision loss to blindness and from progressive eye diseases to established vision loss.

- Universal design in public spaces is essential and represents recommendations for an environment that is safe and inclusive for persons who are blind and partially sighted. Universal design implies:

- The design of the environment should be useful to people with diverse abilities and accommodate a wide range of individual preferences and abilities.

- Simple and intuitive use: the design should be easy to understand and use, regardless of the user’s experience, knowledge, language skills, or current concentration level.

- Perceptible information: the design must communicate necessary information effectively to the user, regardless of ambient conditions or the user’s sensory abilities.

- Preparedness: the design should minimize hazards and the adverse consequences of accidental or unintended actions, and it must be possible to use the design efficiently, comfortably and with minimum fatigue.

6.2.2 Emergency preparedness

- The foundation for emergency preparedness lies in universal design. This is the basic precondition toward facilitating a comfortable and accessible environment for persons who are visually impaired.

- Visually impaired and blind individuals should be educated in disaster preparedness and first aid (for instance via user organizations). All measures that enhance self-efficacy and mobility are essential in preparedness.

- Adequate information about pre-event emergency planning information should be available in accessible formats, i.e. how to evacuate, where to get first aid training and assistance, what should you have accessible at home.

- Information about the rights of people with visual impairment in case of emergency should be disseminated thorough alternative non-visual channels.

- Concrete eliminations of hazards in public spaces, workplaces and at home may include:

- Removing rugs and floor coverings, taping down or removing electrical cords from pathways, and removing large pieces of furniture from the main traffic areas.

- Placing drinking fountains and fire extinguishers along one wall only throughout hallways allows individuals who are visually impaired to trail the other wall without encountering obstacles.

- Providing braille signage and marking emergency exits clearly. Using high contrast and adequate lightning conditions in order to help people find their way out of buildings.

6.2.3 Emergency response

6.2.3.1 Psychological first aid

The same established principles for emergency response and psychosocial first aid must be applied for all population groups. For visually impaired and blind individuals, the following should be taken into consideration:

- Ensure predictability: communicate clearly what has happened and the order of what is going to happen next.

- Identify your role when approaching a person with visual impairment, and touch their shoulder. Place the person next to the wall, and describe the setting. Inform them when you leave.

- When accompanying a person who is visually impaired or blind, the most common companion techniques should be applied: offer to assist the person by letting the person hold your elbow.

- Offer your assistance, listen, and then assist.

- If possible, address people who are blind or have low vision by their names so they know you are speaking to them.

- Ask people who are blind or have low vision what they want or need. Do not direct questions through their companion.

6.2.3.2 Psychosocial aftercare

There may be higher thresholds to the access of mental health services for people with visual impairment resulting in an unmet need for psychological treatment in this group.

- There is a need for increased knowledge among health personnel about the mental health adversities associated with visual impairment.

- Increasing awareness of mental health adversities and facilitating mental health care services for visually impaired individuals should be addressed by health care authorities and user organizations in collaboration.

- Functional impairment in addition to vision loss may imply higher risk for mental health adversities.

- Isolation and bullying increase the risk for mental health adversities in blind and visually impaired individuals.

7

Intellectual disabilities, dementia and autistic spectrum disorder

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The most common mental and cognitive disorders are:

- **Intellectual disability** – primarily arrested or incomplete mental development; it influences all cognitive components (cognition, memory, speech; sometimes also locomotion and social interaction).

- **Dementia** – acquired reduction or loss of cognitive capacity, slower mental pace, and problems in remembering, maintaining and recalling information, disordered judgment and decision making, problems with planning, declining emotional control and self-control, reduced adaptability, behavioural disorder, cognitive deficit. Mostly occurs in old age.

- **Autism** – social interaction disorder and restricted, repetitive activities and interests. Autistic spectrum disorder affects motion, emotion, will, cognitive functioning and speech. It impacts personality and also the ability to adapt.

- **Disorder of cognitive functions** – resulting from other mental disorders (schizophrenia, mood disorder, neuroticism, use of psychoactive drugs).

In practice the disorders mentioned are very often combined with other difficulties including motion disorders or hearing and visual disorders.

Risks facing target groups

- Higher vulnerability – intellectual disability has a strong influence on how persons with a cognitive disorder perceive and understand information from the outside world, how they cope with a stress situation/disaster and recover after the experience.

- Reduced adaptation to new conditions – especially with sudden unexpected events or when changes occur

- Reluctance to be evacuated, distrust of strangers

- Clients living by themselves are difficult to identify – so are their needs
- Difficulties in communication, limited understanding of instructions

Specific difficulties of older people

- Loss of cognitive functions
- Higher risk of injury (bone fracture etc.)
- Reduced mobility and efficiency
- Changes in thermoregulation (less effective in adapting to weather changes)
- Reduced immunity (propensity to diseases)
- Lower stress tolerance
- In case of need to leave their home, they experience powerful distress (in a change of environment, they are torn out of their social network)

7.1 Literature analysis on people with intellectual disabilities

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The analysis about needs of people with intellectual disabilities was mainly carried out from April to September 2016. The research analysis was limited by the very low number of studies focused on the topic of mentally disabled persons in disasters. The same applies to the analysis of guidelines and handbooks. A first step was the identification and mapping of research findings, guidelines and handbooks, practice examples and tools to provide an overview of existing knowledge about the special needs of people with intellectual disabilities and existing recommendations and training materials for experts.

With regard to intellectual disabilities we can see that due to the higher prevalence of (prior) traumatization in people with mental disabilities, disasters/emergencies can cause re-traumatization or arouse strong feelings of helplessness. People with mental disabilities have a higher need of support and care and an increased risk of long term complications. One characteristic of persons with intellectual disabilities relates to the awareness of danger which can be limited or absent; dangerous situations may be interpreted as meaning that the person her-/himself was responsible for the danger (Greenspan, Switzky, & Woods, 2011). There is also a high risk that stimuli are misunderstood, therefore an action may be inappropriate in a particular situation (e.g. fear when facing firefighters). They often pay attention to irrelevant stimuli, for example concentrating on the blue light instead of on emergency alerts. Generally people with intellectual disabilities show stress reactions similar to the reactions of people without disabilities in disasters and emergencies but they might be more intense and they have different coping strategies. In some cases persons with intellectual disabilities may present epileptic seizures, cardiovascular problems, incontinence, a heightened need for attention, self-harming behaviour, fear and defensiveness towards physical proximity and/or aggravation of existing behavioural problems (Irblich, 2006a, 2006b; Irblich & Blumenschein, 2011). Trauma reactions specific to this population include stereotypical behaviours, challenging behaviours, and reduced self-care (Wigham, Hatton, & Taylor, 2011).

Psychological problems or post-traumatic stress disorder are often not identified in people with mental disabilities. People with intellectual impairments and people without disabilities often show similar grief reactions. However, reactions may be misinterpreted. Specific tests for improved identification of PTSD exist which appear to have a good level of reliability for individuals with intellectual disabilities (Hall, Jobson, & Langdon, 2014). People with mental disabilities who have experienced a traumatic event may require special psychological care. Trained mental health professionals can help them in identifying and coping with the trauma (Ballan & Sormanti, 2006).

- 140 studies (37 of which are specifically about people with intellectual disability)

- 76 guidelines and handbooks (10 of which are about people with intellectual disability)

- 54 tools (6 of which are for people with intellectual disability)

- 13 practice examples (none of which is specifically for people with intellectual disability)

The full list of resources is published on the EUNAD webpage www.eunad-info.eu.

7.1.1 Definitions and terms: General learning disability/intellectual disability/mental retardation

The most influential definition is that of the American Association on Mental Retardation (1992), which defines mental retardation as involving significant impairment in intellectual functioning with significant impairment of at least two areas of adaptive functioning and age of onset before the age of 18.

The terms most often in use are general learning disability, intellectual disability/impairment, and mental retardation. They refer to generalized neurodevelopmental disorder, which includes impaired intellectual and adaptive functioning. An intelligence score below 70 and difficulties in managing autonomous everyday living are generally accepted as characterising the impairment. The specific behavioural problems represent a developmental delay in childhood and adolescence regarding intellectual and social functioning. Persons with mild learning disability may be able to function at a semi-independent level. Nevertheless, they require assistance and support throughout their lives. Persons with severe forms of intellectual disabilities depend heavily on the health care system.

"Various terms are used in the West for mental retardation, including mental subnormality, mental deficiency, feeble mindedness (late 19 Century term), and mental disability. The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, (DSM-IV-TR, 2000) defines MR as a central nervous system dysfunction producing an IQ below 70; this results in significant deficiencies in two or more life skills, such as self-direction, academic skills, social skills, communication, health, and work. Five subdivisions are identified: mild (IQ 50/55 to 69), moderate (35/40–50/55), severe (20/25–35/40), profound (under 30/25) and severity unspecified (suspected, but not testable)." (Greydanus & Pratt, 2005, p. 859).

Syndromes associated with mental retardation include for example autism, cerebral palsy, Down syndrome, fragile X syndrome, myelomeningocele, neurofibromatosis, Prader Willi syndrome, velocardiofacial syndrome, Williams Syndrome.

In our project, we focus on learning disabilities in general. Two forms of mental disabilities are focused upon separately because of their specific characteristics with regard to emergency situations.

Autism Spectrum disorder

The autism spectrum disorder (ASD) represents a group of developmental impairments. Symptoms of ASD may persist to adulthood. Ratings estimate that 1% of children are affected with autism spectrum disorder (Kogan et al., 2009) with an imbalance between boys and girls. Autistic spectrum disorders occur four to five times more frequently in boys (CDC, 2010). The shape and severity of the corresponding symptoms vary between affected individuals. Individuals with autism show impairments in three different domains:

- Social interaction (restrictions to interpretation of nonverbal communication, limited ability to build up relationships with peers, limited interest in sharing emotions with others)

- Communication (late onset or no verbal communication and no compensation by gestures, or no ability to engage in conversation with others, stereotypical repetitive language)

- Behaviour (often narrow, repetitive patterns of behaviour)

DSM-V subsumes under the term autism spectrum disorder the following subtypes: Autistic disorder, Asperger's disorder, Rett syndrome and childhood disintegrative disorder. The manual offers three levels of severity: Requiring support (Level 1), requiring substantial support (Level 2) and requiring very substantial support (Level 3). These levels may serve to design individualized treatment plans. Interventions aim at the improvement of speech, language, social skills and behavioural aspects.

Prevalence rates of people with intellectual/learning impairments in Europe and worldwide

In Europe individuals affected by intellectual disability mostly attend special institutions like kindergartens or schools for people with special needs. Children with intellectual problems often live with their families whereas many adults with intellectual disabilities stay in housing facilities for individuals with disabilities (Braddock, Emerson, Felce, & Stancliffe, 2001). Persons with mental disabilities generally need support in daily activities. The worse the impact of the disability on the person, the less they are able to take part in demanding activities. This may lead to helplessness in self-care (Nota, Ferrari, Soresi, & Wehmeyer, 2007).

People with intellectual disabilities are amongst the most disadvantaged social groups in Europe (European Intellectual Disability Network, 2003). As traditional patterns of care tend to institutionalize these people, social isolation and exclusion are frequent. Some European countries have therefore started to increase social inclusion of persons with intellectual disabilities. The common trend goes to community living and away from institutionalization.

Prevalence is less than 1% in all European countries. Epidemiological studies suggest that 3 to 4 per 1,000 people of all ages suffer from severe intellectual disability. In the 28 countries of the European Union this is between 1.5 and 2 million people. In the case of mild intellectual disability, studies estimate about 2.3 to 2.7 million affected people in the EU.

Global prevalence studies show that while among adults the rates vary between 3–6/1000, among children the rates are between 3–14/1000. Particularly among children, the rates vary a lot depending on diagnostic systems, the age of the child, and the source of administrative data. For example, using IQ-based clinical guidelines would give higher estimates than those based on more comprehensive adaptive behaviour and psychological assessments (King et al., 2009). A 2011 meta-analysis of international studies found the prevalence of individuals across the life span to be 1.04% (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). A follow-up meta-analysis of international studies, extending the work of Maulik et al. (2011), found the ID prevalence of children/adolescents and adults to range from .05 to 1.55% (McKenzie, Milton, Smith & Ouellette-Kuntz, 2016).

(see: http://www.asha.org/PRPSpecificTopic.aspx?folderid=8589942540&section=Incidence_and_Prevalence)

Dementia

When examining the topic of reactions and needs of people with mental disabilities in emergencies and disasters we must also include another group, namely people with dementia.

Dementia is a disorder caused by brain damage that increases with age.

ICD 10 (10th Revision) labels four criteria that must be fulfilled for a diagnosis of dementia:

1. A memory decrease which leads to problems in everyday life activities or makes independent living difficult or impossible

2. A decline in cognitive abilities like thinking, planning and organizing everyday life. This leads to problems or the inability to live independently.

3. At the beginning, orientation in space and time remains possible for the affected. At later stages, orientation is more and more impaired.

4. An impairment in emotional control, motivation or changing social behaviours. This manifests itself in emotional irritability, apathy or impairments in social behaviour like eating, dressing and interaction.

The Clinical Dementia Rating (Berg, 1988) creates 5 categories describing the severity of dementia

It rates the severity from a range from 0 to 3.

- No dementia (CDR = 0): The person has no decline in cognitive function and memory. The person is able to live completely independently, solves everyday problems well and is fully orientated.

- Questionable dementia (CDR = 0.5): Slight impairment in managing everyday life and activities. The person is fully orientated apart from slight difficulties with time contexts. Constant mild forgetfulness and partial recall of events are characteristic.

- Mild dementia (CDR = 1): Independent living and difficult hobbies and tasks are no longer possible. The person is no longer independent and needs encouragement and support from others. At this stage, affected persons have moderate problems with cognitive tasks like problem-solving. Memory problems concerning recent events occur. The forgetfulness impacts everyday activities.

- Moderate dementia (CDR = 2): During this stage of dementia, memory is already severely affected. The person can only remember profoundly processed material. Recall of recent events and declarative memory are impaired. In most situations, the person is disoriented in time and often in place. The person experiences severe problems with cognitive tasks and their social judgement ability decreases. Affected persons manage simple chores and his or her interests are restricted. At this point assistance is needed for tasks like dressing, hygiene and handling of belongings.

- Severe Dementia (CDR = 3): This subtype is characterized by a severe memory loss; only fragments of autobiographical memory remain. The person is not oriented in time and space. They can no longer use cognitive functions like judgment or problem solving. People with severe dementia need extensive help with personal care and are frequently incontinent.

There are different diseases with dementia symptoms. The most common is Alzheimer's disease, followed by vascular dementia, mixed dementia and fronto-temporal dementia. Less common causes of dementia include Parkinson's disease, severe alcohol abuse, Creutzfeldt-Jakob disease, Huntington's disease, Pick's disease.

Prevalence of dementia in Europe and worldwide

The risk for developing dementia increases rapidly with advancing age. Reviews (Jorm et al., 1987; Hofman et al., 1991; Ritchie et al., 1992) have shown that the prevalence rate for dementia lies between 0.7–1% in persons between 60 and 64. This rate increases with advancing age. People between 85-89 years have a significantly higher risk of developing dementia. The prevalence rates lie between 16.4% up to 23.6%. In Europe the general prevalence rate over all age groups is 1.55%. The European Commission (2006) estimates that a total of more than 7 million people in Europe suffer from dementia.

Looking at worldwide prevalence we see that age-standardized prevalence for those aged 60 years varied within a narrow band of 5%–7% in most world regions, with a higher prevalence in Latin America (8.5%), and a distinctly lower prevalence in the four sub-Saharan African regions (2%–4%). It was estimated that 35.6 million people lived with dementia worldwide in 2010, with numbers expected to almost double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. In 2010, 58% of all people with dementia lived in countries with low or middle incomes, with this proportion anticipated to rise to 63% in 2030 and 71% in 2050 (Prince et al., 2013, p. 64).

7.1.2 Persons with learning/intellectual disabilities in emergencies and disasters

According to some prejudices people with disabilities do not often experience emergencies, have no conscious awareness of emergencies and do not talk about traumatic memories. It is also claimed that helpers are well prepared to deal with people with intellectual disabilities in cases of emergency. Furthermore it is often stated that emergency preparedness would only foster a feeling of insecurity among people with intellectual and learning disabilities. However, studies have shown that emergencies quite often also involve people with learning disabilities (Stough & Mayhorn, 2013). Additionally, people with learning disabilities do consciously experience emergencies, and even in cases where it cannot be established that they consciously experience emergencies, it cannot be concluded that the traumatic event has no consequences for them (Ballan & Sormanti, 2006). Studies have also shown that emergency helpers are not well prepared for the specific needs of people with disabilities, whereas caregivers of people with intellectual disabilities often do not know how to deal with traumatic events or disasters. Finally, it cannot be concluded that emergency preparedness automatically makes people feel insecure because it depends to a great extent on how (programs on) prevention or preparedness are conducted (Mevissen & de Jongh, 2010).

Persons with intellectual disabilities are defined as having an $IQ < 70$ and they often have difficulties in acquiring knowledge and verbal comprehension. They may face additional limitations, such as requiring a concrete, action-guided introduction to new circumstances and may be unable to live independently (American Psychiatric Association, 2013). Adults with intellectual disabilities often have a caregiver, provided for by governmental legislation. The performance of people with intellectual and learning disabilities depends on a well-structured and well-known environment, well-known caregivers and practiced action steps. In unknown situations, therefore, persons with intellectual disabilities react with a higher degree of helplessness and uncertainty (Wüllenweber, Muehl & Theunissen, 2006).

Prevalence of traumatization among persons with intellectual disabilities

Research also shows that there is a higher prevalence of (prior) traumatization in persons with intellectual and learning disabilities because of prior medical interventions, abuse by family or institutions, risk of physical abuse in public, high risk of accidents influenced by a lower awareness of dangerous situations and experiences of loss (e. g. of caregivers) which can be particularly threatening because they are heavily dependent on caregivers (Irblich, 2006a, 2006b; Irblich & Blumenschein, 2011). According to Greydanus and Pratt (2005), the most difficult group to manage and support are individuals who are not mentally retarded but have below-average levels of intellectual function (IQ scores 70–85). In adolescence, this group is particularly at risk of victimization: young women do not have the intellectual capacity to learn how to prevent rape while young men often get into trouble with authorities because they are easily led astray by their cognitively superior peers (Greydanus & Prat, 2005).

How do people with mental disabilities experience disasters/emergencies?

Due to the higher prevalence of (prior) traumatization in people with intellectual disabilities, disasters/emergencies can produce a re-traumatization or give them a strong feeling of helplessness. They have a greater need of help and care and an increased risk of long term complications. One characteristic of persons with intellectual disabilities relates to the awareness of danger which can be delayed or absent; dangerous situations might also be interpreted as meaning that the person her-/himself was responsible for the danger (Greenspan, Switzky & Woods, 2011). In some cases persons with intellectual disabilities may show severe somatic stress reactions like epileptic seizures, spasticity, cardiovascular problems, incontinence, heightened need for attention, self-harming behaviour, fear and defensiveness against physical proximity and/or aggravation of existing behavioural problems (Irblich, 2006a, 2006b; Irblich & Blumenschein, 2011).

Challenges for people with mental disabilities in disasters

According to Stough (2015) disaster planning related to people with intellectual disability needs to take into account that people with intellectual impairments (1) experience disproportionate risk in disaster situations, (2) are often excluded from relief processes and are disadvantaged in disaster support situations, (3) may need specialized disability-related supports, (4) often need assistive technology and special rehabilitative services, (5) rely on their family and community networks as important supports in disaster situations, and (6) need special attention during recovery and rebuilding (see also World Report on disability (WHO, 2011))

Thus, *"People with intellectual disabilities are more likely to need additional assistance during evacuation, experience more tangible losses during disaster, and require more intensive support in the recovery phase following disaster. Enabling access to mainstream systems and services, improving human resource capacity, and providing adequate funding for recovery and disaster mitigation are strategies to increase disaster resilience for individuals with intellectual disabilities."* (Stough, 2015, p. 138).

The report mentions that Costa Rica is one country that has designed emergency disaster management policies and incorporated disability rights policies that cut across governmental functions and promote interagency cooperation (Stough, 2015).

"Having such policy structures and legislative supports is advantageous for people with intellectual disability, whose support needs often cut across different functional areas." (Stough, 2015, p. 138).

People with dementia in emergencies and disasters

Older people often have a variety of impairments. Comorbidity is rather high. Thus, sensory, physical and intellectual impairment are very often combined in older people. As we showed in another EU project (PrepAge[2]) older people face a great variety of challenges in disaster situations.

The challenges and needs of older people in disasters arise around the following topics. They are connected to older people's vulnerabilities, their low social status and a generally low level of preparedness in organisations caring for older people (PrepAge des research report, 2014, p. 37).

- Invisibility of older people
    - Neglect of vulnerability factors and intersectionality
    - Lack of identification and data on vulnerable older people

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[2] ECHO/SUB/2013/661043 PrepAge enhancing the preparedness of older people in disasters 2014–2016, http://prepage.eu/en/

  - Exclusion and insufficient policies and laws for older people in disasters
- Discrimination and lack of protection
  - Marginalization of older people
  - Risk of abuse of older people
- Lack of financial support
  - Economic neglect of older people in disasters
  - Older people's lack of resources before and after disaster
  - Barriers to receiving and applying for support
- Need for additional health resources and support
  - Disruption of infrastructure
  - Unnecessary institutionalization
  - Lack of medical resources for older people
  - Higher risk of injury, mortality and morbidity in older people
- Need for adequate facilities and accessible distribution points
  - Inaccessible hygiene and health facilities, inadequate shelters
  - Limited access to distribution
- Need for adequate nutrition of older people
- Higher risk of stress-related problems
- Difficulties in evacuation
  - Lack of means (transportation etc.) for older people
  - Lack of understanding for special needs (e.g. pets) of older people

    - Lack of concepts (shelter, transport etc.) for evacuation of older people

- Lack of adequate warning systems for older people
- Low level of preparedness among older people and agencies caring for older people

Legal status of people with intellectual impairment

In principal the legal rights for people with intellectual impairment are the same as for people without impairments. Nevertheless, people with severe intellectual impairments are considered unable to execute these rights and therefore have a legal guardian (often a family member). A formal representative can also be appointed by court. Most services believe that if people are able to give consent to living conditions and working conditions they should be allowed to choose the kind of support/care that they want but mostly they are not given a choice. In particular, people with challenging behaviour, people with severe intellectual disability and people with autism live under very restricted conditions. This includes restricted choice about medical treatment and support in emergency and disaster situations.

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7.2 Research results

7.2.1 Needs and reactions of persons with intellectual disabilities in case of disaster and possible supportive interventions for caregivers

Fernanda Heinke, Lena Richter, Robert Bering

Introduction

This study focussed on intellectually disabled survivors. Due to the lack of knowledge about the special needs and posttraumatic reactions of people with intellectual disabilities and the lack of management requirements and support structures, it is necessary to emphasize useful information about the experiences and behaviour of people with intellectual disabilities in cases of disaster.

Method

A qualitative study was constructed based on the results of previous investigations and on the five essential elements of immediate and mid-term mass trauma intervention by Hobfoll and colleagues, concerning safety, calming, sense of self- and community efficacy, connectedness and hope (Hobfoll et al., 2007). The study was implemented in person. Seven participants with an intellectual disability were interviewed as well as one person with no disability. Different types of intellectual disabilities were involved, including Down syndrome, mental retardation and autistic spectrum disorder. Some participants were accompanied by a caregiver. Results were evaluated by content analyses (acc. to Mayring, 2015)

Results

Our study shows that in cases of emergencies or disasters, people with intellectual disabilities are more dependent on others than people without a disability. Their emotions and thoughts concern fear, vulnerability, and worries about others and themselves, so they do not differ much from those of people with no intellectual disability. The most common reactions in emergency situations reported by participants are looking for help, asking questions about what is happening and getting out of the situation to rest and to avoid being in the way of helpers, so these can take care of other affected persons. First responders in emergency settings should provide a secure environment, be near to the person, and give explanations about the incident and further procedure. They should also have a positive attitude and transfer feelings of optimism. Touching the people with intellectual disabilities, for example holding the hand or putting an arm around them, is advocated by most participants but should be tested carefully. The affected people's personal items and relaxation techniques are helpful in creating feelings of safety, calmness and reassurance, but the presence of their trusted companions is even more helpful.

In reference to the recovery phase, i.e. the time after the disaster or crisis, participants stated that emotions like sadness, worry, weakness and disorientation can arise. There may also be a tendency to repress many thoughts concerning the disaster. A need for conversations and social closeness arises. Stressful situations or situations similar to the incident will be avoided. Professional aid can be useful in ensuring appropriate processing of the traumatic event and emotional support. However, therapeutic support depends on the patient's cognitive ability and the therapist's knowledge about the treatment of intellectually disabled persons. The feeling of being connected to others and having companions around them, as well as concentrating on hobbies and retaining the familiar daily structure, encourages the process of re-entering routines after crises and gives feelings of calmness and safety.

Some participants reported that preventive emergency plans in residential communities can provide a structured procedure in case of disaster. However, all participants agreed that a safety advisor in every residential community or private home is preferred. The safety advisor's tasks should include, among other things, informing those affected and their relatives and explaining what has happened and what will happen, staying calm, knowing about necessary contacts and relieving the victim by taking responsibility for the situation. Individual emergency tool kits filled with personal items could also help to stabilize emotions after stressful situations.

Discussion

Crisis intervention management for the intellectually disabled should be enhanced by training first responders to impart knowledge about proper behaviours towards people with intellectual disabilities and thus minimize traumatic consequences. In addition, people with intellectual disabilities need more care and inclusion into the community than others to enable them to recover from stressful incidents. A trained safety advisor in every community containing people with intellectual disabilities, who is able to react as efficiently as possible could therefore help to prevent potential damage in crisis scenarios. Future implementation should concentrate on examining more cases and using different methods such as group surveys or discussions and interactive approaches to gain further information.

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7.3

Recommendations for people with intellectual disabilities, dementia and autistic spectrum disorder

Note: in this text we use the term “mental disability” to cover three sub-groups of disabilities. By the term “people with mental disability” we understand people with either intellectual disabilities, dementia or autism spectrum disorder. If we give recommendations for a specific group, we use the specific diagnostic term.

The following recommendations are based on multiple sources. One of these is the literature analysis of the topic, mainly using the guidelines based on research or particular experiences. Another source were workshops with representatives of caregivers for people with mental disability, emergency rescue services’ representatives, therapists and other specialists working with the target group. They shared their experiences and expertise and gave feedback to the information from the literature sources. In this way they also evaluated previous results and recommendations. Another source was a qualitative study carried out within the frame of the EUNAD projects.

In the following recommendations we clearly indicate if they are meant for the whole group of persons with “mental disability” or if they are specially focused on only one group – people with intellectual disabilities, dementia or autistic spectrum disorder.

The University of Innsbruck and the Charles University in Prague were the implementing institutions with comprehensive support from the University of Würzburg – Department special education, especially Thomas Spaett.

7.3.1 Emergency preparedness

The most important aspects in the prevention phase are raising awareness and training activities:

- **Raise awareness** within the community for people with mental disabilities. Community connectedness is very important, using local sources which can support the correct reaction of people with intellectual disabilities to emergency situations and efficient evacuation.

- **Promote trust in the community** – a bridge for communication with clients. Clients usually trust their local organization/caregivers they are in touch with.

- Train all helpers in psychosocial support and psychological first aid for people with mental disabilities including first responders and first aid personal. Ensure that coercive methods are only used as the very last resort.

- Ensure that all personnel is aware of national legal regulations regarding the use of coercive methods.

- **Design emergency plans** and set up intervention teams in facilities for people with mental disabilities. Institutions/service providers that provide services to people with specific needs through permanent or temporary accommodation and care should have emergency aid plans for at least the first 72 hours.

- Promote local interagency cooperation/networking between different care organizations and emergency organizations/cooperate with other organizations for people with mental disabilities.

- Implement local teams specialized in working with people with mental disabilities for intervention in disasters.

- Cooperate with emergency workers including local authorities and organizations to improve emergency preparedness of people with intellectual disabilities (planning, evaluating of preparedness and knowledge, raising awareness of needs and capacities of people with disabilities).

- Develop communication networks for unexpected events for people with mental disabilities. Prepare a contact list of relatives, close persons or a list of cooperating organisations that can give support in case of emergency.

- We recommend creating an identification bracelet (name + contact of service provider) for each person.

- Create a list of specific reactions and needs of each person. This list should also include a list of medication and dosage (client card in emergency form, i.e. laminated A4 form, portable).

- Prepare medication to cover 14 days.

- Knowledge of evacuation plan for staff and clients is essential and should be trained and tested at least once a year. Organize exercises for caregivers and for people with mental disabilities. Primary caregiver – should check whether people with intellectual disabilities are prepared for a disaster/emergency situation.

  - Actively involve persons with mental disabilities in exercise and drills but provide an environment that does not induce too much hyperarousal. If some people with mental disabilities are considered likely to become too stressed, exclude them from the drill but train with the rest of the group.

  - For people with dementia the training may not have a positive effect. Training for helpers and caregivers may be more efficient; this in turn may lead to a better and calmer evacuation procedure in case of emergency.

- Transport plans primarily for patients with mobility issues should be well prepared in advance.

- Plan of substitute accommodation/shelter – choosing adequate (similar) institution.

- Cooperate with media so that information is also suitable for people with mental disabilities (simple language).

Advantages of involving community organizations in emergency planning

- **Organizations providing daily services for people with mental disabilities have the best awareness about their clients' reactions needs and vulnerabilities during emergency situations.**

- Local organizations may or may not be connected to the state organizations providing services primarily to certain groups of people. These organizations know how to contact e.g. homeless people, low-income people and older people.

- Community organizations are experts in active searching, giving recommendations, maintaining contact with groups of volunteers, and being able to provide special services. Language and cultural sensitivity is important.

- Involving these organisations in emergency planning, preparation and training is possible and recommended.

- Mapping and support in availability/accessibility – i.e. for people living alone and not in institutions – can be only done in close cooperation with local communities.

7.3.1.1 Training and preparation

Cooperation of emergency workers with local organizations:

- Provide seminars, workshops for all staff and volunteers, exchange mutual knowledge and experience (between caregiving organisations and emergency personnel), provide knowledge about target groups and train specific ways of initiating communication and how to deal with people during evacuation.

- Carry out regular exercises (if possible clients should know e.g. "their" firefighters and should not be afraid of them, but firefighters should also get to know their potential "clients") – training in the use of protective equipment, evacuation etc.

- Use "Open doors days" – connecting organizations, public and emergency workers to get to know each other but be aware that cooperation is only effective if it is long term.

- Direct experience reduces fear and prejudice in all involved parties.

Suggestions for preparing the target group

- In some cases practical training and preparation in the organizations is not possible due to the clients' state of health. Develop other forms of exercise, but be aware that in most cases it is possible and effective to actively include especially people with intellectual disabilities in exercises.

- Provide a safe and understandable framework in exercises and training with people with intellectual disability.

- Importance of individual plans – including a basic kit/package of emergency preparedness.

- Persons with limited mobility should be supported in arranging emergency transport plans in advance.

- Contents of kit/package:

    - Identification bracelet (name, date of birth + contact of service provider or assistant);

    - List of specific individual needs of each person (name of a client, contact to close person or assistant, actual list of medication and dosage (client card in emergency form, i.e. laminated A4 form, portable);

    - Medication in prepared dosage for 14 days.

7.3.2 Emergency response

In the response phase psychological first aid must be adapted to the skills and needs of persons with mental disabilities.

First contact to persons with mental disabilities

- Respect the dignity and independence of people with intellectual disabilities during an emergency: For example: Don't treat persons with intellectual disabilities like children, talk to in a manner that is appropriate to their age.

- Take into account that despite all effort some people with mental disabilities will not be able to understand.

- According to the degree of impairment, communicate with the assistants or staff to get needed information.
- Ensure orientation according to the degree of impairment.
- Pay attention to nonverbal signals and try to respond to these adequately.
- Explain each action you perform verbally even though there might be a lack of speech comprehension.
- Use simple, slow, but not infantilizing language.
- Be careful in the case of physical proximity (caution: Individuals with intellectual disabilities might fear medical interventions).
- Some people with intellectual disability or autistic spectrum disorder use assistive technologies to communicate.

- Ensure that basic needs are covered and promote stress reduction:
  - Assess needs depending on the degree of impairment (e.g. restricted communication possibilities or obsessions with certain concerns (toy/mother).
  - Permit stereotyping or automutilitative behaviour (reduction of tension and calming down).
  - Minimize additional sources of distress – for example switch off emergency vehicle light.
- Enhance feelings of protection, safety and stabilization:
  - Involve trusted individuals, familiar environment, belongings, assistive technologies, activities; establish contact to persons of trust (parents).
  - Implement security by providing distance or proximity (individual differences).
  - Promote the feeling of self-efficiency and independence as much as possible.
  - Be aware that concrete and actual experience is more important than imagination.
  - Be aware of group thinking and group behaviour (calming group behaviour).
  - Keep attention on dynamics and emotion transmission in a group of clients. On the other hand, evacuation of clients in groups may give them feeling of safety.
- Involvement of caregivers:
  - In most cases caregivers are affected by the disaster themselves and restricted in their actions; they cannot care for more individuals at the same time. Therefore: Cooperate with caregivers, help them to help or include other capable persons of trust.
  - Support and advocate for caregivers.
  - Instruct trusted people how they can help.

- Information dissemination:
  - Focus on few key points and concrete information (support via gestures).
  - Use clear, guided communication.
  - Seek information from family members.
  - Involve local caregivers and institutions.
  - Ensure counselling for caregivers and facilities for persons with intellectual impairment.
- Responding to self-harm and harm towards others:
  - Pay attention to the safety and protection needs of helpers.
  - Act in an effective and in the least harmful manner.
  - In severe cases contact medical personnel to support with medical treatment.
  - Permit grief.

Specific communication aspects of older people with dementia

- Address clients using their names or titles (not using “grandma”, “grandpa”).
- Be active in checking for possible communication barriers and adjust your communication.
- Calm down possible sources of noise – TV etc.
- Don’t use a loud voice, unless you are sure the client is hard of hearing.
- Respect clients’ slower pace and protect them from time stress.
- Repeat information several times and/or use writing on paper, when the information is complicated.

Specific communication aspects of people with intellectual disabilities

- It always depends on the level and strength of the disorder. Staff and assistants are most familiar with clients' specifics.
- Be aware of different rules of communication! (take the whole situation into account). There are different levels of verbal communication – they may have trouble using "yes/no" correctly.
- Don't underestimate clients in communication – avoid childish talk, communicate with them like with adults. Avoid paternalism.
- Expect high suggestibility – people are easily influenced by others.
- Be aware of a tendency to be dependent on other people.
- Expect poor orientation in unknown environment.
- Clients may react in a "strange way", in their own way (i.e. can react very loudly to a very small change).
- They may ask strange questions and repeat them over and over again.
- They may talk to themselves.
- Sometimes they laugh when other people don't.
- They use facial expressions less or in their own way.
- They may get into strange body positions.
- Very often they don't respect communication (personal) space.
- Calm them down, explain what is going on.
- Use simple language. Avoid specialist terminology, phrases, irony etc.
- Use nonverbal communication:
    - Illustrative gestures – point at body, at concrete objects etc.
    - Use pictures/picture cards

- Use assistive technologies (talkers and other technical aids) if available
- Verify their understanding
- Allow more time for answering
- If they don't understand show them what you mean or use different words or sentences.
- Use concrete expressions and exact timing: instead of saying, "We will go for a walk in two hours" it is better to say, "We will go for a walk after lunch".
- Always speak about one topic/one object/one thing at a time.
- Be clear in letting the person know that the conversation is finished or that you are leaving.
- During transport, use physical contact (holding hands) until you pass on a client to a familiar person; it is best to involve persons the clients know!

Specific communication aspects of people with autism spectrum disorder

- They may not communicate verbally, and may not always react or react with one word. Be aware of nonverbal signs.
- They may have trouble with the correct use of yes/no.
- They may not ask usual questions – e. g. a question that doesn't correspond to the person's age or that is unusual (repeatedly asking about measures such as height, weight, technical questions, time of city transport etc.) or asking about the same thing over and over again.
- Conversation is often not suitable to the situation (they don't respect social context; do not differentiate between conversation partners).
- They very often talk to themselves.
- Inappropriate laughter with no meaning.
- Stereotypes – repeating the same words, sentences, songs, verses etc.

- Verbalism – “verbiage”, accumulation of words or sentences used incorrectly.
- Echolalia – repeating words, sentences, phrases. It may be immediate or postponed.
- Hyperacusia – hypersensitivity to audio impulses with inappropriate reactions (aggression – towards all around, or themselves).
- Overgeneralization of words – i.e. everything red is blood.
- Some may not be able to generalize – “a car” – they may mean only one specific car, e.g. a toy from their childhood.
- Their talk may have a mechanical and formal sound.
- They may speak about themselves in the 3rd person (he/she/it), very small usage of the 1st person.
- Many have difficulty in using and understanding irony or abstract expressions.
- Eye contact – they often have problems in establishing and maintaining eye contact, looking “through” you, not stable in looking at you, looking at objects for a very long time etc.
- Facial expressions – little or no ability to express and understand emotional expressions (sadness, happiness).
- Use of gestures – little or no ability to express or to understand gesticulation (hand waving etc.).
- Inappropriate body position or movements (shrugged shoulders, nodding, and spinning).
- Communication (personal) space – not respecting it; their personal space can be either too big or too narrow.
- Prosodic factors (melodies, rhythm of talk etc.) – the voice may be too high or too low; monotonous, staccato (short talk), legato (prolonged talk).
- Other communication forms – using another person’s hand as a tool to get something (putting a hand on the door means “open the door”).

- They may have very high tolerance of pain (they don't mind their own injury) or strange ways of expressing pain.
- **They may have very low tolerance of waiting.**
- They may have **rage attacks** (including aggression towards their surroundings or towards themselves) while waiting for something or in situations that bring changes in their rituals or as a reaction to a specific impulse (word, context …).

Communication/interaction strategies for people with autism spectrum disorder[3]

- Avoid sudden movements.
- Move slowly, performing exams from distal to proximal.
- Explain what you plan to do in advance and as you do it. Explain where you are going and what they may see and who might be there. This may avert unnecessary anxiety and/or outbursts of aggression from the patient. Individuals who appear not to understand may have better receptive language, which may not always be entirely evident.
- Expect the unexpected. Clients with autism may ingest something or get into something without their caregivers realizing it. Look for less obvious causality and inspect carefully for other injuries.
- If possible ask a caregiver what the functional level of the individual with autism is, then treat accordingly. Stickers, stuffed animals and such items which are used to calm young children may be helpful even in older patients.
- Attempt to perform exams in a quiet spot if at all possible, depending on the severity of injury and safety of the scene. Demonstrating what the exam will consist of on another person first may help the person with autism have a visual knowledge of what your intentions are.

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[3] Rzucidlo, S. F. (2007). Autism 101 for EMS, from SPEAK Web site: www.papremisealert.com

Evacuation of people with intellectual disabilities

- People with intellectual disabilities may need more time to mobilize support, to arrange transport and to find a suitable target place to evacuate to.

- People with limited mobility should be supported to arrange emergency transport plan in advance.

- Research shows that most emergency situations happening in nursing homes or hospitals were well managed thanks to flexible staff and other people (friends, families). Staff providing primary medical care may be interrupted or busy due to the evacuation process and it may make it difficult to give the necessary care.

- Shelters in big buildings such as schools may cause disorientation to people with intellectual impairment and dementia. The noise, and more and quicker activity may cause chaos. An unknown environment and a gathering of many people may be a problem for people with autism.

- It is necessary to support persons with intellectual disabilities in adjusting to a new environment – as a first step it is important to minimize confusion and then re-establish structure as soon as possible.

- In case of evacuation of an institution for people with mental disabilities we recommend cooperation with a second similar institution where clients can be transported and looked after in similar way.

- In substitute accommodation/shelter, services must be accessible – including communication technologies (interpreter, assistive technologies, printer, assistance for people with mental disabilities etc.).

7.3.3 Emergency recovery

In the recovery phase normality and additional care should be established.

- Support in re-establishing daily activity structures; help in regaining normality/ returning to the usual functioning of services and continuity of care.

- Refer to therapy if needed/ Ensure psychological care if needed.

- Focus on stabilization techniques.

- Criteria showing that additional care is required:
  - Prolonged or recurrent severe signs of distress (in spite of medical treatment), sleeplessness, restlessness, no ingestion, dissociation, lacking involvement in group behaviour, lack of understanding or acceptance
- Give mental health care if needed and appreciate the work of caregivers.
- Provide counselling for facilities with special needs to ensure long term recovery. Coach caregivers in how to support clients.
- People with intellectual disability can and should be involved in mourning rituals.
- The risk target group usually obtains less financial and material help after disasters. That is why they need more support and guidance.
- The problems start with managing official procedures including the requirement to fill in forms on a computer and to apply online.
- People with intellectual disabilities often have poor orientation in a new environment. A person with an intellectual disability often has problems in directional orientation and numbers. If it is necessary to send this person somewhere to an office it is always better to go with him/her as a guide. Although this person may find the right office he/she is still afraid to enter and so often leaves with no result or keeps waiting, letting other people go in (overtake).
- Lower capacity to understand written text. We should read the text together, explain it, and ensure they understand. We should not just give the paper to the client to fill in.
- People with mental disabilities can be afraid of losing social or other benefits.
- Older people may be ashamed to accept help (they may perceive it as being stigmatizing) or may feel that other people need help more.

8

Physical impairments

Ask Elklit, Louise Damsbo Simonsen, Adnan Todorovac

Physical impairments have many forms. They may entail congenital limb and torso motor impairment, mobility disabilities after injuries, limited mobility due to age, bedridden patients, people with different levels of self-care, and various compensatory devices (dentures, crutches, walkers, wheelchairs).

Some may have a **simultaneous involvement of speech and facial muscles** (lay people can sometimes confuse the symptom with drunkenness or mental retardation).

Because combined disabilities occur so frequently, we give some guidelines here that apply to people with physical disabilities.

Physical disability does not affect the affected person's understanding of what is communicated, but if we want to establish trust, it is good to provide these people with the maximum possible comfort.

Not all people with physical disabilities experience a **combination of mental and physical or sensory impairment.** The type of help required differs in these people as do their self-help and self-care capabilities.

Immobilized patients: Each movement is carried out according to the will of another person, but the ability to perceive it is retained. These patients are physically the most vulnerable.

Long-term bedridden patients have chronic problems, sensory deprivation, whole body pain, and bedsores, while sensitivity of sensation is preserved. Decisions are often made "about them without them". Do not underestimate the importance of communication with them!

8.1 Review of research

Adnan Todorovac, Louise Damsbo Simonsen, Ask Elklit

Rahimi (1993) examined how PD individuals acted and felt during the earthquake in Loma Prieta in 1989. The results showed that a lack of activity during the earthquake was not due to the PD individual's feeling vulnerable or unsafe; instead the individuals who reported no or little fear during the earthquake were more likely to stay passive. The PD individuals did not think of themselves as vulnerable, and those who felt vulnerable initiated self-protective action in response to the hazards present in their immediate surroundings. These findings might suggest that PD individuals have a psychological advantage when adapting to a changing environment because they already deal with changing and difficult physical and environmental limitations in everyday life.

However in a study regarding people's emergency preparedness, Smith & Notaro (2009) found that PD individuals were more likely to state that they were not prepared for an emergency than non-PD individuals. Furthermore, they found that PD individuals including women, minorities, non-white and individuals with low income and low educational status were at higher risk of being unprepared for an emergency. Sever (2015) conducted research on disabled individuals living in bombarded areas in Israel in 2006. The results showed that the disabled individuals had difficulties entering the evacuation shelters, and that they did not want to ask for further help because they felt the shelters were not adequate for their functional needs. Some of the disabled individuals who had a place to evacuate to had no way of getting there. Furthermore, the disabled individuals who lived alone and did not evacuate were left behind without any safety net because many of their neighbours had been evacuated. Individuals that lived in care facilities and were dependent on others 24/7 were left alone without treatment, assistance and sometimes without food and water when the care personnel evacuated with their families.

In a further study, after the hurricanes Bonnie, Dennis and Floyd in the USA, Van Willigen, Edwards, Edwards & Hessee (2002) found that households with a PD family member were less likely to evacuate from their homes than other families. Reasons for not evacuating were attributed to a lack of access to transportation, shelters, services and assistance. In addition, many of the interviewees who used wheelchairs argued that they would not evacuate without their wheelchair. Shpigelman & Gelkopf (2017) investigated the experiences, challenges and needs of individuals with lifelong disabilities who had been exposed to chronic politically violent events. They found that external stressors including environmental conditions and the response to these stressors played a major role for people with disabilities in dangerous situations. Most of the participants reported stress due to the inaccessibility of the physical environment, including difficulty in locating and finding a shelter within a short time and difficulties entering a shelter whose opening was not wide enough to accommodate a wheelchair. The study concluded that environmental barriers might limit the PD individual's functioning and might increase their level of distress. To sum up, these studies show that it is important to have an effective evacuation system and evacuation plan for PD individuals when a disaster or traumatic event occurs.

Guidelines

Practical guidelines and evacuation guides have been published in great numbers (National Fire Protection Association, 2016; City of Los Angeles Department on Disability, 2002; Server, 2015; American Red Cross Disaster Services, 2016), but there is still a lack of scientifically-based guidelines. This descriptive study is the first of its kind to be conducted in Denmark. It was part of a larger, two-year project funded by the European Commission. The project entitled The European Network for Psychosocial Crisis Management – Assisting Disabled in Case of Disaster (EUNAD) (www.eunad-info.eu) focused on developing and implementing standardized EU human rights-related assistance programs for people with disabilities, including PD individuals. The project represents a collaborative research effort between partners from Germany, Czech Republic, Austria, Norway, and Denmark. The goal of the present study was to gain insight into the experiences of PD individuals with accessing first response, healthcare and trauma-informed aftercare services following experiences of disasters, and their suggestions for improving these services. The rationale behind this was that their experiences with accessing services in connection with other crisis situations could help highlight potential areas for improvement in service provision that are also likely to be relevant in times of disaster. Our specific research questions were as follows:

- What difficulties were encountered during crisis situations? And how did the participants react under and after crisis situations?

- What experiences did the participants have when interacting with health-care professionals (e.g. hospital staff, psychologist) and in general with the municipality?

- What future directions should be taken to better assist PD individuals in the event of disasters and other crisis situations?

8.2 Research results

8.2.1 No one left behind – The accessibility of medical and psychosocial services following disasters and other traumatic events: Experiences of physically disabled individuals in Denmark

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Introduction

We are all vulnerable in times of disaster. Physically disabled (PD) individuals are particularly vulnerable and are frequently overlooked in disaster situations (Handicap International, 2005). PD individuals are primarily divided into three groups: 1) wheelchair users, 2) ambulatory mobility and 3) respiratory (National Fire Protection Association, 2016). Wheelchair users are vulnerable because of their dependence on their wheelchair to move around. Problems when evacuating might arise if individuals in wheelchairs have to manoeuvre through narrow spaces, move over rough or uneven surfaces or use toilet and bathing facilities in places not suitable for PD individuals (National Fire Protection Association, 2016). Other problems that might arise for individuals using wheelchairs are the potential need of a pair of heavy gloves to protect their hands or a situation where a tyre might puncture if they run over glass or debris. If it is not possible to continue the evacuation in the wheelchair, the PD individual has to be carried (City of Los Angeles Department on Disability, 2002). Likewise PD individuals in wheelchairs cannot seek shelter under tables as it is recommended in cases of earthquake nor can they evacuate quickly out of buildings with stairs (Server, 2015). These problems mean that wheelchair users usually are dependent on others in cases of emergency where it is necessary to evacuate.

People with ambulatory mobility are not able to use certain limbs or coordinate their movements. Problems might arise if they have to walk, climb steps or slopes, stand for extended periods of times or reach and use fine finger manipulation (City of Los Angeles Department on Disability, 2002). People with respiratory issues may have difficulties in evacuating due to dizziness, nausea, breathing difficulties, tightening of the throat or difficulty concentrating. These people may require rest breaks while evacuating (ibid.).

It is difficult to say exactly how many physically disabled individuals there are in Denmark: first of all, because there is no registration for physical disabilities in Denmark, and second, because it is difficult to give a precise definition of the term physically disabled. The World Health Organization (WHO) estimates that approximately 10–15 percent of any given population has some sort of handicap (Danish Handicap Association, 2017). Of the 16–64 year old in Denmark, 26% reported a self-rated physical handicap (Centrale Handicap Advices, 2014). A study from 2002 by the Denmark State Bank showed that 744,000 individuals in Denmark between 15 and 66 years have long-lasting health problems or a handicap. This corresponds to every 5th individual in this age group. 6% had long-lasting health problems or a handicap in the "arms or hands category", while the numbers were 10% for the "legs or feet's" category, and 28% for the "back or neck" category (Denmark's Statistic, 2002). More recent figures showed an increase in the last three years in social services for individuals with mobility incapacity (Denmark's Statistic, 2017). According to the Danish Statistical Bank, there were approximately 4,200 individuals with a physical mobility incapacity who received social security (Denmark's Statistic, 2017).

An important piece of legislation for PD individuals is the Convention on the Rights of Person with Disabilities (CRPD), adopted by the General Assembly of United Nations on 13th of December 2006 (UN General Assembly, 2007). The CRPD provides the full range of rights for persons with disabilities, including during situations of armed conflict, humanitarian emergencies and natural disasters (Mittler, 2015). Denmark and many other European countries have signed and ratified the CRPD. In the context of post-disaster service provision, State Parties and public authorities have a responsibility to ensure that medical and psychosocial services are adapted to meet the specific needs of people with disabilities, including PD individuals.

Consequent to Denmark ratifying the CRPD, the Danish Emergency Management Agency is obligated to provide equal opportunity and accessible services to assist PD individuals especially in the events of disaster. Regarding the organization of local emergency responses to disasters and accidents, guidelines laid down by the Danish Emergency Service Act stipulate that local councils are responsible for providing reasonable assistance for personal injuries and property damage. This obligation also covers persons with disabilities (UN Committee on the Rights of Persons with Disabilities (CRPD), 2017). However, to be effective, post-disaster assistance should also promote the psychosocial well-being of survivors. First response, healthcare and trauma-informed aftercare services play a crucial role here. It is not currently known whether such services in Denmark are properly equipped to respond to the specific needs of PD individuals following disasters. Documenting the experiences of PD individuals of accessing these services is therefore crucial.

To our knowledge no Danish studies exist that investigate how PD individuals experience a traumatic situation and the services after the event. Moreover, we are aware of only a limited number of international studies on PD individuals exposed to traumatic events [Server, 2014; Smith & Notaro, 2009; Rahimi, 1993; Shpigelman & Gelkopf, 2017; van Willigen et al., 2002).

Methods

Participants

Disasters are relatively uncommon in Denmark, hence recruiting PD individuals with disaster experience proved difficult. We therefore expanded our recruitment strategy to include PD individuals who had experienced other critical situations (e.g. accidents, personal crises). A total of twelve (n = 12) PD individuals were selected to participate in this study (Table 1). All were of Danish nationality. The majority (n = 9) were males. Participants' age ranged from 23 to 54 years. Five (n = 5) were wheelchair users and five (n = 5) were electrical wheelchair users due to either acquired injuries in accidents, sclerosis, osteoporosis, cerebral palsy or congenital disability. One wheelchair user also had respiratory issues. Two (n = 2) had ambulatory mobility. We recruited participants through several handicap organizations, Danish Handicap Associations (DH), via a workshop at the University of Southern Denmark, and through advertising on social media (e.g. Facebook).

Table 1: Summary of characteristics of study participants (n = 12)

Pseudonym	Sex	Age	Reason for physical disability	Wheelchair/Ambulatory disability/Respiratory issues
Brian	M	40+	Working accident	Electric Wheelchair
Rasmus	M	40+	Sclerosis	Wheelchair
Simon	M	50+	Traffic accident	Electric Wheelchair
Oliver	M	30+	Cerebral palsy	Electric Wheelchair
Sebastian	M	30+	Congenital Osteoporosis	Electric Wheelchair and Respiratory issues
Birgitte	F	40+	Ehlers-Danlos syndrome	Ambulatory disability
Pernille	F	20+	Dysmelia	Ambulatory disability
Anna	F	60+	Congenital physically disabled	Electric Wheelchair

Pseudonym	Sex	Age	Reason for physical disability	Wheelchair/Ambulatory disability/Respiratory issues
Mathias	M	40+	Broken spine due to accident	Wheelchair
Tobias	M	50+	Broken spine due to accident	Wheelchair
Søren	M	20+	Traffic accident	Wheelchair
Carsten	M	30+	Parachute accident	Wheelchair

* Ages are not precise for anonymity reasons

Materials

A semi-structured interview guide was developed by the authors. The first part identified a crisis situation (e.g. daily crisis, disaster or terrorism) and included open-ended questions (e.g. "How did you react in the crisis situation? Thoughts? Feelings?" and "How far did you experience the professionals as experienced in helping people with physical disabilities?"). The second part of the interview guide focused on the individual's coping with the situation and possible psychological help seeking (e.g. "Has your life changed after the crisis situation?" and "Where did you seek support after the crisis situation? Family, friends, professionals?"). The third and final part included questions about future recommendations for professionals (e.g. "What should professionals be aware of when rescuing people with a physical handicap?" and "What could emotionally hurt you in an attempt to rescue you?"). The participants were likewise encouraged to include any experiences they might consider relevant.

Procedures

Data collection took place between October 2016 and June 2017. The authors followed the Nordic ethical guidelines for psychologists. Prior to the interviews, participants were informed about the study objectives as well as issues of anonymity and confidentiality. They were also informed about their right to drop out of the study at any time. All participants provided verbal consent to participate in the study. The interviews were conducted by the two first authors. Three of the participants were interviewed in a group. The others were interviewed on an individual basis. Interviews lasted approximately 1–3 h. The majority of the interviews took place in participants' homes or other places nearby (e.g. workplace, community center). All interviews were recorded on tape. The interviews were subsequently transcribed by the authors. We each reviewed the transcripts several times and identified key recurring themes associated with each category of research question. The authors discussed the themes during face-to-face meetings. Disagreements about themes were deliberated until consensus was reached.

Results

The main themes emerging from the analysis are presented in this section.

Category 1: Difficulties encountered during crisis situations

One major complaint almost all of the PD individuals had in common was that there was a lack of guidelines and evacuation plans in case of emergency. None of the participants were familiar with any general recommendations or guidelines. Furthermore, in some cases when there was an evacuation plan, it had not considered the physical state of the PD individuals and would not be effective or easy to carry out in case of an emergency. Another problem was that sometimes when equipment was described as handicap-friendly it might be useable for individuals with mild PD but not suitable for the individuals with more severe PD. One participant, Tobias, stated that putting a handicap-friendly sticker on something would not make it handicap-friendly. Several PD individuals should have to try it out before it could be called handicap-friendly.

One individual experienced when visiting his rehabilitation physiotherapist that the evacuation plan was to get everybody up onto a flat roof from where they were to climb down a ladder. The roof was accessible through a door raised 35 cm from the floor, without a ramp.

> > *“My physiotherapist said, ‘You are not the problem. We will get you down’. But they did not know what to do with the electrical wheelchair that weighs 100 kg by itself. They had to rethink that. They had an evacuation plan, but it was not optimal!”* (Søren, wheelchair).

The majority of the PD individuals stated that they have to plan their entire day around their disability. Despite the planning, many of them had not thought about their general emergency preparedness and lacked sufficient planning and thought in case of something unplanned would happen. Many of the participants believed that it was important to consider possible crisis-related situations, or at least have thought about what to do if an emergency emerged. However, several reported that they themselves were not ready in cases of an emergency.

> *"It is important that we think about what we are going to do and how I want people to react if I find myself in a situation of crisis. These are not pleasant thoughts but they are important to consider, because only when you are ready to die can you truly live."* (Pernille, ambulatory disabilities).

A few PD individuals had discussed the issue of potential crisis with their helpers and relatives, and had stated that in cases of emergency the person had to save himself and not risking their own life in trying to save the PD individual.

> *"Then I came home, and I said to my husband. We have to talk about if something happens in the metro or something like that. Have you considered you may have to run and abandon me? Then he looks at me and says; We cannot do that! And I say; You might have to. What if we agree that is what I want you to do?"* (Birgitte, ambulatory mobility).

Instead of planning what to do in case of emergency, more of the PD individuals had the belief that everything would work out fine, even if they were not prepared. Almost all of the PD individuals who had 24 hours of help stated that they were sure their helper could save them and therefore did not think about what to do if a crisis situation occurred. Anna states that "having the autonomy and freedom to do what you want is more of a priority than safety."

Some of the PD individuals explain that it can be difficult to make general recommendations on evacuation plans for PD individuals because there are so many different types of physical disabilities; a person with ambulatory disabilities and a person in an electric wheelchair does not necessarily require the same type and range of help. An extra problem arising for PD individuals who do not use a wheelchair is that their disability might be invisible. It might therefore be hard to gain the help they need. Pernille emphasises that she has a prosthesis which means she cannot run; this can be hard for others to understand in a crisis situation because the prosthesis is not so easy to spot.

> *"No two wheelchair users have the same needs, and it is therefore difficult to put into a system [...]. You have different needs, so it is important to listen to the individual needs instead of pinning them down."* (Brian, electrical wheelchair).

Because of the different needs, one PD individual, Mathias, suggested that if you make an evacuation plan based on the worst case of physical disability, then you are ready to help almost all types of physical disabilities in case of emergency. It might even be easier to evacuate the individuals whose disability is less severe because they might not need as much help as planned.

Many of the participants agreed that test evacuations are a good idea and can make a real evacuation easier, but they also underlined that a test evacuation loses its purpose if the disabled individual is left behind because it is too difficult to include them. One individual in an electric wheelchair, Oliver, was left behind in a test evacuation at work and would stand inside and wave to his colleagues that had been evacuated to the ground outside. He emphasizes that in a test evacuation you find out the best possible way out and where you need improvements. It is also the time where you can agree upon who has to lift the person if it is not possible to bring the wheelchair. An ambulatory mobility individual, Birgitte, often experienced being left behind in test evacuation situations in school because there were a lot of stairs that would take too long for her to walk down by herself and it was too difficult to help her down.

Another participant in a wheelchair, Søren, experienced a fire alarm that started in a museum. He was with another disabled man who was in an electric wheelchair. The elevator did not work and when they got to the emergency exit there were five steps up to the door and no ramp. Søren could drag himself up the stairs, but his companion could not. When the staff arrived, they told him he had to leave the man in the electric wheelchair because they could not get him up the stairs.

> > *"I told them that it did not work. They thought this was a kind of situation that they learned something from. Luckily for them it was a false alarm, because if it was not a false alarm, what would they have done? The man had his wife and children with him, but he was just to be abandoned. I told them they had to have a ramp and they answered they would take it into consideration. I think it should not be considered. It should just be done!"* (Søren, wheelchair).

Two of the participants had ideas could be implemented that could help PD individuals in crisis situations. One participant, Pernille, suggests that in public places there could be a giant yellow pillar where PD individuals, in case of emergency, could go and find help from someone who had been educated in how to help PD individuals. Another participant, Tobias, suggested there could be an extra high table in case of earthquake where a person in a wheelchair can drive under or a table that can be raised or lowered.

One of the participants, Mathias, explained that the law requires that ramps have to be 4 meters wide and that the slope has to be slow rising. Both he and other participants thought that in an evacuation situation it does not matter that much if the slope is a little bit steeper or the ramp a little bit narrower, as long as a wheelchair can get up and away from the danger. A ramp gives a chance to escape whereas no ramp can make it almost impossible for some disabled individuals to get evacuated. Making buildings more handicap-friendly is not something that necessarily cost a lot of extra money. Anna described that when the new building for The Danish Handicap Associations were built, they focused on making it handicap friendly. This resulted in a building that it was easier for PD individuals to escape from in case of evacuation with elevators working even in case of fire. This project ended up costing the same as if the building had been built without the extra consideration for PD individuals.

Category 2: Reactions under and after crisis situations

The PD individuals' reactions under crisis situations ranged from freezing completely to getting very involved in sorting out the problem. Some of the individuals had a hard time asking for help while others just wanted their lives prioritized and help to get away and survive, and things like wheelchairs and the risk of broken bones came second. A PD individual, Mathias, stated that the only thing that you can do in situations of crisis, where you as an individual are dependent on your wheelchair and cannot evacuate yourself, is to scream for help and pray that someone comes to your rescue.

The reactions after the crisis situations ranged as much as the reactions under the crisis situation. Some of the individuals became more watchful while others were not affected by the situation. None of the participants saw a psychologist directly because of reactions arising after a crisis situation. Instead some of the participants sought out help from other PD individuals, who had already faced similar situations, and described how it can be helpful to talk to people who can relate to your situation. One individual, Rasmus, told that the happiest and most positive PD individuals and those who share the most experiences were the ones who had been physically disabled the longest.

> *"A psychologist can never say: I know how you feel, because they cannot understand. I was offered help from a psychologist right after my incident, but I said no. I would rather talk to another physically disabled person or other individuals in the same situation as me than with a psychologist."* (Søren, wheelchair)

According to several PD individuals, thinking about emergency situations can be too negative, which makes them more prone to try to think more positive thoughts and avoiding the negative. Some of the participants described that the general PD individual starts off by being negative when he/she first receives the news about being disabled. Later most PD individuals become more and more positive as he/she learns to live with the disability.

> *"You can get sick of it, if you always have to think about all the negative stuff and what might happen. It is always the family that worries more about what might happen. It is only a problem if you make it a problem."* (Søren, wheelchair)

However some PD individuals still deny that they have a disability or that their disability makes them different from everybody else. They are trying to live their lives as normally as possible without considering the disability.

> *"I am just like everybody else. I am not disabled. I might be in a wheelchair but I am not disabled."* (Sebastian, wheelchair)

Category 3: Interactions with healthcare services

Some of the PD individuals state that they have encountered hospital personnel that lacked both empathy and knowledge about differences between physically disabled individuals and individuals without physical disability. Birgitte always felt she got too much attention because of her rare disease; when she is hospitalized a lot of extra doctors enter her room just to watch. She does not feel the doctors are taking her feelings into consideration. Brian have also experienced doctors that lacked empathy.

> *"The first doctor I talked to when I woke up after surgery, his first words were, 'Do not expect to be able to move more than you can now'. That was harsh. It was not what you needed to hear as the first thing after waking up. [...] After five to six days I complained about pains in the middle of the night. A doctor comes in and the first thing he says is, 'Sit up straight so I can listen on your back'."* (Brian, electrical wheelchair).

Simon experienced how a lack of knowledge about PD individuals can cause more damage than healing when getting treated in the hospital. After breaking a leg the doctor put on a cast that resulted in a wound that worsened his condition more than a broken bone.

> *"When you cannot feel anything, you must not put on a cast. The first time I broke my leg they treated me like everybody else. They put on a cast and before I could convince them that I should not have a cast, and the chief of surgery convinced them, 14 days had passed, and I had got a pressure sore on the heel that took over a year to heal. [...] You have to think different when you are paralyzed. They did not take that into consideration; it was very problematic."* (Simon, electrical wheelchair).

Furthermore, several PD individuals stated that their own expertise on their disability was not taken into consideration by the hospital's social offices. Most of the staff were trying to lecture about the disability but no one seemed to have the time to listen to what experiences the PD individuals had themselves. One PD individual, Birgitte, stated that when she tried to offer ideas for better solutions on how to improve things at the hospital, she was ignored because of the lack of resources.

All the individuals who had a handicap helper said they often experienced that when encountering new people, the latter often communicated with them through their helper. The newly encountered people assumed that a physical disability was equal being totally disabled and not being able to have a conversation. Therefore the PD individuals had to tell them that they are fully able to communicate themselves. They pinpoint the need to feel autonomy even though they need help. Likewise, the PD individuals underlined the importance of remembering the person behind the handicap and remembering to show empathy and not just sympathy. They need information about evacuation plans like people with no disabilities.

> *"I have experienced a couple of times that when I am out shopping in places I have not been before and I have my helper along, people tend to communicate to the helper and not me. My helper tries to explain that I am the one they should talk to. Sometimes we act like we do not know each other, thereby forcing the employers to talk to me. It is just because people do not know better."* (Sebastian, electric wheelchair).

Category 4: Municipality problems

Several PD individuals have had different experiences in services provided by the municipalities. It varies a lot from municipality to municipality how much help they will grant a PD individual and how hard the individual has to fight to get the things he is legally entitled to.

One participant recounts that first of all there are too many small laws and regulations and that you as a PD individual have to know exactly what you are entitled to; otherwise you might not get what you need. Therefore many PD individuals state that you have to be socially skilled and know how to provide the best arguments.

> *"Some municipality offices are totally insane. They are trying to save money on everything, and people are not getting the most basic stuff. I know someone who could not get granted something they needed, so they moved to a different municipality and got a handicap car. It is not fair that some people get everything they need and things they don't need, while 10 others do not get the most basic stuff for their disability. There is a lack of guidelines."* (Mathias, wheelchair)

When the municipalities have budget cuts it can have serious impact on PD individuals. Simon experienced in his municipality that his help service was reduced from 20 hours a day to 11 hours a week. Because of this he did not get help getting turned around at night to avoid bed sores, which resulted in pressure ulcers and later blood poisoning. He ended up staying at the hospital for 9 months because of this. Afterwards when he moved to another municipality he got back his help for 20 hours a day. Another PD individual, Birgitte, feels obligated to equip herself with several helping devices such as collars, walking sticks and knee shin pads when going to meetings with her social worker at the municipality, even if she doesn't need those specific helping remedies that exact day. When Birgitte is wearing her assistive devices, her experience is that communication is easier and that the social workers understand that she has a handicap even though you might not see it without the devices. Birgitte once took a test that concluded she needed help at home, and the municipality urged her to apply for help. She has applied more than once because she kept getting rejected because she was married and therefore had a spouse that could help her. One time she was granted help to clean the house, but this was retracted when they found out they made a mistake and that she was married.

> *"The municipality office says that the test concludes that you need help in your home, and encourages to apply for help. Then you do that and get rejected because you are married and have homebound children. The municipality office knows this [...]. If I was to file a divorce, and live by myself and still had homebound children, then I could get all the help I need. But I am so silly that I am married."* (Birgitte, ambulatory disabilities).

Recommendations

This is the first study to investigate barriers faced by PD individuals in Denmark when accessing medical and psychosocial services following disasters and individual traumatic experiences. The use of semi-structured interviews enabled us to gain an in depth understanding of participants' experiences.

Regarding difficulties encountered during interactions with healthcare professionals, all our participants expressed concerns about the lack of guidelines for evacuating PD individuals in situations of crisis. This finding is consistent with those of previous international studies investigating PD individuals' experiences with evacuations (Server, 2015; Shpigelman & Gelkopf, 2017; Van Willigen et al., 2002). Test evacuations are a good way to prepare how to evacuate, but even though it makes the evacuation longer and more difficult, it is important to include the PD individuals as it will not be any easier to evacuate them in a real danger situation.

It should be considered that there are a lot of different handicaps, and that healthcare professionals should be aware of special individual needs. Equally, it should be mentioned that PD individuals react differently in different situations of crisis. Participants in electric wheelchairs specify that their wheelchair is extremely important for them to bring along, because if they leave their wheelchair they will be absolutely helpless, whereas this is not so important for the participants in non-electric wheelchairs. It is important to remember that PD individuals with different disabilities can have very different needs in cases of crisis. Therefore it should be considered that guidelines should be suitable for PD individuals with more severe disabilities, because this can also ease the evacuation for PD individuals with less severe disabilities.

Another important point is that PD individuals should prepare themselves and talk with their family and friends about what to do if a crisis situation occurs. Some PD individuals might take for granted that their helper will evacuate them in times of crisis, and it is therefore important to talk about the different expectations the PD individual and the helper might have.

Some participants felt that healthcare professionals lacked knowledge about the difference between treating PD individuals and non-PD individuals. This lack of knowledge can lead to more harm than good when treating PD individuals. Some of the participants experienced that the healthcare professionals showed limited empathy and did not listen to the recommendations the individuals presented afterwards.

Furthermore PD individuals experienced that several times the healthcare professionals and other professions did not communicate directly with them but with their helper. It is therefore important that healthcare professionals are instructed in the differences between treating different PD individuals and non-PD individuals and do not just leave this information for the specialized doctors. It is also important to show empathy and maybe consider the help PD individuals offer when they come with ideas and support in how to improve the treatment of PD individuals.

As a PD individual living in Denmark, you have to consider which municipality to live in, as there are big differences between municipalities in relation to how hard it is to get help and services. Likewise, you as a PD individual have an obligation to know the laws and what you can demand; otherwise it can be hard to get the help you need. More general guidelines on what PD individuals have the right to could improve living standards and quality of life for some PD individuals.

Therefore the following could be considered when making guidelines for PD individuals:

Recommended Guidelines

- Guidelines for the municipality and the government
    - Make general recommendations for PD individuals in case of evacuation.

  - Make it easier and more equal for PD individuals to get access to the help they need.
  - When planning a new building, consider making it easier for PD individuals to escape.
  - Place more ramps in places where it can be difficult to evacuate a PD individual.
  - Provide information campaigns about how to offer help to PD individuals in evacuation situations.
- Guidelines for Healthcare professionals
  - Extend the knowledge about differences in treating PD individuals and non-PD individuals.
  - Remember there is a person behind the handicap and show empathy.
- Guidelines for evacuation
  - Extend the knowledge of how to evacuate PD individuals in situations of crisis.
  - When evacuating a PD individual, inform them about what is going to happen.
  - Include the PD individuals in the test evacuations.
  - Bring their wheelchair if possible.
  - Remember not all disabilities are visible.
  - Make space on the road and to evacuation buildings so people who are in a wheelchair or are inhibited can make their way through.
- Guidelines for the PD individuals
  - Be informed about the evacuations possibilities.

  - Prepare an emergency preparedness kit (e.g. gloves, support bandages, etc.).
  - Talk to friends and family about what to do in a crisis situation.

- Guidelines for caregivers and families
  - Provide emergency preparedness training.
  - Respect the autonomy of the PD individual.

The limitations of the present study are acknowledged. The reliance of this study on convenience sampling and its small sample size restrict the generalizability of the findings. In addition, our study sample consisted of PD individuals who all functioned well mentally in their daily life. All the PD individuals were of ethnical Danish nationality and had an average-to-above socioeconomic status. It is possible that the experiences reported by our participants present a more positive depiction of healthcare service provision following disasters and other traumatic events than those of the target population at large. Because it is not a common thing in Denmark to experience disasters the current article presents a picture of less severe traumatic experiences and might not show the same results as if it was conducted with more severe traumatic experiences.

While some of our recommendations may also apply to the provision of services for other PD sub-populations, future research is still needed to yield additional recommendations. Furthermore, since the scope of this study was limited to investigating the perspectives of PD individuals on the accessibility of services typically responsible for responding to disasters, future research should inquire into their perspectives on emergency preparedness initiatives implemented in Denmark as well as in other countries. Our recommendations are consistent with some of the Key Recommendations for Supporting Persons with Disabilities in Disasters from Austria (Juen et al., 2016) and the Emergency Evacuation Planning Guide for People with Disabilities from America (National Fire Protection Association, 2016). Because it is uncommon for disasters to happen in Denmark, some of the recommendations from other countries seem unnecessary, but it is still important to consider if they should be implemented in Denmark as well.

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8.3 Recommendations for physically impaired people

The following recommendations are based on multiple sources, one being the literature analysis of the topic, mainly using the guidelines based on research or particular experiences. Another source was a workshop with emergency rescue services representatives, therapists and other specialists working with the target group and a physically impaired participant. They shared their experiences and expertize and gave feedback to the information from the literature sources. A third source was a qualitative study carried out within the frame of the EUNAD projects.

The University of Southern Denmark and the Charles University in Prague are the implementing institution.

8.3.1 Emergency Preparedness

- Make general recommendations for PD individuals in case of evacuation.
- Implement ways to make it easier for first responders to access important information concerning the disability, e. g. QR codes connected to the individual or individual medicine cards (used in some countries).
- When planning a new building, consider making it easier for PD individuals to escape.
- Extend the knowledge of how to evacuate PD individuals in crisis situations.
- Implement emergency preparedness training.
- Extend the knowledge of differences in treating PD individuals and non-PD individuals.
- Information campaigns should provide information to professionals and the general population on how to offer help to PD individuals in evacuation situations.
- Make work places in the public sector responsible for disabled employees and, as far as possible, make individual evacuation plans.
- Include PD individuals in test evacuations.
- Implement first aid and fire rehearsal evacuations in elementary school that include how to handle the most common disabilities.
- Ensure education for elementary school children regarding disabilities.

8.3.2 Emergency Response

- Be informed about evacuation possibilities.
- Remember there is a person behind the handicap and show empathy.
- When evacuating a PD individual, inform them about what is going to happen.
- Bring the wheelchair, if possible.

- Remember that not all disabilities are visible.
- A physically disabled individual may appear to be mentally disabled, even when this is not the case. Verify the state of disability and always treat with dignity.
- Beware of increased risk of bone breakage or muscle weakness – inappropriate handling causes risk of injury.
- Involve disabled individuals more in treatments, rights and plans.
- Remember that some individuals cannot support their own body or hold it upright.
- Ask about specific needs and how to help with the transportation.
- Respect the autonomy of the PD individual.
- Show respect and do not override the individual's own competence.
- Respect an alternative reaction. Individuals with disabilities have often learned to live with their physical limitations and might react unexpectedly.
- Provide information that is timely, reasonable, and true and contact or communicate with relevant caregivers if needed.
- Assign specific individuals to communicate with the patients and be aware of special needs.
- Prepare an emergency preparedness kit (e.g. gloves, support bandages, etc.).
- Encourage the physically disabled to talk to friends and family about what to do in a crisis.

8.3.3 Recovery (Psychosocial)

- Make psychological counselling for individuals with disabilities and their relatives more easily accessible.

8.3.3.1 Implications for rehabilitation

- Medical and psychosocial services should be properly prepared to assist PD individuals.

- The Danish study highlighted difficulties faced by PD individuals when accessing healthcare and psychosocial services. These centred on a lack of guidelines and lack of fully optimal professional services in both healthcare and the municipality offices. Guidelines should be produced for healthcare and psychosocial services, and professional services; in both healthcare and the local authorities should initiate collaboration to fully optimize their operation for the PD population.

- Regarding rehabilitation after disasters, evidence-based information about how to service the needs of PD populations should be disseminated to professionals, and preferably incorporated into training programs and evacuation plans.

8.3.4 Guidelines for communication and interaction with people with physical disabilities

We apply the same basic principles as with people with cognitive and perception difficulties:

- We treat the person like any other person.

- It often helps **to ask** the individual how to **help with transport** and what his specific needs are.

- To stabilize people it helps to **provide information** (timely, reasonable and true) and contact and communication with close persons. We arrange contact with a close person.

- When communicating with a person with physical disability, **we always maintain his human dignity and respect.**

- We offer help, **ask** what we can do and what the individual can do him/herself.

- We **strive for the individual’s own activity,** we do not override his own competence.

- We adapt to his/her abilities.

- We **do express sympathy** for the person, **we respect differences** in movement. People with disabilities have often learned to live with their disabilities.

8.3.5 Specific recommendations

- Beware of increased bone breakage or muscle weakness - inappropriate handling brings a risk of injury.
- For wheelchairs, follow the wheelchair user's recommendations.
- Wheelchair handling – fold and unfold a wheelchair: apply brakes, remove cushion (if any), adjust the footrest, rotate them out or remove them, hold the midpoint of the seat at the front and back, pull upwards and fold the wheelchair. To unfold push the seat. Beware of finger injuries when handling.
- Transport of wheelchair down stairs: 1. Take the wheelchair forwards down the steps; 2. Grip the handles firmly and tilt the wheelchair, balancing on the rear wheels; 3. Move the wheelchair to the top of the first step; 4. Use your body as brake while gently lowering the wheelchair; 5. Control the descent with your body, keeping the rear wheels tight against the stair edge and rolling the wheelchair forward and down the step; 6. Don't let the chair drop unevenly or too quickly. A second person helps at the front of the wheelchair. A light person can be carried downstairs in the wheelchair.
- Getting up the stairs likewise (pull the wheelchair with its back to the stairs).
- On uneven, stony or sandy terrain we push a wheelchair with a person backwards. (When pushing forward, the wheels crash).
- If we want to lift a person out of the wheelchair, we should to ask how we can grasp him or her.
- Before setting a person on the wheelchair, we apply brakes and remove the armrest.
- Electric wheelchairs are heavy (100kg or more), so it is better to transport them without the wheelchair user. The motors can be disconnected and the wheelchair can be pushed mechanically.

- When moving from an electric to a mechanical wheelchair next to it, the armrests can be removed.

- The necessary width of the toilet door should be ensured as well as the height of the washbasin.

9

Key recommendations for assisting persons with disabilities in case of disaster

Barbara Juen, Alexander Kreh, Michael Lindenthal

9.1 Policy recommendations

- **Political commitment.** Governments must make clear decisions and include in their political agenda the commitment to make a serious effort to develop effective disaster risk management for people with disabilities. As part of the more general endeavour to ensure the safety of their constituent populations, they must consistently pay attention to such people's needs.

- **Coordination and continuity.** In order to guarantee the effective development, application and monitoring of emergency systems for people with disabilities, one particular body of governmental administration must be responsible for co-ordination and the continuity of initiatives. It will be the task of the coordinating body in close cooperation with all relevant stakeholders to make sure that all relevant information is collected and centralised.

- **Networking.** If risks are to be identified and solutions found, at least one network should exist that allows stakeholders to meet and exchange information about the challenges to be met. These networks should always be open to new members and should take full account of evolutionary changes in technology, habits and expectations.

- **Strategic planning.** A master plan should be set up and constantly updated. The organisation of training activities and the evaluation of emergency exercises should be part of a constant process of adaptation of the master plan.

- **Knowledge management.** A coherent program of knowledge management should be used to ensure the transfer of acquired know-how to those who can benefit from it. This knowledge would facilitate the organisation of training activities and allow emergency schemes constantly to be improved. Specific added value should be provided by the involvement of people with disabilities and their organisations.

- **Identification and optimisation of resources.** The evaluation of a master plan and constant updating of its capacities, and the general level of knowledge, should allow stakeholders to estimate needs regarding financial, organisational and human resources. At the same time, the best possible use of existing or new resources may allow the action plan to be improved.

- **Communication.** In order to ensure that everyone is kept informed about the state of preparedness, a good communication policy is needed. Energetic dissemination of information will ensure that more and more relevant stakeholders are contacted and involved in the preparedness process.

9.2 Key recommendations for disaster management

- Disability should become a core, cross-cutting theme in disaster and emergency management.
- Disability must be systematically taken up across all aspects of the disaster management cycle[4].
- All types of disabilities must be considered.
- Both helpers and people with disabilities must be prepared.
- Disaster and emergency information, services and facilities must be fully accessible for people with disabilities in pre, acute and post disaster situations.

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[4] "The main thought behind the disaster management cycle is one of awareness. Disasters are also seen as something one can prepare for, ideally prevent or at least diminish in its effects and not only something one has to respond to, once the disaster happened (see e.g. Challen et al., 2012; Elliot and Smith, 2004)" (Juen et al., 2015, p.28–29).

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9.3

Key recommendations for emergency/disaster managers, planners and responders

- **Identification of people with disabilities:**
  - Identify people with disabilities who live in the community.
  - Develop a special needs registry.
- **Planning with the disability community:**
  - Develop disability-inclusive disaster/emergency plans.
  - Include local disability groups & service providers in the planning process (also include mental disability groups).
- **Disaster preparation, education and training of people with disabilities:**
  - Publish information and tools for people with disabilities to improve their awareness and preparedness.
  - Information events and training can help to improve the awareness and preparedness of people with impairments.
- **Training of disaster/emergency workers:**
  - Improve their awareness, knowledge and skills, enabling them to better address needs of people with disabilities in disaster/emergency.
- **Notification and communication:**
  - Provide different ways to inform people with disabilities in case of disaster.
  - Television stations must be responsible for providing information for people with hearing, visual or cognitive impairments:
    - Provide important information both visually and acoustically,

    - Include a sign language interpreter/open-captioning,
    - Frequently repeat the most essential emergency information in a simple message format so those with cognitive disabilities can follow.
  - Emergency hotlines during an event should include TTY (teletypewriter) numbers.
  - Provide information in alternate formats (e.g. Braille, cassette, large font, etc.).
- **Provide psychosocial support:**
  - General psychosocial support recommendations:
    - Ensure safety,
    - Provide a calming environment,
    - Enhance self and community efficacy,
    - Enhance connectedness,
    - Support in maintaining hope.
- **Evacuation:**
  - People with disabilities may require special assistance to escape from a disaster.
  - To include people with mental disabilities, instructions need to be clear, repetitive and straightforward.
  - Use emergency transport fleets with wheelchair lifts or ramps.
  - Include barrier-free non-emergency vehicles in disaster plans.
- **Sheltering:**
  - Interior and exterior routes, entrances and toilet rooms must to be accessible for people with disabilities.

  - Allow service pets in the shelter.
  - Provide adequate medical care and special equipment.
  - Train staff in the basic procedures for providing accessible communication (exchanging notes, read printed information, etc.).
  - Establish Special Needs shelters.
- **Recovery:**
  - During the recovery phase, the priority must be to restore or address those services and needs most critical to people with disabilities.
  - Provide barrier-free psychological care.
  - Disaster and emergency management must take into account the need for rehabilitation and follow-up services for persons with disabilities and injured people.

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9.4 Key recommendations for people with disabilities

- **Be informed:**
  - Learn about the types of hazards that may impact your community and about specific types of emergencies.
  - Inform yourself about specific services and programs for people with disabilities in disaster or emergency and contact your local emergency management agency.
  - If possible: register yourself at your local emergency management agency. Some agencies maintain registers of people with disabilities so you can be located and assisted quickly in a disaster.
- **Create a Support Network:**
  - The network should include people you know and trust and who can check on you within minutes to see if you need help. At home, work, school, or in the community, your support team should help you identify and secure resources and assess your needs before, during, and after a disaster.
- **Prepare Emergency/Disaster Preparedness Kits:**
  - Basic Emergency Supplies Kit,
  - Disability Related Supplies and Other Equipment,
  - Portable “Ready Kit”,
  - Make an emergency information list (Contact information of the people in your support network).
  - Make a medical information list (Information about your special medical needs).

- **Create a communication plan:**
  - Make sure you and your support network have each other's contact information and alternate ways to communicate if phones are not working (such as an assigned meeting place, using pagers, email or other technology not reliant on phone lines).
- **Make an evacuation plan for home, work, school, etc.:**
  - Identify a primary and secondary way to evacuate the house or building.
  - Identify transportation resources.
  - Include service providers in the planning process.
  - (Make a plan for your service pet).
- **Consider different shelter options:**
  - Shelter-in-place,
  - Public shelter/Special needs shelter,
  - → consider how these shelters meet your needs.

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9.5 Key recommendations for caregivers/family members/ helpers of people with disabilities

- **Respect the independence of the person with disabilities**
  - Discuss with the person with impairments how you can help. Even though it may be important to evacuate quickly, respect their independence to the extent possible. Don't make assumptions about the person's disabilities.
- **Work together with the person with disabilities to prepare for various disaster and emergency events:**
  - Prepare a disaster/emergency plan.
  - Prepare a disaster/emergency kit.
- **Service provider preparedness:**
  - Nursing homes, hospitals and other providers of long-term services must make response plans for the safety of their service recipients and staff during an emergency or disaster. Those plans must include well-tested transportation procedures in the case of evacuation.
- **Training:**
  - Take part in emergency preparedness training for caregivers.
  - Conduct emergency/disaster exercises and training for people with disabilities.
- **Recovery**
  - Hold a briefing of the activities that took place during the disaster/emergency.

- **Children with disabilities**
  - Explain the dangers of various disaster or emergency events for a child and discuss how to prepare.
  - Teach children how and when to call your local Emergency Medical Services number for emergency help.
  - Schools should include the needs of students with disabilities in their disaster/emergency plans.

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10

Guideline development and implementation: importance of international cooperation and local tailoring

Michel Dückers

Importance of international cooperation

In recent decades, different international guidelines have been developed to promote the quality of psychosocial support to people confronted with disasters and major events like flooding, terror attacks, industrial incidents and environmental threats. The EUNAD-IP project is part of a longer tradition in Europe to combine and synthesize information from research, experts and practice in different countries and language areas, and to translate them into practical guidance and supportive tools. Earlier projects like TENTS, EUTOPA and OPSIC focused on general principles and guidance for PSS, regardless of event types or particular target groups. EUTOPA-IP and EU CBRN are examples of projects with particular accents, respectively uniformed services and chemical, biological, radiological and nuclear incidents. EUNAD and EUNAD-IP, were aimed at potentially affected individuals with disabilities. During EUNAD-IP information was obtained from people with various disabilities and collected by reviewing available literature. This information was used to formulate recommendations that were discussed with representatives of people with disabilities, policy-makers, and international experts. The products created in cooperation with partners across Europe belong to the main project deliverables and are publicly accessible. Recent analyses, conducted in the context of the TENTS and EUTOPA projects, highlighted variation in the degree to which recommendations were implemented in different European regions (Witteveen, Bisson, Ajdukovic, Arnberg, Bergh Johannesson, Bolding, et al. 2012; Dückers, Witteveen, Bisson & Olff, 2017) and identified a gap between guidelines and practice (Te Brake & Dückers 2013). The projects already mentioned can be seen as a first step in the implementation of PSS recommendations. EUNAD-IP strengthened and expanded the existing shared European knowledge base on PSS for people with disabilities in the wake of a disaster or major incident.

Importance of local tailoring

The next step is that the contents of the European knowledge base find its way into local initiatives to develop and implement standards in the context of different member states and the communities within them. After all, defining standards, norms and other types of guidance is a necessary starting point, yet every general standard needs to be translated to the unique local context where it will be used. To overcome cultural discrepancies and idiosyncrasies, and the risk of knowledge products being welcomed as “not invented here”, it is indispensable to involve local stakeholders and interest groups, especially the user groups, in the knowledge-translation. Furthermore, within communities specific target groups and contexts can be identified within the sub groups of people with disabilities that require further tailoring in terms of guidance and support (e.g., ethnic groups or children). Finally, many factors play a role in the implementation of guidelines, interventions and tools (e.g. Greenhalgh et al., 2004; Vos et al., 2010; Michie et al., 2011; Eccles et al., 2012; Flottorp et al., 2013). Such factors can partly be anticipated in European projects such as EUNAD-IP. Nevertheless, in the end many stakeholders at different levels share a responsibility in closing the gap. Future projects can contribute to a better understanding of different local contexts and available conditions, together with their implications for implementing PSS guidelines and tools.

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11.5 Acknowledgement

We would like to thank all participants of both the national and European workshops and pilot trainings for their involved discussions, their expert advice, as well as their continuous contributions to the evaluation of the EUNAD and EUNAD IP results.

Full account to following organizations, participants and speakers of workshops and trainings of EUNAD:

Local workshop in Norway (NO): Center of Psychotraumatology/Alexianer/University of Cologne (Robert Bering); **Fire and rescue** (June Persdatter Martinsen); **Fire and Rescue Services, Oslo** (Lars Grimsgaard); **Gjøvik College** (Johnny Nersveen); **Statped** (Harald Garder Beil, Hilde Holtsmark, Torill Lorentsen, Liv Strand); **Psychologist, private practice** (Åsa Frostad Fasting); **The advisory board for hearing impaired individuals** (Anne Mette Dahl, Trude Lillegjerde, Frøydis Mørk); **The Norwegian Association for Blind and Visual impaired individuals** (Kari-Anne Flaa, Sverre Fuglerud); **The Norwegian Association for Deaf individuals** (Sissel Gjøen); **The Norwegian Association for hard of hearing individuals** (Steinar Birkeland); **The Norwegian center for hearing and mental health, Oslo University Hospital** (Marianne Eliassen, Randa Nilsen, Beate Øhre, Lene Hanne Urnes, Britta Barman Wold); **The Norwegian centre of violence and traumatic stress studies** (Trond Heir, Marianne B Hansen, Randi Saur); **The Regional Center for Hearing and Mental Health** (Mette P Uthus)

Local workshop in Denmark (DK): Capital Region Psychiatry/Psychiatric Center Ballerup, Deaf Team (Annebrit Hjort, Per Jensen, Jeannette From Taubert); **Center for Deaf, Odense** (Signe Stein Rasmussen); **Center for Psychotraumatology, University of Southern Denmark** (Anders Elbæk Christoffersen, Ask Elklit, Tina Jeppesen, Lotte Skøt); **Course instructor/team coordinator Rescue Center Denmark** (Eigil G. R. Hvid); **Danish Deaf Association** (Lars Knudsen); **Family- and psychotherapist, Private clinic** (Pia Nielsen); **Head nurse** (Jeannette From Taubert); **Hearing impairment Center for Disability, Technical Support and Social Psychiatry, Social Services** (Hanne Langeland); **Police school, National Police** (Steen Herlev Larsen, Lotte Krag); **Psychologist unit, FALCK Healthcare** (Mikkel Andersen, Helle Berentzen, Martin Zimling); **Sign Language interpreter** (Susanne Ørum, Jørgen Sandholt)

Local workshop in Germany (DE): ASB KV Coburg-Land e. V. Krisenintervention (Heinz Rembor); **Bavarian association of blinds and visually impaired** (Svenja Seibold); **Centre for**

psychotraumatology, Krefeld (Prof. Dr. Robert Bering, Florentine Gerwinn, Sabine Krüger, Simone Ludwig, Dr. Dieter Wagner); **City administration Düsseldorf, Emergency Psychology** (Dr. Thomas Poschkamp); **Clinic Europakanal Erlangen, psychiatric department deaf and hard of hearing** (Dr. Inge Richter, Thomas Stritzke); **Federal Office of Civil Protection and Disaster Assistance, BBK** (Claudia Schedlich, Gisela Zurek); **German Association for blind and visually impaired** (Klaus Hahn); **German Deaf Association** (Wolfgang Bachmann); **Integrationsfachdienst Köln** (Sonja Denker, Jennifer Söhn); **Johanniter Emergency Care** (Leander Strate); **LWL Klinik Lengerich, treatment centre deaf and hard of hearing** (Prof. Dr. Hans-Jürgen von Giesen, Dr. Ulrike Gotthardt); **SbE** (Birgit Sudek); **Sign Language interpreter** (Bastienne Blatz, Sandra Wolfien); **Skarabee** (Rafael Grombelka); **Südbayerische Wohn-& Werkstätten für Blinde u. Sehbehinderte** (Dr. Birga Gatzweiler); **University Cologne, department pedagogic and didactics for deaf and hard of hearing** (Prof. Dr. Thomas Kaul)

Local workshop in Czech Republic (CZ): APPN o.s., 365 o.p.s (Mgr. Marie Horáková, Pavlína Spilková); **Association of Organisations of Deaf and Hard Hearing and their Friends, Klub nedoslýchavých Help** (Mgr. Věra Strnadová); **Charles University** (PhDr. Hedvika Boukalová, Karolína Citavá, PhD., PhDr. Zbyněk Galvas, PhDr. Simona Horáková Hoskovcová, PhD., Karolina Klasová, PhDr. Štěpán Vymětal, PhD.); **City of Olomouc** (Ing. Hana Hegerová, Ing. Jan Langr); **Club of Loss Hearing people** (Anica Dvořáková); **Czech Blind United** (Ing. František Brašna, Mgr. Viktor Dudr, Marie Kebrdlová, Ondřej Veselý); **Czech Police** (kpt. Mgr. Patricie Hausknecht, mjr. Mgr. Jana Jungwirtová); **Czech Union of the Deaf** (Ing. Martin Novák, Mgr. Ota Panský); **Deaf and Hard Hearing United** (Pavel Šturm); **DG Fire and Rescue** (plk. PhDr. Zuzana Vrbová); **Federation of Parents and Friends of Hearing Impaired** (Mgr. Adéla Dědečková, Mgr. Věra Doušová, Mgr. Jana Fenclová); **Fire and Rescue** (npor. nstržm. Jaroslav Gondko, Ing. Hynek Milota, kpt. Mgr. Soňa Pančochová); **National Council of Health Impaired People** (Mgr. Jitka Vrchotová); **Okamžik** (Ing. Miroslav Michálek, Ing. Šárka Vojtíšková); **Police Presidium** (plk. Mgr. Vladimír Voska); **Sign language interpreter** (Monika Boháčková); **Transcription** (Nikola Gronesová, Tomáš Portych); **TyfloCentrum Praha o.p.s.** (Ing. Jiřina Polášková, Jan Příborský); **Tyfloservis o.p.s.** (Olga Buriánková, PhDr. Josef Cerha, Mgr. Petra Helebrantová)

Pilot trainings in Prague (CZ): (1) Charles University (PhDr. Hedvika Boukalová, Mgr. Petra Helebrantová, PhD., PhDr. Simona Horáková Hoskovcová, PhD., Jakub Kamberský, Alžběta Knorková, Martina Šašková, Karel Straka, PhDr. Štěpán Vymětal, PhD.); **Czech Army** (Jana Černá, Mgr. Silvie Fryčová, kpt. Patricie Hausknecht, kpt. Mgr. Jana Jalovegová, kpt. Mgr. Jana Jungwirtová, Mgr. Michaela Löserová, kpt. Mgr. Renata Šanderová, Mgr. František Sokol, kpt. Mgr. Lenka Štréblová, Mgr. Drahomíra Švancarová, por. PhDr. Lenka Svítková, kpt. Mgr. Gabriela Tabachová, kpt. PhDr. Lenka Vlášková, , Mgr. Michal Zelenka); **Czech Police** (Mgr. Jiří František Průža); **DG Fire and Rescue** (plk. PhDr. Zuzana Dittrichová); **Ministry of Interior** (Mgr. Lucie Fenclová, PhDr. Irena Gruberová, Miroslava Mocová); **Police Presidium** (nstržm. Jaroslav Gondko, kpt. Bc. Jiří Janhuba, pprap. Lukáš Kaiser, nprap. Ivan

Martin, kpt. Mgr. Soňa Pančochová, nprap. Martin Sladký, por. Bc. Šmahlík Stanislav, nstržm. Karel Teska, plk. Mgr. Vladimír Voska); **Tamtam, o.p.s.** (Věra Doušová) **(2) Charles University** (PhDr. Hedvika Boukalová, PhD., Mgr. Petra Helebrantová, PhDr.Simona Horáková Hoskovcová, PhD., PhD., Jakub Kamberský, PhDr. Štěpán Vymětal); **Tamtam, o.p.s.** (Věra Doušová); **DG Fire and Rescue** (plk. PhDr. Zuzana Dittrichová); **Fire and Rescue** (Mgr. Tomáš Adámek, nstržm. Bedřich Bačovský, npor. Mgr. Lukáš Balaštík, kpt. Ing. Jaroslav Bárta, kpt. PhDr. Dagmar Bortlík Fišerová, por. Bc. Marie Brabcová, kpt. PhDr. Michal Černík, ppor. Aleš Chromý, nstržm. Miroslav Dobrovodský, nprap. Mgr. Novotný František, Ph.D., npor. Martin Gaier, ppor. Mgr. David Hrbáček, kpt. Mgr. Pavel Hurta, nprap. Petr Janda, plk. Mgr. Štěpán Kavan, mjr. Mgr. Marcela Kopaňáková, Bc. Tomáš Kubeš, nprap. Jan Kyselý, pprap. Jan Letko, nstržm. Jiří Líbal, nprap. Karla Machalová, nstržm. Mgr. Lukáš Malík, por. Bc. Monika Malinová, kpt. Mgr. Jana Majzlíková, nstržm. Petr Matějka, pprap. Tomáš Müller, nprap. Jiří Necid, nstržm. Michal Nespěšný, Ph. D., por. Bc. Tomáš Nocar, kpt. Mgr. Soňa Pančochová, nprap. Martin Prchal, nprap. Bohdan Skála, nprap., npor. Pavel Skoupil DiS., nstržm. Miroslav Slezák, Jaroslav Smutný, pprap. Stanislav Smutný, mjr. Mgr. Hynek Sojka, npor. Mgr. Přemysl Švajda, ppor. František Eli Svoboda, nstržm. Bc. Milan Tesař, por. Bc. Jana Váchová, mjr. Mgr. Kvapilová Vladimíra, mjr. Bc. Zdeněk Vlasák, nprap. Jiří Vlček, pprap. Aleš Vomastek, DiS., pprap. David Vorlíček)

Pilot training in Ahrweiler (DE): Alexianer Krefeld GmbH (Florentine Gerwinn); **Arbeiter-Samariter-Bund Kreisverband Coburg Land e.V.** (Heinz Rembor); **Deutsches Rotes Kreuz Kreisverband Dortmund e.V.** (Volker Kraja); **Europarat/Council of Europe** (Dr. Mechthilde Fuhrer); **Gesundheitsamt Landeshauptstadt Düsseldorf** (Christine Druyen, Sabine Rau); **Landesschulamt und Lehrkräfteakademie** (Marion Müller-Staske); **Malteser Hilfsdienst e.V.** (Harald Trampert); **Notfallseelsorge im Landkreis Ludwigsburg** (Ulrich Gratz); **Stadt Dormagen Feuerwehr und Rettungsdienst** (Jürgen Hildebrandt); **Stadt Frankfurt am Main, Amt für Gesundheit** (Peter Waterstraat); **Stadt Frankfurt am Main, Der Magistrat – Branddirektion** (Volker Wilken); **Stadt Gladbeck, Feuerwehr** (Peter Frank, Manfred Labotzke)

Pilot training in Oslo (NO): The Norwegian center for hearing and mental health, Oslo University Hospital, specialized in the assessment and treatment of mental health disorders of hearing impaired (Fifteen clinical staff members attended, among others: Britta Barman Wold, Marianne Eliassen, Beate Øhre, Lene Randa Nilsen, Hege Saltnes, Hanne Urnes); **The Norwegian centre of violence and traumatic stress studies** (Marianne B Hansen, Trond Heir, Marianne Jakobsen)

Pilot training in Odense (DK): Capital Region Psychiatry/Psychiatric Center Ballerup, Deaf Team (Annebrit Hjort, Per Jensen, Jeannette From Taubert); **Center for Deaf, Odense; 1st interview participant** (Susanne Ørum -Sign Language interpreter); **Center for Disability, Technical Support and Social Psychiatry, Social Services** (Hanne Langeland); **Center for Emergency Communications, National Police** (Steen Herlev Larsen); **Center for Psychotraumatology, University of Southern Denmark** (Anders Elbæk Christoffersen, Ask Elklit, Tina Jeppesen, Lotte Skøt); **Danish Deaf Association** (Lars Knudsen, Jørgen Sandholt – Sign Language Interpreter); **FALCK Healthcare, Psychologist Unit** (Helle Berentzen); **Police School, National Police** (Lotte Krag); Private clinic (Pia Nielsen); **Rescue Center Denmark** (Eigil G.R. Hvid); **The Rescue Workers' Developmental Secretariat (3F)** (Mikkel Andersen, Martin Zimling)

1st International Conference in Prague/CZ – 2013: APPN, 365 o.p.s,Czech Republic (Pavlína Spilková); **ASNEP, European Forum of Sign Language Interpreters (EFSLI). Institute of the Deaf for Specialized Education, Teiresias – Support Centre for Students with Special Needs, Czech Republic/USA** (Tim Curry); **Assistance for visually impaired, Czech Republic** (Jaroslav Rusnák); **Association of the Deaf and Hard of Hearing in the Czech Republic** (Farah Curry, Pavel Šturm); **Austrian Red Cross, Austria** (Ruth Warger); **Bavarian association of blinds and visually impaired, Germany** (Svenja Seibold); **British Red Cross, UK** (Moya Wood-Heath); **Center for psychotraumatology Krefeld, Germany** (Robert Bering, Florentine Gerwinn, Simone Ludwig, Christina Schlossmacher); **Charles University in Prague, Czech Republic** (Barbora Balková, Hedvika Boukalová, Simona Hoskovcová, Martina Míčková, Merle van den Akker, Anna Vojtíšková, Štěpán Vymětal); **Czech Blind United, Czech Republic** (Rudolf Volejník); **Czech Union of the Deaf, Czech Republic** (Martin Novák); **Danish Deaf Association, Denmark** (Lars Knudsen, Vibe Michelsen, Jørgen Sandholt); **Department of Health, London, UK** (Gillian Dacey); **Dutch knowledge & advice centre psychosocial care concerning critical incidents, IMPACT/Arq, The Netherlands** (Annelieke Drogendijk); **Expert with visual and hearing disabilities, University in Budapest, Hungary** (Krisztina Kovács); **Federal Office of Civil Protection and Disaster Assistance, BBK, Germany** (Claudia Schedlich, Gisela Zurek); **Federation of Parents and Friends of Hearing Impaired, Czech Republic** (Věra Doušová); **Fire and Rescue Service of the Czech Republic** (Jaroslav Gondko, Soňa Pančochová, Zuzana Vrbová); **German Deaf Association** (Wolfgang Bachmann); **Israel Trauma Coalition, Israel** (Talia Levanon, Ruvie Rogel); **Ministry of Interior of Bulgaria** (Ilina Nikolova); **Ministry of Interior of the Czech Republic** (Magda Koutková, Štěpán Vymětal); **Norwegian Centre for Traumatic Stress Studies, Norway** (Marianne Hansen, Trond Heir, Hanne Urnes); **Psychologist-expert, assistance for visually impaired, Germany** (Claudia Susanne Heinrich); **RISC Slovakia** (Lenka Juričeková); **Swedish National Centre for Disaster Psychiatry, Sweden** (Philip Arnberg); **The Spanish Society for Psychotraumatology, Traumatic Stress and Dissociation, Spain** (Francisco Orengo Garcia); **University of Cologne, Germany** (Thomas Kaul); **University of Innsbruck, Austria** (Heidi Ulrike Siller, Ruth Warger); **University of Ottawa/CA** (Tracey O'Sullivan); **University of Sheffield, UK** (Graham Turpin); **University of Southern Denmark** (Ask Elklit, Tina Jeppesen, Lotte Skøt); **University of Zagreb, Croatia** (Helena Bakic)

2nd International Conference in Cologne (DE) – 2014: Arbeiter-Samariter-Bund, Germany (Heinz Rembor); **Association of German Professional Psychologists, Germany** (Gabriele Bringer); **British Red Cross, UK** (Moya Wood-Heath); **Center for Psychotraumatology Krefeld, Germany** (Robert Bering, Florentine Gerwinn, Simone Ludwig, Lena Richter

Christina Schlossmacher, Jennifer Söhn); **Charles University in Prague, Czech Republic** (Hedvika Boukalová, Simona Hoskovcová); **Civil Protection Luxembourg-Psychosocial Intervention Team (GSP), Luxembourg** (Charles Brück); **Czech Deaf and Hard-of-hearing Association, Czech Republic** (Marie Dolezalova, Barbora Herzanova); **Danish Deaf Association, Denmark** (Lars Knudsen, Vibe Michelsen, Jørgen Sandholt); **Deputy Executive Secretary of the European and Mediterranean Major Hazards Agreement of the Council of Europe, France** (Mechthilde Fuhrer); **Dutch Knowledge & Advice Centre for Psychosocial Care Concerning Critical Incidents** (IMPACT/Arq), **Netherlands** (Magda Rooze); **Escola Superior de Saúde de Portalegre, District Coordinator from Civil Protection Psychosocial Intervention Team in Crisis and Emergency Situation, National Civil Protection Coordination Group, for the National Civil Protection Psychosocial Teams development, Portugal** (Miguel André Telo de Arriaga); **European Forum of Sign Language Interpreters (EFSLI). Institute of the Deaf for Specialized Education, Teiresias – Support Centre for Students with Special Needs, Czech Republic/USA** (Tim Curry); **European Union of the Deaf, Belgium** (David Hay); **Federal Office of Civil Protection and Disaster Assistance (BBK), Germany** (Verena Blank-Gorki, Annika Fritsche, Tobias Hahn, Lisa Krapp, Mark Overhagen, Rike Richwin, Claudia Schedlich, Ralph Tiesler, Gisela Zurek); **German Association of the Blind and Visually Impaired/European Association of the Blind, Germany** (Jessica Schröder); **German Deaf Association, Germany** (Wolfgang Bachmann); **German National Working Committee on Fire Brigades, Germany** (Jochen Stein); **Instituto Europeo di Psychotraumatologia e Stress Management, Italy** (Bruno Cappagli); **International Deaf Emergency, USA** (Emmanuel Jacq); **Israel Trauma Coalition/The Community Stress Prevention Center, Israel** (Mooli Lahad, Talia Levanon); **Ministry of the Interior of the Czech Republic, Czech Republic** (Barbora Balková, Štěpán Vymětal); **National Center for Hearing Impairment and Mental Health, Norway** (Hanne Urnes); **Norwegian Centre for Traumatic Stress Studies, Norway** (Marianne Hansen, Trond Heir, Randi Saur); **Rush University-Medical Center** (Stevan Hobfoll); **Sign Language Interpreters** (Inger Caludan and Jorgen Sandholt/DK, Cindy Cave/BE, Tim Curry/CZ/USA, Britta Meinecke and David Niemann/DE); **The Spanish Society for Psychotraumatology, Traumatic Stress and Dissociation, Spain** (Francisco Orengo Garcia); **University of Southern Denmark** (Ask Elklit, Tina Jeppesen, Lotte Skøt)

Full account to following organizations, participants and speakers of workshops and trainings of EUNAD IP:

Local workshop in Innsbruck (AT): Austrian Red Cross Tirol (Bernd Döring); **Lebenshilfe** (Martin Reiter); **Psychotherapist** (Walter Krug); **Tiroler Soziale Dienste** (Michael Wieser); **University of Innsbruck** (Judith Leitner, Barbara Juen, Alexander Kreh, Priya-Lena Riedel)

Local workshop in Czech Republic (CZ): Centre of Social Services Tloskov (PhDr. Matěj Lipský); **Charles University** (PhDr. David Čáp, PhDr. Hedvika Boukalová, PhDr. Simona Hoskovcová, PhDr. Štěpán Vymětal); **Children Centre Paprsek** (Mgr. Vanda Prasetová); **Children's**

hearing center Tamtam o.p.s. (Mgr. Věra Doušová); **Czech Police, Svět záchranářů** (por. PhDr. Zdena Papežová); **DG Fire and Rescue** (Plk. PhDr. Zuzana Vrbová, Plk. PhDr. Martina Wolf Čapková); **Domov Na Hrádku** (PhDr. Jana Pilná, Milena Strasserová); **Emergency Medical Service of South Bohemia Region** (PhDr. Zuzana Fajtlová, DiS.); **Fire and Rescue** (Nstrm. Jaroslav Gondko, Kpt. Mgr. Soňa Pančochová); **Laguna Psáry** (Mgr. Jakub Adámek); **Ministry of Interior** (Mgr. Michaela Kvasničková); **Nautis** (Kateřina Šulcová); **Psychiatric Hospital Bohnice** (Bc. Šárka Čadová, DiS.); **Retirement home Blaník** (Mgr. Oldřich Kumprecht)

Local workshop in Cologne (DE): Alexianer GmbH (Robert Bering, Arno Fuhrmann, Florentine Gerwinn, Maria Jäger, Jennifer Neumann); **Caritas Freiburg** (Réka Balog, Susanne Schmid); **Färbereizentrum für Integration und Inklusion** (Ellen Dieball, Andrea Otto-Erley); **Federal Office of Civil Protection and Disaster Assistance (BBK)** (Frederike Albers, Claudia Schedlich); **Institut Kompass** (Claudia Schmidt); **LVR Klinik Bedburg-Hau** (Birgit Skiba); **LVR Langenfeld** (Johannes Köhler); **Medical Centre for people with disabilities (MZEB)** (Bettina Saathoff); **Projectgroup: Psychology for people with mental disabilities in emergency situations** (Dieter Irblich); **University of Cologne** (Lena Grüter); **University of Würzburg** (Thomas Spaett)

Local workshop in Oslo (NO): Sunnaas rehabilitation hospital/The Norwegian Association for visual impaired and blind (Anne-Mette Bredahl – Psykolog and researcher); **The Norwegian Association for visual impaired and blind** (Gry Berg, Anne Irene Dæhlien, Sverre Fuglerud, Stian Innerdal, Juridisk Rådgiver, Martin Smestad)

Local workshop in Denmark (DK): Center for Psychotraumatology University of Southern Denmark (Sarah Dokkedahl, Ask Elklit, Sille Løkkegaard, Sophia Selsbæk, Louise Simonsen, Adnan Todorovac), **Odense University Hospital** (Carsten Madsen); **participants, five with physical disabilities** (Anne Sophie Byder, Amalie Gersbo-Christiansen, Jeanne Gravfort (Arm-leg deficit organization), Mette Huus, Birgit Kirk-Knudsen, Michael Købke, Kimmie Koch, Katarina Korn, Sofie Krogh (muscular dystrophy), Albert Larsen (disabled veteran), Nanna Lindekilde, Bente Meldgaard, Helle Poulsen, Annelie Preuthun, Camilla Søderquist, Karen Thaulov, Martin Thomsen (disability assistant); **Psykologerne Fyn** (Mariann Krogh); **Special Hospital** (Ellen Madsen); **The Danish Association of the Physically Disabled** (Susanne Olsen)

Expert meeting for Toolkits in Germany (DE): Berufsverband Deutscher Psychologinnen und Psychologen (BDP), Projektgruppe Notfallpsychologie für Menschen mit geistiger Behinderung (Dieter Irblich); **Carl von Ossietzky Universität Oldenburg, Institut für Sonder- und Rehabilitationspädagogik** (Dr. Marie-Christine Vierbuchen); **Deutsches Rotes Kreuz, Landesverband Nordrhein e.V.** (Linn Richter); **Federal Office of Civil Protection and Disaster Assistance (BBK)** (Frederike Albers, Volker Harks, Claudia Schedlich, Gisela Zurek); **Julius-Maximilian-Universität Würzburg, Institut für Sonderpädagogik** (Thomas Spaett);

Notfallpädagogisches Institut /Medical School Hamburg (Prof. Dr. Harald Karutz); **Verband Sonderpädagogik e.V. (vds), Bundesverband** (Marianne Schardt)

Pilot training in Innsbruck (AT): Austrian Red Cross (Christian Schneider, Heinz Wolf); **Austrian Red Cross Tirol** (Veronica Biebel); **Clinic for medical psychology, Innsbruck, Austrian Red Cross** (Thomas Beck); **Lebenshilfe** (Elisabeth Spielmann); **Lebenshilfe Tirol** (Kathrin Gietl); **Psychotherapist** (Walter Krug); **Tiroler Soziale Dienste** (Michael Wieser); **University of Innsbruck** (Lena Eberle, Judith Leitner, Sandra Mayer, Yasmin Schüssler)

Pilot trainings in Prague (CZ): (1) Charles University (Zuzana Benešová, PhDr. Hedvika Boukalová, PhDr. Klára Brousilová, PhDr. David Čáp, Pavlína Doležalová, Martina Hanzlíková, Jan Hurych, PhDr. Simona Hoskovcová, Lucie Kafková, Marek Katrňák, Lenka Khánská, Kristýna Langrová, Barbora Nebáznivá, Monika Plesníková, Eva Pražáková, Kristýna Rissová, Barbora Soldátová, Iveta Štěrbová, Hana Vostřelová, Karolína Ženíšková); **Czech Ministry of Interior** (Mgr. Michaela Kvasničková, PhDr. Štěpán Vymětal); **Tamtam o.p.s.** (Mgr. Věra Doušová) **(2) Centre of social Services Tloskov** (PhD. Matěj Lipský); **Charles University** (PhDr. Hedvika Boukalová, PhDr. David Čáp, Karolína Faberová, PhDr. Simona Horáková Hoskovcová, Marie Schmidtová, Julie Žalmanová); **Czech Army** (Plk. Mgr. Marek Nový, Npor. Mgr. Romana Plchová, Npor. Mgr. Patrik Weiss); **Czech Ministry of Interior** (DiS., mjr. Mgr. Tomáš Adámek, kpt. PhDr. Michal Černík, Mgr. et Mgr. Eva Chybíková, nstržm. Tomáš Frejka, pprap. Tomáš Gotvald, PhDr. Irena Gruberová, kpt. Mgr. Pavel Hurta, DiS Bc. Ivan Jakůbek, mjr. Mgr. Marcela Kopaňáková, mjr. Mgr. Vladimíra Kvapilová, Mgr. Michaela Kvasničková, nstržm. Mgr. Antonín Labaj, Ph.D., por. Iveta Losmanová, DiS., kpt. Mgr. Jana Majzlíková, nstržm. Mgr. Lukáš Malík, por. Bc. Monika Malinová, kpt. Mgr. Kateřina Olexová, kpt. Mgr. Barbora Pálková, nstržm. Jan Peták, DiS mjr. Mgr. Ondřej Sezima, pprap. Mgr. Miroslav Švandelík, nstržm. Josef Ulrich, por. Bc. Jana Váchová, nprap. Ing. David Vrzal, PhDr. Štěpán Vymětal, kpt. Mgr. Marek Ženata, nprap. Mgr. Václav Zíka); **Czech Police** (kpt. Mgr. Zuzana Baranová, nprap. Bc. Adriána Blažková, Mgr. Jana Francová, Mgr. Veronika Hejtmánková, kpt. Mgr. Lenka Knitlová, nprap. Bc. Tomáš Komárek, PhDr. Alexandra Machková, Bc. Milan Mádr, Zdeněk Pleva, nprap. Roman Skopal, Mgr. Petra Svatoňová, prap., kpt. PhDr. Lenka Vlášková, pplk. Ing. Miloš Zajíc, kpt. Mgr. Vladimíra Žbánková); **DG Fire and Rescue** (kpt. Mgr. Martina Wolf Čapková, plk. PhDr. Zuzana Dittrichová); **Fire and Rescue** (kpt. Mgr. Soňa Pančochová); **Police Presidium** (Aneta Langerová); **Psychiatry Prague** (MUDr. Jana Schmidtová); **Psychosomatic Clinic Prague** (Mgr. Zuzana Hrušková); **Tamtam o.p.s.** (Mgr. Věra Doušová)

Pilot training in Krefeld (DE): Alexianer GmbH (Robert Bering, Sonja Bühning, Jennifer Neumann, Jennifer Söhn); **Bundesamt für Bevölkerungsschutz und Katastrophenhilfe (BBK)** (Claudia Schedlich); **Zentrum für Gehörlosen Kultur Dortmund** (Claudia van Vrijalden Hoven); **DeafMentoring** (Mauela Bittner); **Diakoniewerk Essen** (Birgit Dechêne, Mechthild Schmiedel); **Erziehungshilfe e.V.** (Marie-Wilhemine Schaper, Alice Wiedemann); **LVR Rheinland** (Horst Bruns); **Gesundheitsamt Düsseldorf** (Dominique Kok);

Gesundheitszentrum Gehörlose (Stefanie Breiteneder); **Integrationsfachdienst** (Tatjana Mundhenk); **LVR Luise-Leven-Schule** (Elke Flohr); **St. Vinzenz-Hospital Dinslaken** (Lena Schwenke); **Theodor-Schäfer Berufsbildungswerk** (Oliver Rien); **Universität zu Köln** (Nele Büchler, Sonja Denker, Anne Gelhardt); **Verein für Hörgeschädigtenhilfe Paderborn e. V.** (Astrid Marke); **Vestische Kinderklinik** (Karen Jahn)

Pilot trainings in Oslo, Norway (NO): (1) The annual meeting for The Norwegian Association for visual impaired and blind, 150 participants. **(2)** Training for clinical psychologists in specialist courses, 23 participants. **(3)** Training for clinical psychologists in specialist courses, 25 participants. **(4)** Training for medical students, 50 participants. **(5)** Training for medical students, 50 participants. **(6)** Training for medical students, 50 participants

Pilot trainings in Odense, Denmark (DK): Center for Psychotraumatology, University of Southern Denmark (Sarah Dokkedahl Ask Elklit, Beatriz Ponce de Leon, Sophia Selsbæk, Louise Simonsen, Adnan Todorovac); **Rare Diseases and The Danish Association of the Physically Disabled** (five participants with physical disabilities: Jeanett Gravfort, Tina Elizabeth Hansen, Michael Købke, Susanne Olsen, Martin Thomasen)

European training, Federal Academy for Crisis Management, Emergency Planning and Civil Protection (AKNZ), Ahrweiler (DE): Civil Protection Luxembourg, Luxembourg (Charles Brück); **Croatian Red Cross, Health and Social Welfare Department, Croatia** (Lorena Brkić); **Directorate General of Health Portugal, Division of healthy lifestyle, Portugal** (Miguel T. de Arriaga); **Federal Office of Civil Protection and Disaster Assistance (BBK) Germany** (Frederike Albers, Volker Harks, Claudia Schedlich, Gisela Zurek); **Lithuanian University of Health Sciences, Department Health Psychology, Lithuania** (Nida Zemaitiene); **Ministery of Public Health Belgium, Department Disaster Management, Belgium** (Astrid S. Fortuin); **Psychological Association Catalunya (COPC), Andorra** (Nathalie Garcia Manitz); **Public Health England, Department Emergency Response, United Kingdom** (Natasha L. Bloodworth); **University Hospital Bratislava, Slovakia** (Miroslava Zimanyiova); **University of Innsbruck, Austria** (Alexander Kreh)

3rd International Conference in Cologne (DE) – 2017: Administration des Services de Secours, Luxembourg (Patrick Friedgen); **Alexianer Institut for Psychotherapy, Germany** (Stefanie von der Ruhren); **Complutense University of Madrid, Spain** (Clara Gesteira Santos); **Civil Protection, Luxembourg** (Charles Brück); **Cyprus Red Cross Society, Cyprus** (Nikos Papadopoulos); **Directorate-General of Health, Portugal** (Dr. Miguel de Arriaga); **European Federation of Psychologists' Associations, Germany** (Florian Stoeck); **European Network of (Ex-)Users and Survivors of Psychiatry (ENUSP), Bosnia and Herzegovina** (Sandra Markovic); **Fachverband für Menschen mit Hör- und Sprachbehinderung e. V. (BLWG), Germany** (Sören Gericke); **Federal Office of Civil Protection and Disaster Assistance (BBK), Germany** (Marion Heymel, Ronja Zimmermann); **Fire Rescue Service of Usti nad Labem Region, Czech Republic** (Jana Majzlíková); **GGD GHOR Nederland, The**

Netherlands (Dr. René Stumpel); **Groupe de Support Psychologique (GSP), Luxembourg** (Raquel Ferreira); **Health Policies at Anti Ghetto – The Project, Bulgaria** (Ilina Petrova Nikolova); **Impact, National Knowledge and Advice Centre for Psychosocial Care concerning Critical Incidents/Nivel – Netherlands Institute for Health Services Research, The Netherlands** (Dr. Michel Dückers, Caroline Six); **Julius-Maximilians University Würzburg, Germany** (Moritz Kastner, Florian Rubenberger, Thomas Spaett); **Lithuanian University of Health Science, Lithuania** (Nida Zemaitiene); **Ministry of Norwegian National Unit for Hearing Impairment and Mental Health (NBHP), Division of Mental Health and Addiction, Norway** (Dr. Beate Øhre); **Public Health, Belgium** (Astrid Fortuin); **Psychiatric Hospital Kosmonosy, working group for the Psychology of Crisis, Disaster and Trauma with the CMPS, Czech Republic** (Barbora Balkova); **Psychological Association Catalunya (COPC), Andorra** (Nathalie Garcia Manitz); **Ressource Center for Rare Disorders (TRS), Norway/Denmark** (Dr. Anne-Mette Bredahl); **Social Work and sign language interpretation, Germany** (Thomas-Paul Gluch); **Sociedad Española de Psicotraumatología y Estrés Traumat ico (SEPET-D), Spain** (Dr. Francisco Orengo Garcia); **University Hospital Bratislava, Slovakia** (Miroslava Zimányiová); **Project Coordinator: Federal Office of Civil Protection and Disaster Assistance (BBK) Germany** (Frederike Albers, Dr. Miriam Haritz, Volker Harks, Sebastian Hoppe, Claudia Schedlich, Gisela Zurek); **Project partners: Centre of Psychotraumatology, Alexianer Krefeld GmbH, Germany** (Phillip Benz, Prof. Robert Bering, Fernanda Heinke, Lena Richter, Jennifer Söhn); **Charles University, Prague, Czech Republic** (Hedvika Boukalova, Simona Hoskovcova, Stepan Vymetal); **Norwegian Centre for Violence and Traumatic Stress Studies, Norway** (Audun Brunes, Marianne Hansen, Trond Heir); **University of Innsbruck, Austria** (Barbara Juen, Alexander Kreh, Michael Lindenthal); **University of Southern Denmark, Denmark** (Sarah Bøgelund Dokkedahl, Prof. Ask Elklit)

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ISBN-13: 978-3-939347-85-9