**Supporting people with mental disabilities in emergencies and disasters**

**Trainer Handbook**

**for Trainings with Caregivers and Emergency Personnel**

**EUNAD IP**

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Introduction 5

How to use the training handbook and power point modules 5

Development of the Handbook 6

Report on guidelines and handbooks regarding people with mental disabilities in disasters 6

Workshop: people with mental disabilities in disaster and emergency situations 6

Summary of workshop results 7

In depth interviews on selected events 8

Summary of results of interviews with caregivers 8

Summary of results of interviews with emergency personnel 9

Pilot training 9

Discussion of input: results 10

Discussion of case example (emergency in home for people with mental disabilities): results 10

Checklists: discussion results 10

Development of training package 10

Types of Mental disabilities (Dementia, Autism spectrum disorders, other mental disabilities) 11

Persons with mental disabilities 11

Intellectual disability 12

Autism Spectrum Disorder 16

Dementia 19

Persons with mental/learning/intellectual disabilities in emergencies and disasters: Results of research/state of the art 22

Trauma, Dissociation and Grief 28

Trauma 28

Defining trauma 28

The brain in trauma 29

Implications for support and therapy 30

Dissociation 30

Defining dissociation 30

Dissociative phenomena during the acute traumatic situation 31

Dissociative Amnesia 31

Dissociative personality parts 31

Affect and dissociation 32

Grief 33

From coping stages to coping models 33

Differentiating between normal reactions and complicated grief symptoms 33

How to support a grieving person/family? 34

Reactions and needs of people with mental disabilities in emergencies and disasters 35

Where does the information come from? 35

Results of ENPS questionnaire 37

Results of caregiver questionnaire 41

Results of caregiver interviews 50

Results of interviews with emergency personnel 53

Roleplay and table top exercise instructions 56

Define Objectives 56

Choose Context and Roles 57

Give a clear introduction 57

Define problems for table top exercise 58

Debriefing after roleplay and table top exercise 59

Evacuation Exercises and drills 59

Framework for developing emergency plans and checklists in facilities for persons wirh mental disabilities 60

Preparedness: What to do before an emergency/disaster happens 60

How to develop an emergency plan 64

Tables 68

Figures 68

References 69

Case examples 78

# Introduction

In the current state, knowledge about the specific reactions, needs and demands of mentally disabled people in disaster settings has been revealed as insufficient among organisations and professionals working in disaster preparedness and response. Furthermore psychosocial emergency care, in terms of secondary and tertiary prevention, poses a substantial gap for disabled people. The EUNAD-IP training package “Supporting people with mental disabilities in emergencies and disasters” seeks to fill this gap and is designed for first responders, social workers, and mental health professionals, seeking training on psychosocial crisis management for people with mental disabilities.

# How to use the training handbook and power point modules

The handbook and powerpoints have a modular structure to enable trainers to take out the parts that are needed to construct a training for a specific group of persons.

**Part one: information**

In the beginning, we give some general information about three forms of mental disabilities: intellectual disability, autism spectrum disorders and dementia. These three were chosen because they are the main groups of affected persons’ caregivers and emergency personnel must deal with.

Furthermore, we give an introduction into trauma, grief and dissociation according to the contents most needed by caregivers and emergency personnel (see development of the handbook).

The information part concludes with a chapter on specific reactions and needs of people with mental disabilities in emergencies and disasters. The powerpoint is divided into a part for caregivers and a part for emergency personnel.

**Part 2: Roleplays and table top exercises**

This part contains case examples and instructions how to do roleplays and table top exercises.

**Part 3: How to develop an emergency plan**

This part contains instructions how an emergency plan can be developed by a facility for persons with mental disabilities.

All powerpoint modules are available for download at

[www.eunad-info.eu](http://www.eunad-info.eu)

<https://www.uibk.ac.at/psychologie/fachbereiche/psychotraumatology/research.html>

# Development of the Handbook

This Training Handbook was developed in the EUNAD IP project (<http://eunad-info.eu/home.html>) and is based on a study done by the University of Innsbruck.

In order to find out about the special needs of persons with mental disabilities in emergencies and disasters as well as training needs for caregivers and emergency personnel we took several steps.

1. Desk research on scientific literature and guidelines
2. Workshop and focus group discussion with experts
3. In depth interviews on specific case examples
4. Pilot training and expert focus group discussion on training needs

In the following we will give a more detailed description of each step.

## Report on guidelines and handbooks regarding people with mental disabilities in disasters

The report can be found on the website. It contains scientific literature and recommendations for people with (mental) disabilities in emergencies and disasters. As there is not much literature on people with mental disabilities, two action sheets have been developed on the specific situation of people with mental disabilities in emergencies and disasters (one in German, one in English) and also put on the website (see report).

## Workshop: people with mental disabilities in disaster and emergency situations

The workshop has been held at the University of Innsbruck, Psychology Department on September 30th 2016. Participants came from 4 different organisations and were mainly leading personnel. All experts had more than ten years of experience in the field.

**In the workshop, we focused on the following topics**

* Input about EUNAD-IP
* Collection of practice examples and experience exchange
* Development and discussions of training needs based on the practice examples

### Summary of workshop results

**Perceived Challenges in emergency and disaster situations with people with mental disabilities**

As we saw in the workshop, EMTs and caregivers have similar views about challenges in emergency situations and disasters but a very different emotional situation.

Generally speaking, emergency personnel needs good cooperation with caregivers and a lot of information about persons with mental disabilities in order to fulfill their tasks.

Caregivers on the other hand are often overwhelmed and anxious because of their enhanced feeling of responsibility and their lack of information and experience about procedures in emergency and disaster situations.

People with mental disabilities themselves often have difficulties in understanding the situation and are highly dependent on the reactions and support of their caregivers. Relatives often are overprotective and do not want the mentally disabled person to get information about death.

**Perceived training needs and ideas for improvement**

Generally, the expert’s opinion is to consider each of the affected groups of helpers separately because their training needs may differ a lot.

There seem to be three areas of “training”

1. Exercises
2. Trainings
3. Checklists

Emergency personnel and management may use exercises to gain experience in interaction with people with mental disabilities, but also to get to know caregivers and their needs, as well as to inform themselves about the specific caregiving facilities and their structures and procedures. In trainings, emergency personnel may learn about specific communication strategies with people with mental disabilities as well as their specific reactions.

Caregivers may learn a lot about emergency and disaster procedures via exercises. They learn about requirements and procedures as well as the use and development of checklists via trainings. Checklists may support them in emergency and disaster situations if they are developed specifically for the facility and event type and if they are used in exercises on a regular basis.

People with mental disabilities may learn a lot about emergencies and disasters via exercises and trainings if they are done often enough, so that they can build up routines and loose fears. Trainings must be adapted to their needs and safety has to be of utmost importance. Positive outcome is of utmost importance.

Relatives should be actively involved in exercises and preparedness activities such as the development of emergency sheets and procedures for emergencies regarding their relative.

**Workshop feedback**

The workshop was a great success and we gained a lot of information from each of the participants. The exchange between emergency and caregiving organisations was experienced as very important and positive by the participants. The climate in the group was nice and productive and discussions went very well.

## In depth interviews on selected events

Expert interviews have been conducted to get more in depth information about the specific needs and reactions of people with disabilities in emergencies and disasters. These interviews took place during the workshop above in the form of focus group discussions.

In depth interviews were done based on case examples that the experts had experienced themselves. 11 experts came from caregiving organisations, 5 experts came from emergency organisations. 21 case examples from different emergencies and disasters could be collected.

**Emergencies experienced by caregivers were the following**

* Death of a relative
* Death of a client in a disability facility
* Violence
* Loss of persons of trust
* Medical emergencies

**Emergencies experienced by emergency personnel were**

* Death of a relative
* Death of a caregiver
* Medical emergency
* Delivering a death message
* Supporting through viewing of dead body
* Evacuation
* Rescue

### Summary of results of interviews with caregivers

As the results show, stress reactions and needs are the same in mentally disabled as in non-disabled persons, but reactions may be stronger, more nonverbally expressed and with a later onset. Dissociation and regression as well as aggression may occur more often. Dissociation is often not recognized as the differentiation from disability related behaviour is often not easy.

Grief reactions are not as continuous as with non-disabled persons and a lack of understanding endanger recovery, especially when no information is given to protect the client.

Regarding coping, strategies using social support seem to be diminished and adaptation to new situations seems more difficult. A regular daily schedule, routines and rituals and a continuity in caregivers seem to be crucial.

Knowing the client, good cooperation and communication between caregivers, emergency personnel and relatives seem to be the most important factors in emergencies.

### Summary of results of interviews with emergency personnel

Also with emergency personnel we see the importance of a good cooperation and communication between emergency personnel and caregivers/relatives. Furthermore, emergency personnel expresses a need for trainings of specific communication strategies.

Finding emergency shelters and ensuring contact with persons of trust seem to be the biggest challenges in bigger events and disasters. Regarding reactions and needs as well as helpful interaction, emergency expert’s narratives do not differ from caregiver’s narratives.

The interviews gave us a lot of information that has been used for the development of the training package and will be further used for recommendations and training handbook. The concept for the handbook can be seen below.

## 

## Pilot training

The aim of the pilot training was to present and discuss some formats that we plan to use in the handbook, namely PowerPoint input, exercises based on case examples and a framework for developing checklists for emergencies.

For the pilot training, the following input has been developed (see Annex).

1. A PowerPoint presentation on specific reactions and needs of people with mental disabilities
2. A case example to be used for exercise and case discussion
3. A preliminary checklist to be used as a framework for a discussion on how to develop a checklist based on a case example

The training took place at the University of Innsbruck on January 20th, 2017**.**

Participants came from caregiver and emergency organisations, they had at least ten years of experience.

**Terms of reference were the following**

* Input on reactions and needs based on expert interview results
* Case example used for group discussion
* Checklist draft discussion based on case examples

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### Discussion of input: results

Discussing PowerPoint input, we saw that more focus must be put on the differentiation between three groups of disabled people: persons with minor and medium level mental disability, people with autism spectrum disorders, and people with dementia. These seem to be the biggest groups in the facilities and therefore the primary target groups.

The general contents needed were trauma, grief and dissociation; information on the above-mentioned groups, a part on reactions and needs as well as coping of people with mental disabilities in general and specific information on the three groups.

### Discussion of case example (emergency in home for people with mental disabilities): results

The case example was about a person with ASD who had an accident in the housing facility leading to a bleeding head wound. The emergency doctor in this case treated the patient in the facility and did not take him to hospital (which goes against regulations).

In the discussion of the case example the need for an exchange between caregivers and emergency personnel became clear. Either group did not know enough about the procedures and needs of the other group. They found it very informative to exchange their views. Joint trainings and exercises seem to be of utmost importance.

### Checklists: discussion results

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

We can provide a framework for checklist construction that supports facilities in developing checklists. Using case examples these checklists may be developed in a workshop setting.

## Development of training package

Based on the expert interviews, workshop results and results of pilot training, a training package was developed that contains the following contents

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* Information for caregivers and emergency personnel (PowerPoint presentations and input in training handbook)
* Additional Information for trainers: how to do exercises (based on case examples)
* Framework for developing a checklist (to be done in a workshop using case examples)

# 

# Types of Mental disabilities (Dementia, Autism spectrum disorders, other mental disabilities)

## Persons with mental disabilities

*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 year of 18.

The terms most often in use are general learning disability, intellectual disability/impairment, mental retardation. They refer to generalized neurodevelopmental disorder, which includes impaired intellectual and adaptive functioning*.* Intelligence score under 70 and difficulties in managing autonomous everyday living consensually characterizes the impairment. *The specific behavioral 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 are for example Autism, Cerebral palsy, Down Syndrome, Fragile X syndrome, Meningomyelocele, neurofibromatosis, Prader Willi syndrome, Velocardiofacial Syndrome, Williams Syndrome.

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

## Intellectual disability

According to DSM V (APA, 2013) intellectual disability or intellectual development disorder forms a group of heterogeneous syndromes with multiple causes. Onset of the impairment is in the developmental period, when the individual fails to meet appropriate developmental milestones. If intellectual disability goes along with a genetic syndrome, affected may show a characteristic phenotype (e.g. Down syndrome) or characteristic behaviors. Meningitis, encephalitis or head traumata in the developmental period are other possible causes of intellectual disability. Generally, intellectual disability is nonprogressive, except certain forms of genetic disorders like Rett Syndrome or Phillip syndrome.

According to DSM-5, the following criteria must be met for the diagnosis of intellectual disability:

1. Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing.
2. Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community.
3. Onset of intellectual and adaptive deficits during the developmental period.

Referring to DSM-5, severity levels of intellectual disability (intellectual development disorder) are the following:

1. Mild
2. Conceptual domain

* Difficulties in learning and academic skills in school aged children (reading, writing, time, money)
* Support is needed in one or more areas to meet age related expectations
* Impairment of executive functions, abstract thinking, short term memory and the functional use of academic skills in adults
* In contrast to age related mates concrete approach to problems and solutions

1. Social domain

* Compared to age mates, immature behavior in social interactions (difficulties in adequately perceiving peer’s social cues)
* Communication, conversation and language more concrete or immature
* Difficulties in regulating emotions and behavior on levels expected for age
* Limited understanding of risk in social situations
* Immature social judgment
* Risk of being manipulated by peers

1. Practical domain

* Support is needed with complex daily living tasks (support in adulthood typically focuses on transportation, home and child care, organizing, banking, money management)
* Employment is often seen in jobs which do not emphasize conceptual skills
* Required support to make health care and legal decisions, to learn and perform a skilled vocation, to raise a family

1. Moderate
2. Conceptual domain

* Individuals conceptual skills largely behind age related peers
* Slow development of language and pre-academic skills in preschoolers
* Slow progress in reading, writing, mathematics and the understanding of time as well as limited understanding of these domains in school age children
* Elementary skill development in academic skills in work and personal life of adults
* Ongoing assistance needed for conceptual tasks of daily life
* In some cases, conductance of all responsibilities to a legal warden

1. Social domain

* Marked differences across all developmental domains in social and communicative behavior
* Spoken language as primary tool for social communication, but less complex than peers
* Ties to family and friends are present, the individual may have successful friendships across life, in adulthood romantic relationships are possible
* Social cues may not be perceived or accurately interpreted
* Limitation of social judgment and decision making abilities
* Assistance of caretakers needed with life decisions
* Friendships with age related peers affected by communicative or social restrictions
* To succeed in work, profound communicative and social support is needed

1. Practical domain

* Extended period of time is needed to teach and remind the individual in manners of personal needs (eating, dressing, hygiene)
* Participation in household tasks possible in the presuppose of extended teaching
* Jobs with limited requirements of conceptual and communicative skills may be achieved when support from coworkers, supervisors is guaranteed to meet social expectations, job complexities and other responsibilities such as health care decisions, scheduling, transportations and money management
* Recreational activities may be developed and practiced with additional support over an extended period of time
* Maladaptive behavior seldom occurs

1. Severe
2. Conceptual domain

* Limited attainment of conceptual skills
* Little understanding of written language or concepts involving numbers, quantity, time or money
* Throughout life extensive help in problem solving by caregivers

1. Social domain

* Spoken language limited in terms of vocabulary and grammar
* Single words or phrases and supplementation through argumentative means characterize the speech
* Communication focuses on everyday experiences
* Language is used more commonly for communication than for explication
* Ability to understand simple speech and gestures
* Relationships with relatives and persons of trust are a source of pleasure and help

1. Practical domain

* Support is needed for all activities of daily life (meals, dressing, bathing, elimination)
* Requirement of permanent supervision
* Inability to decide responsively regarding the well being of self and others
* Support and assistance at home in recreation and at work is required till adulthood
* Skill acquisition demands ongoing support and long term teaching
* A minority shows maladaptive behavior including self injury

1. Profound
2. Conceptual domain

* Conceptual skills involve the physical world rather than symbolic processes
* Use of objects in a goal directed fashion (for self care, work, recreation)
* Skills based on physical characteristics may be acquired (matching and sorting)
* Functional use may be lessened by co occurring motor and sensory impairments

1. Social domain

* Limited understanding of symbolic communication in gesture and speech
* Simple instructions or gestures may be understood
* Nonverbal, non-symbolic communication of needs and emotions
* Social and emotional communication through gestures and emotional cues
* Enjoyment of relationships with well known family members, trusted individuals and caretakers
* Co occurring sensory and physical impairments may affect many social activities

1. Practical domain

* Dependence in aspects of physical care, health and safety
* Assistance in daily work tasks may be possible
* Simple actions with objects may function as a basis for some vocational activities

Examples for recreational activities may include: listening to music, watching TV, going out for a walk

* Physical and sensory impairments lead to barriers in participation

**Differential Diagnosis**

The DSM-5 gives the following information on differential diagnosis of intellectual disabilities (American Psychiatric Association, 2013).

**Major and mild neurocognitive disorders**

Intellectual disability is categorized as a neurodevelopmental disorder and is distinct from the neurocognitive disorders that are characterized by a loss of cognitive functioning. Major Neurocognitive disorder may co-occur with intellectual disability (e.g. an individual with Down syndrome who develops Alzheimer's disease, or an individual with intellectual disability who loses further cognitive capacity following a head injury). In such cases, the diagnoses of intellectual disability and neurocognitive disorder may both be given (American Psychiatric Association, 2013).

**Communication disorders and specific learning disorder**

Impaired communication and learning domains but no deficits in intellectual and adaptive behavior. Communication and specific learning disorders may co-occur with intellectual disability (American Psychiatric Association, 2013).

**Autism spectrum disorder**

Intellectual disability is common among individuals with autism spectrum disorder. Assessment of intellectual ability may be complicated because of their social- communicative and behavior deficits, which may lessen understanding and complying with test procedures. Re assessments are recommended because IQ scores in autism spectrum disorder may be unstable, particularly in early childhood (American Psychiatric Association, 2013).

**Other Comorbidities**

Co-occurring mental, neurodevelopmental, medical, and physical conditions are frequent in intellectual disability, some conditions (e.g. mental disorders, cerebral palsy, and epilepsy) are three to four times higher than in the general population. The prognosis and outcome of co-occurring diagnoses may be influenced by intellectual disability. Identifying symptoms such as irritability, mood dysregulation, aggression, eating problems, and sleep problems, as well as adaptive functioning in various settings can only be assessed with a person who knows the client well. The most common co-occurring mental and neurodevelopmental disorders are attention-deficit/hyperactivity disorder, depressive and bipolar disorders, anxiety disorders, autism spectrum disorder, stereotypic movement disorder (with or without self-injurious behavior), impulse-control disorders, and major neurocognitive disorder. Major depressive disorder may occur throughout the range of severity of intellectual disability.

(American Psychiatric Association, 2013)

According to Kapell et al. (1998) Patients with mental retardation displayed higher prevalence of hypothyroidism, nonischemic heart disorders and visual impairments compared to general population. Adults with Down syndrome have a higher prevalence of thyroid dysfunction, cardiac disorders and visual impairments compared to adults with other forms of mental retardation (including Down Syndrome patients).

## Autism Spectrum Disorder

**Main Features and Prevalence**

ASD belongs to the group of neurodevelopmental disorders, also known as “pervasive developmental disorders” (Faras et al., 2010, p. 2). Deficits in the domains of communication, social reciprocity, as well as restricted, repetitive and stereotyped patterns of behaviors or interests are characteristic for ASD. Restricted ability to interpret nonverbal communication and to build up relationships with peers count as further characteristics of affected. Those impairments are directly linked with communication difficulties, expressed by a late onset and repetitive stereotypical language or no verbal communication at all. Further typical symptoms are narrow and repetitive patterns of behavior. The severity and the manifestation of the symptoms vary among affected persons and might alter by the acquisition of further developmental skills (ibid.).

According to the estimates of the Autism and Developmental Disabilities Monitoring Network (ADDM) from 2012, approximately 1 in 68 children is detected with ASD in the United States (CDC, 2017). The average prevalence in Europe is estimated to be between 1% and 2% (ibid.). The mean prevalence rate in Europe is estimated to range between 1% and 2% (ibid.). Furthermore, ASD occurs four to five times more frequently among boys than among girls (Christensen et al., 2016). Having said that, the DSM-5 indicates that females suffering from autism disorder in clinic samples often exhibit intellectual impairments or language delay, which might be the reason why females with subtler manifestation of social and communication difficulties go unrecognized (APA, 2013).

For a more thorough overview on prevalence rates see <http://www.asha.org/PRPSpecificTopic.aspx?folderid=8589942540&section=Incidence_and_Prevalence>

**Development and course**

Early developmental delays in children suffering from ASD show between the age of 12 and 24 months. However, the date of recognition depends on the severity of symptoms. Severe symptoms might be recognized even earlier than 12 months, whereas subtler forms may be noted later than 24 months of age. Furthermore, a relatively rapid loss of social or language skills in the second year of life are considered to be alarming. In contrast, behavioral features of ASD – such as the lack of interest in social interaction in the first year – are evident in early childhood. Therefore, impaired social and communication abilities may impede learning through social interaction. In the majority of the cases, individuals with ASD show developmental gains during adolescence. A minority with superior skills in language and intellectual capacities is able to live and work independently in adulthood. Even students with above-average intelligence may struggle during their academic career due to problems to adapt and cope with change. The future occupation depends strongly on the individual’s special interests and skills. The level of functioning depends on the severity of impairment, many individuals remain socially naive and vulnerable. Adults appear to display difficulties in processing and responding to complex social cues. Even though individuals more elaborated compensatory strategies for perceived social challenges struggle in novel situations and suffer from the effort of having to consciously calculate what is socially intuitive for most individuals and anxiety. A higher vulnerability to anxiety and depression may be detected. Furthermore, the organization of practical demands might cause problems.Compensation strategies, coping mechanisms, and interventions may be adopted to reduce difficulties in at least some areas of functioning (APA, 2013).

**Definition in the DSM-5**

As opposed to previous editions of the DSM-5 (APA, 2013), there is no more distinction between Autism Spectrum Disorder, Asperger’s Syndrome and Pervasive Developmental Disorder not otherwise specified. The DSM-5 does not longer differentiate between those three types by the category Autism Spectrum Disorder which includes all three former forms and differentiates solely by severity within the category: requiring support (Level 1), requiring substantial support (Level 2), and requiring very substantial support (Level 3). The classification of severity is based on impairments in social communication, as well as on restrictive and repetitive patterns of behavior (APA, 2013). The three above mentioned levels of severity serve to generate individualized treatment plans and interventions to improve speech, language and social skills as well as behavioral aspects. Furthermore, the DSM-5 (APA, 2013) lists four diagnostic criteria. Criterion A is the impairment of reciprocal social communication and social interaction. Criterion B are restricted, repetitive patterns of behavior, interests, or activities. Criteria C and D indicate that symptoms are present from early childhood and restrict everyday functioning in a clinically relevant way. The detection of functional impairments varies from one individual to another and depends on the characteristics of the affected individual and the environment. However, manifestations of the disorder also vary greatly depending on the severity of the autistic condition, developmental level, intellectual level, language ability, treatment history, current support and chronological age, as the word “spectrum”implies (APA, 2013).

Most people affected by ASD show intellectual impairment and/or language impairment. Not only their ability to produce language but also comprehension and the pace of speaking might be affected. Moreover, even affected individuals with average or high intelligence exhibit an unsteady profile of abilities. Among common motor deficits are clumsiness, other unusual motor sings, and unusual pace. Self-injury (e.g. head banging, biting the wrist) and other demanding behaviors are more likely in under-aged individuals with ASD than among people with other disorders (e.g. intellectual disability). Other possible characteristics are light catatonic episodes. However, fully developed catatonic episodes (including mutism, posturing, waxy flexibility) might also occur with the highest risk in adolescent years. Deficits in nonverbal communicative behaviors can be detected by absent, reduced, or atypical use of facial expressions, eye contact, gestures, body orientation, or speech intonation. It has to be taken in account that conspicious features of noneverbal communication might also depend on cultural norms. The use of functional gestures might be evident, however the spectrum of their repertoire is smaller. Further issues might present in the consideration of appropriate behavior in specific situations, particularly in situations where skills of flexibility or compliance with social norms are requiered. Consequently, individuals with ASD may prefer solitary activities, as well as interaction with individuals that are not age appropriate. However, a longing for establishment of friendships without realistic ideas what friendship entails might exist. Tehrefore, relationships with siblings, coworkers and (in)formal caregivers are important to consider (APA, 2013).

Further characteristics of ASD consist of restricted, repetitive patterns of activities, behavior and interests. Inter-individual differences of typical manifestations depend on age, ability, current support, and type of intervention. Stereotyped or repetitive behaviors vary from simple motor stereotypies (e.g. hand flapping, finger flicking) to repetitive use of objects (e.g. spinning coins, lining up toys) or repetitive speech (e.g. echolalia, parroting of heard words, referring to himself or herself as “you”, stereotyped use of words, phrases, or prosodic patterns). Other characteristics consist in an excessive adherence to routines and restricted patterns of behavior, characterized by distress at apparently small changes and insistence on adherence to rules might be observed. Subsequently, the routines of affected persons may interfere with their ability to execute everyday tasks and adapt to novel situations. Other common features are rigidity of thinking, ritualized patterns of verbal or nonverbal behavior, and strongly restricted, fixated interests in unusual intensity. This intense focus and routines might be related to hyper- or hypo activity to sensory input, and manifest in extreme reactions to specific sounds, textures, tastes, appearance of food, or excessive food restrictions. Further common characteristics of ASD are related to senses and include excessive smelling or touching of objects, fascination for lights or moving objects, even indifference to pain, heat or cold is possible. Adults living with a light level of ASD (without intellectual or language disabilities) might be able to learn to suppress repetitive behavior in public. It is important to realize that the special interests mentioned above may be perceived as a source of pleasure, which provide a solid foundation and motivation for education and future employment (APA, 2013).

**Risk factors**

Environmental

Basically, two types of risk factors for ASD can be distinguished: unspecific environmental on the hand and genetic risk factors on the other hand. As unspecific environmental factors count advanced parental age, low birth weight, but also fetal exposure to valproate (medication for epilepsy), which may enhance the risk of ASD.

Genetic and physiological

Genetic and physiological risk is usually determined by heritability estimates which bases on twin concordance rates. According to the estimated heritability, the twin concordance rates range from 37% to even higher than 90%. In 15% of cases of ASD the disorder is associated with genetic mutations (de novo mutations in specific genes). Despite the detection of the known genetic mutation, a polygenetic cause of the disability has to be taken into account (APA, 2013).

**Comorbidities**

Persons with ASD are also likely to exhibit other psychiatric symptoms. ASD is usually associated with structural language disorders or intellectual disability, characterized by the inability to comprehend as well as construct sentences with proper grammar. About 70% of persons with ASD present at least one comorbid mental disorder, 40% even two or more. Common comorbid mental disorders are ADHD, developmental coordination disorder, anxiety disorders, depressive disorders, and other comorbid diagnoses. Other commonly associated medical conditions are epilepsy, sleep constipation, and sleep problems (APA, 2013).

## Dementia

Regarding our topic of reactions and needs of people with mental disabilities in emergencies and disasters we have to include another group namely people with dementia.

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

ICD 10 (WHO, 1992) labels four criteria that have to be fulfilled to diagnose 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 behaviors. This manifests itself in emotional irritability, apathy or impairments in social behavior like eating, dressing and interaction.

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.

According to DSM-5 (American Psychiatric Association, 2013), the term neurocognitive disorders (NCD) refers to a group of disorders that are characterised by a significant decline of neurocognitive functioning in at least one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual-motor, or social cognition). These symptoms are either a concern of the affected individual or represent a fundamental impairment in cognitive functioning. The second criterium of NCDs refers to dependence in everyday activities such as requiring assistance in paying bills or managing medications. The cognitive deficits do neither occur exclusively in the context of a delirium nor are better explained by other mental disorders. Examples for a decline in memory include difficulties to remember a short grocery list or following toe plot of a television programme. Executive problems include difficulties to manage tax records, planning family celebrations or resuming interrupted tasks. According to the extent of the impairment, NCDs are subdivided into three classes: At the level of a mild NCD individuals recognize problems in cognition and in managing complex tasks. They need either extra time or effort or developed compensatory strategies. At this stage affected or relatives may not be aware of the restrictions as symptoms and rather see them as normal, especially in the elderly. Therefore, it is important to determine the difficulties relatedness to cognitive loss rather than to motor or sensory limitations. The differentiation between mild NCD and usual deficits associated with normal aging is especially difficult in older individuals. In elderly, there are on the one hand multiple causes for cognitive decline. On the other hand, NCD often occur in the context of medical illness and sensory deficits. For mild NCD the cognitive performance in neuropsychological testing lies in the 1-2 standard deviation range. For major NCD, which defers to the term dementia in DSM-5 the performance is typically 2 or minor standard deviations below the appropriate norms. At this level, functional and cognitive impairment has risen so far that assistance is required in several life domains.

The affected neurocognitive domains are complex attention, executive function, learning and memory, language, perceptual motor skills and cognition. Referring to the level of severity there occur different impairments in each cognitive domain concerning level of functioning.

Complex attention

* Major NCD
* Increasing difficulties in environments with multiple stimuli (TV, radio, conversation)
* Easily distracted by competing events in the environment
* Inability to attend unless input is restricted and simplified
* Difficulties in holding new information in mind (recall of recently given addresses or phone numbers or report of recent statements)
* Inability to perform mental calculations
* Thinking takes longer
* Cognitive processing based on simplified or diminished components
* Mild NCD
* Normal tasks take longer than previously
* Beginning errors in routine tasks
* Increasing need of double checking at work
* Relieved thinking when not competing with other tasks (Radio, TV, cell phone)

Executive function

* Major NCD
* Abandonment of complex projects
* The need to focus on one task at a time
* Relies on others to plan activities of every da life or to make decisions
* Mild NCD
* Increased effort in completing multi staged projects
* Difficulties in multitasking or resuming interrupted tasks
* Complains about increased fatigue due to extra effort to organise and make decisions
* Diminished feeling of joy in social contexts due to increased effort required to follow shifting conversations.

Learning and memory

* Major NCD
* Several repetitions in conversation, often within the same conversation
* Inability of keeping track of a short list of items when shopping or planning the day
* Requirement of frequent reminders in the management of tasks
* Mild NCD
* Difficulties in recalling recent events
* Increased dependence on list making or calendar
* Need of occasional reminders or rereading in keeping the plot of a story
* Looses overview concerning paid or unpaid bills

Language

* Major NCD
* Difficulties with expressive or receptive language
* Frequent use of general phrases
* Preference of general pronouns to names (in severe cases inability to recall names of close friends and family)
* Idiosyncratic word usage, grammatical errors, stereotyped speech, echolalia, automatic speech, mutism
* Mild NCD
* Noticeable word finding difficulties
* Substitution of specific terms though general terms

Perceptual motor abilities

* Major NCD
* Significant difficulties with previously familiar activities (using tools, driving motor vehicle)
* In dusky conditions or under lowering level of light navigating in familiar environments is confused
* Mild NCD
* Need to rely on maps or other persons to ensure orientation
* Feeling of disorientation, when not concentrating oin a task
* Greater expand of effort on tasks as carpentry, assembly sewing or knitting.

Social cognition

* Major NCD
* Lack of socially adequate behaviour
* Insensitivity to social standards of political, religious or sexual topics of conversation.
* Excessive focus on topics despite disinterest of the group or lacking feedback
* Decision-making without regard to safety
* Little or no insight to changes
* Mild NCD
* Subtle changes in behaviour or attitude (described as a change in personality)
* Diminished ability to recognize social cues or read facial expressions
* Decreased empathy
* Increased extraversion or introversion
* Decreased inhibition
* Episodic apathy or restlessness

**Prevalence of dementia in Europe and worldwide**

The risk for developing dementia is rapidly increasing with progressing 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 progressing age. People between 85-89 years have a significant higher risk to develop 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%.

If we take a look at the worldwide prevalence we see the following:

“Age-standardized prevalence for those aged 60 years varied in a narrow band, 5–7% in most world regions, with a higher prevalence in Latin America (8.5%), and a distinctively 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).

## Persons with mental/learning/intellectual disabilities in emergencies and disasters: Results of research/state of the art

According to some prejudices people with disabilities do not experience emergency often, have no conscious awareness of emergencies and do not talk about traumatic memories. Furthermore, helpers are claimed to be 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 ensured that they consciously experience emergencies, it cannot be concluded that the traumatic event has no consequences for them (Ballan & Sormanti, 2006). Furthermore, studies showed 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 does not automatically make people feel insecure because it highly depends on how (programs on) prevention or preparedness are conducted (Mevissen-Renckens, Lievegoed, Seubert & de Jongh, 2011).

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

**Prevalence of traumatization among persons with intellectual disabilities**

Additionally research 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 the public, high risk of accidents influenced by a lower awareness of dangerous situations and experiences of loss (if these are caregivers) which can be more threatening because of high dependency 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 disabled but do not have average levels of intellectual functioning (IQ scores 70 – 85). Especially these adolescents are at risk of victimization: Young women do not have the intellectual capacity to learn how to prevent rape. Young men often get into trouble with authorities because they are easily led astray by their cognitively superior peers (Greydanus & Pratt, 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 put them in a strong feeling of helplessness. They have a higher 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 late or absent; dangerous situations might furthermore be interpreted in the way 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 the action can be inadequate in the particular situation (e.g. fear when facing the firefighters). Normally they often focus attention to irrelevant stimuli, for example, they pay attention to blue light instead of concentrating on emergency alerts. Generally, people with intellectual disabilities show stress reactions similar to reactions of other affected people without disabilities but they might have differing coping strategies during and after the emergency/disaster situation. In some cases, persons with intellectual disabilities may react with severe somatic stress reactions like epileptic seizure, spasticity, cardiovascular problems, incontinence, heightened need for attention, self-harming behavior, fear and defense towards physical proximity and/or aggravation of existing behavioral 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 disabilities (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 have needs for assistive technology and special rehabilitative services, (5) their family and community networks are important supports in disaster situations, and (6) need special attention during recovery, 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 are 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 disabilities may be very often combined in older people. As we could show in another EU project (PrepAge[[1]](#footnote-1)1) older people face a great variety of challenges in disaster situations.

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.

1. Invisibility of older people
   1. Neglect of vulnerability factors and intersectionality
   2. Lack of identification and data on vulnerable older people
   3. Exclusion and insufficient policies and laws for older people in disasters
2. Discrimination and lack of protection
   1. Marginalisation of older people
   2. Risk of abuse of older people
3. Lack of financial support
   1. Economic neglect of older people in disasters
   2. Older people’s lack of resources before and after disaster
   3. Barriers to receiving and applying for support
4. Need for additional health resources and support
   1. Disruption of infrastructure
   2. Unnecessary institutionalization
   3. Lack of medical resources for older people
   4. Higher risk for injury, mortality and morbidity in older people
5. Need for adequate facilities and accessible distribution points
   1. Inaccessible hygiene and health facilities, inadequate shelters
   2. Limited access to distribution
6. Need for adequate nutrition of older people
7. Higher risk for stress related problems
8. Difficulties in evacuation
   1. Lack of means (transportation etc.) for older people
   2. Lack of understanding for special needs (pets) of older people
   3. Lack of concepts (shelter, transport etc.) for evacuation of older people
9. Lack of adequate warning systems for older people
10. Low level of preparedness among older people and agencies caring for older people

(PrepAge, 2014, p. 37)

**Legal status of people with intellectual disabilities**

In principal, the legal rights for people with intellectual disability are the same as for people without disabilities. Nevertheless, people with severe intellectual disabilities 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. Especially 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 (European Union Agency for Fundamental Rights, 2013).

**Recommendations for people with intellectual disabilities in emergencies and disasters**

Summarising the findings from different guidelines the following recommendations can be made. For a more thorough overview see the desk research report done by UIBK at <http://eunad-info.eu>

*General recommendations*

General recommendations focus on political commitment, networking and strategic planning

* **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 intellectual disabilities. As part of the more general endeavor to ensure the safety of their constituent populations, they must consistently pay attention to these people's needs.
* **Coordination and continuity**. In order to guarantee the effective development, application and monitoring of emergency systems for people with intellectual disabilities, one particular body of governmental administration must be responsible for coordination and the continuity of initiatives. In close cooperation with all relevant stakeholders, it will be the task of the coordinating body to make sure that all relevant information is collected and centralised.
* **Networking**. At least one network should exist that allows stakeholders to meet and exchange information about the challenges to be met if risks are to be identified and solutions are to be found. 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 programme 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 will be provided by the involvement of people with intellectual disabilities and their organisations.

* **Identification and optimisation of resources**. The evaluation of a master plan and constant updating of its capacities, as well as 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.

*Recommendations for the Prevention phase*

In the prevention phase, raising awareness and trainings are the most important aspects.

* Raise awareness within the community for people with intellectual disabilities
* Train all helpers in psychological care for people with intellectual disabilities including first responders and first aid personnel
* Design emergency plans and construct intervention teams in facilities for people with intellectual disabilities
* Organize exercises for caregivers and for people with intellectual disabilities
* Promote local inter-agency cooperation/networking between different organizations of care and emergency organisations
* Implement local teams specialized on people with intellectual disabilities for intervention in disasters

*Recommendations for the Response phase: Psychological First aid*

In the response phase, psychological first aid has to be adapted to the skills and needs of persons with intellectual disabilities.

* First contact to persons with mental disabilities
  + 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 a simple, slow, but no infantilizing language
  + Be careful in the case of physical proximity (caution: Individuals with intellectual disabilities might fear medical interventions)
* Ensure basic needs 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 behavior (reduction of tension and calming down)
* Enhance feeling of protection, safety and stabilization
  + Involve trusted individuals, familiar environment, belongings, activities, contact to persons of trust (parents)
  + Implement security by providing distance or proximity (individual differences)
  + Promote the feeling of self-efficacy 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 behavior (calming group behavior)
* 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 a clear and guided communication
  + Seek information from family members
  + Involve local caregivers and institutions
  + Ensure counseling for caregivers and facilities for persons with intellectual disabilities
* Responding to self-harm and harm towards others
  + Pay attention to the safety and protection needs of the helpers
  + Act in an effective and in a most harmless manner
  + In severe cases contact the medical personnel to support with medical treatment
  + Permit grief

*Recommendations for the Recovery phase*

In the recovery phase normality and additional care have to be established

* Support in restructuring of daily activities; help to regain normality
* Refer to therapy if needed
* Criteria for additional care:
  + Prolonged or recurring severe signs of distress (in spite of medical treatment), sleeplessness, restlessness, no ingestion, dissociation, lacking involvement in group behavior, lacking understanding or acceptance
* Give mental health care if needed and appreciate work of caregivers
* Provide counseling for facilities with special needs to ensure the longterm recovery

Our literature research produced the following results which can be found on the website

* 140 studies (37 of which are about people with intellectual disabilities)
* 76 guidelines and handbooks (10 of which are about people with intellectual disabilities)
* 54 tools (6 of which are for people with intellectual disabilities)
* 13 practice examples (none of which is specifically for people with intellectual disabilities)

The full lists of resources are published on the EUNAD website (<http://eunad-info.eu>).

# Trauma, Dissociation and Grief

## Trauma

### Defining trauma

As stated in the DSM-5, trauma is an emotional reaction to life-threatening experiences, such as (threatened) death, serious injury or sexual violence (American Psychiatric Association, 2013). The traumatizing experience may be direct (first-hand) or indirect, e.g. when witnessing a traumatic situation in person, when learning that a close relative or friend was exposed to violence or when fulfilling professional duties and being repeatedly or extremely exposed to traumatic experiences, for example as a first responder. The DSM-5 further specifies that indirect exposure does not include exposure through media and that if the event involved actual or threatened death, it must have been violent or accidental.

Fischer and Riedesser (1998) understand as the defining criterion of trauma: a vital discrepancy between (extreme) situational threat and one’s own coping abilities, leading to shattered assumptions about the world and the self. Levine (2008, p. 21) argues that trauma “does not have to stem from a major catastrophe.” In his view trauma is not in the event but in the body.

During the traumatic situation, typical reactions are

* Being overwhelmed, feeling helpless, not able to set priorities and plan ahead which stems from a reduced frontal lobe activation
* Cognitive impairment: stick to first idea, not able to see alternatives
* Hyperactivity, feeling no hunger, thirst, pain which stems from high Sympathicus Arousal
* Dissociation (see ppt) which is a kind of self protection of the body and includes derealisation, depersonalisation, emotional Numbing, disscoiative amnesia, Stupor, not being able to comprehend, shock

After the traumatic event, uncontrollable memories (intrusions, flashbacks) triggered by reminders are typical. They are mainly sensory (images, sounds, smells...). These intrusions are accompanied by high stress. The hyperarousal which is functional during the traumatic situation, does not subside immediately after the trauma but goes on for a while leading to sleeping problems, irritability and concentration difficulties. As a reaction to this, avoidance and denial are typical. While these feelings are normal, some people have difficulties moving on with their lives and may develop Posttraumatic Stress disorder (characterized by persisting intrusions, Avoidance, Hyperarousal and negatives changes in thoughts and feelings longer than one month after the trauma and experienced in a clinical relevant manner) or other psychological disorders. Longer-term reactions include anxiety, depression, strained relationships and even physical symptoms like headaches or nausea (American Psychiatric Association, 2013). For a more thorough overview of the DSM-5 criteria see for example: https://www.ptsd.va.gov/professional/PTSD-overview/dsm5\_criteria\_ptsd.asp

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### The brain in trauma

Rothschild (2004) explains what happens in the brain when confronted with danger and emotion – and what goes wrong when a person is traumatized.

**The limbic system and the amygdala**

The limbic system, an area of the mid-brain, it is our “early-warning system”. Part of the limbic system is the amygdala. By releasing hormones such as adrenaline, the amygdala immediately generates an emotional response to stressful information we perceive through our five senses (sight, hearing, touch, taste, smell) and then elicits a skeletal-muscle response. During (perceived) threat, the amygdala initiates fight, flight, or freeze responses. The amygdala is therefore crucial for survival. The amygdala also stores information (emotions and sensory information) in a fragmented way. In normal stress situations, the frontal lobe reevaluates the situation and decides about possible reactions. During trauma, the conncetion to the frontal lobe is inhibited, thus reactions become automatic and very fast which is important for survival. These reactions are fight, flight, or freeze, and attachment behavior, all organized via the brain stem. Evoluntionary these reactions have a survival function, in modern society these responses may become nonfunctional. Also, routines can be activated this way. Therefore, routines that have to be trained excessively before the trauma - for example CPR trained by medical personnel or EMT and paramedics - can be very helpful in potentially traumatic situations. In case of a post-traumatic stress disorder (PTSD), the amygdala keeps alarming (independently from the frontal lobe) from actual danger by sending sensory memory initiated by everything that reminds of the trauma. This leads to the same bodily responses as during the traumatic situations (Rothschild, 2004).

**Hippocampus and cortex**

The hippocampus is responsible for contextualizing the information we perceive through our senses, helping us for example to differentiate between a snake and a stick. It re-assesses the amygdala’s immediate response and when appropriate sends an all-clear signal to the amygdala. Together with the limbic system the amygdala is part of the early warning system of our body, the hippocampus is “the dispatcher” of the initial information that then reaches the cortex (frontal lobe).

The cortex is the outermost layer of the brain. Here is where our thinking and problem solving capacity lies, giving us the ability for judgment, deliberation, contrasting and comparison. Moreover, the cortex stores memory – including traumatic ones. However, if the amygdala releases high levels of stress hormones, the hippocampus malfunctions. Then, crucial context information never reaches the cortex, impeding a rational evaluation of the situation.

Apart from contextualizing initial information, the hippocampus has another function that is crucial in handling traumatic experiences. It enables the resolution and integration of traumatic memories, as it structures traumatic memories, segmenting them into a beginning, a middle, and an end. If the hippocampus is functioning well, it gives the cortex the information it needs to recognize when a trauma is over. In posttraumatic stress disorder the ability to drive down the traumatic stress reaction is impaired (Rothschild, 2004).

### Implications for support and therapy

The brain needs a functioning hippocampus to signal the amygdala that the body no longer needs to be alerted and to enable the cortex to recognize when a trauma is over. The hippocampus only functions well when stress levels are low. Consequently, a successful support and therapy must create a safe environment in which stress hormone levels remain low. In psychosocial acute interventions, this is reached by providing five crucial elements: Safety, Connectedness with significant others, self and collective efficacy, calm (the ability and capacity to distance oneself from the trauma and calm down) and hope (Hobfoll et al., 2007).

Rothschild (2004) emphasizes that the ability to contain anxiety, bodily sensations, emotion and memories at will – what she calls “applying the brakes” – must be the first step in therapy before working through the trauma itself. Another therapeutic approach that specializes on trauma and bodily sensations was developed by Levine (2008): Somatic Experiencing(®) which also “emphasizes guiding the client's attention to interoceptive, kinesthetic, and proprioceptive experience“ (Payne et al., 2015).

Stabilization techniques involve strategies that help us come back into our resilience zone (the zone where sympaticus and parasympaticus activity are relatively low and in balance). These are for example: social contact, routines and rituals, body movement, anchors (activities, places, persons, objects that help us to calm down). In activating these resources we can supprt trauma survivors effectively. Resources can be physical, psychological, interpersonal and spiritual (Levine, 2008).

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## Dissociation

### Defining dissociation

In general, dissociation is considered as a survival strategy which enables people to protect themselves in extremely threatening situations. A survival strategy is required when body and mind are no longer capable of protecting themselves. On the one hand, dissociation is a valuable and supportive strategy: it enables persons to reduce the overwhelming distress created by the traumatic situation, by “disconnecting” themselves from the situation. On the other hand, this process leads to a partial or complete inability of the brain to put together perceptions from different qualities into a normal complete memory of an experience. As a result, integration of traumatic experience is hindered (Van der Hart, Nijenhuis & Steele, 2006)**.**

According to Nijenhuis and Van der Hart (2011), this inability to integrate experiences hinders the development of an awareness and acceptance of reality, as well as the reflection on and adaptation to reality. The lack of integrative capacity can particularly be related to the experience of potentially traumatizing events (Nijenhuis & Van der Hart, 2011).

### Dissociative phenomena during the acute traumatic situation

During a traumatic experience derealisation and depersonalization might occur. Persons affected by trauma describe derealisation as having experienced time differently. Time might be experienced extremely slow or extremely fast. Furthermore, events are experienced as film like and strange. In depersonalization, persons describe that they have experienced themselves out of their body during the traumatic situation. Another feature is emotional numbing, consequently emotions cannot be felt (American Psychological Association, 2013).

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### Dissociative Amnesia

A main feature of Dissociative Amnesia is the inability to recall autobiographical information. In addition, amnesia affects an event or a period of time, a specific aspect of an event, or the identity and life history (American Psychological Association, 2013).

Dissociative Amnesia can involve fugue, when the temporary loss of one’s identity or memory is accompanied by physical flight, such as purposeful travelling or bewildered wandering. Dissociative fugue is rare in persons with dissociative amnesia but common in dissociative identity disorder (American Psychological Association, 2013).

Most people are initially unaware of their temporary loss of memory, which can be described as “amnesia for their amnesia.” They recognize lost time when circumstances make them realize that autobiographical information is missing or when their personal identity is lost. Others immediately notice that they missed out on time (American Psychological Association, 2013).

Another important aspect is that the episodes of memory loss do not occur during the course of another mental health disorder, such as post-traumatic stress disorder or due to alcohol or other drugs. Furthermore, they cannot be linked to neurological or other medical condition, nor are they the consequence of a head injury (American Psychological Association, 2013).

There is an increased risk of suicidality and other self-destructive behaviours in individuals with Dissociative Amnesia. Suicidal behaviour is most likely to occur when the amnesia suddenly diappears as excruciating memories are able to emerge and to overwhelm the individual (Nijenhuis & Van der Hart, 2011).

### Dissociative personality parts

Personality is a self-organising psychobiological system consisting of modules and subsystems. Subsystems are blocked or promoted whilst higher order systems choose brain activities that can adapt best to the current situation. The integrative capacity develops during childhood via psychobiological maturing of the hippocampus and the prefrontal cortex, which are the brain areas responsible for integrative functions. A secure attachment of the child to his or her caregivers supports physical and psychological regulations (Nijenhuis & Van der Hart, 2011).

Repeated traumatic experiences especially during early childhood can destroy this development and lead to a lack of integration of traumatic experiences, which serves as the basis for the development of dissociative personality parts. The lack of integration of a personality manifests itself in the existence of two or even more stable but insufficiently integrated parts or subsystems of the personality. This is what we call “dissociation” or – in the words of Nijenhuis and Van der Hart (2011, p. 418) – the “structural dissociation of the personality.” In this specific form of organisation, different subsystems exist in a rigid and separated manner. Although popularly described as a *separation* of the personality, dissociation is actually much better described as a *division* of the personality, “because dissociative parts of the personality are not fully separated from one another.” (Nijenhuis & Van der Hart, 2011, p. 419)

According to Nijenhuis and Van der Hart (2011), each dissociative subsystem “includes its own at least rudimentary first-person perspective.” Dissociative parts and states can operate in sequence or in parallel and be activated or not. Theoretically, each dissociative part is able to be in charge and can interact with other dissociative parts and individuals. The division of personality leads on the one hand to “negative” dissociative symptoms (something is missing) like functional losses such as amnesia and paralysis. On the other hand, “positive” symptoms (something is added) like intrusions in form of flashbacks or voices, but also psychoform symptoms like hearing voices. Furthermore, somatoform symptoms might be observed, such as anaesthesia or tics. Finally, a lack of coherence and coordination of personality appears (Nijenhuis and Van der Hart, 2011). Direct results include disorganised and disoriented attachment patterns, great fear of attachment and extreme feelings of threat when loss of attachment is perceived or imminent (Van der Hart, Nijenhuis & Steele, 2006)**.**

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### Affect and dissociation

According to Dell (2006), thoughts and emotions seemingly coming out of nowhere, or finding oneself carrying out an action as if the action was controlled by a force other than oneself, are often described as being “taken over” by an emotion which does not seem to make sense at the time (Dell, 2006). Sudden feelings of strong sadness without an apparent reason, and then the vanishing of those feelings in the next moment, may serve as an example. Another example is when a person finds himself or herself engaging in activities that they would not normally carry out, but are not able to quit.

## Grief

Loss and grief are essential parts of human life. The understanding of how human loss and how the goals and outcomes of grief therapy are conceptualized underwent several changes in recent decades. Early stage theories got replaced by more recent model theories which also consider further dimensions of grief. Hall (2014) depicts those changes in understanding grief and elaborates on current theories which include a focus on cognitive, social, cultural and spiritual dimensions of grief and loss.

### From coping stages to coping models

Grief has often been described in stage theories, albeit without enough scientific evidence. Nevertheless, stage theories have become deeply implemented in cultural and professional beliefs of loss (Tamlyn & Downe-Wamboldt, 1997). Stage theories serve as an attempt to bring a sense of order in a complex process and suggest that „recovery” and “closure” are the final stage of mourning. However, stage theories are not completely capable to comprehend the complexity and diversity of the grieving process adequately. Hence, stage models lack to address the multiplicity of needs experienced by bereaved people, their families and intimate networks. Those needs might be physical, psychological, social and spiritual (Hall, 2014). This is why most researchers prefer coping *models* over coping *stages*. A popular coping model is provided by Worden (2008) which suggests that grieving should be considered as an active process that involves four concrete grief tasks:

(1) To accept the reality of the loss,

(2) To process the pain of grief,

(3) To adjust to a world without the deceased (including both internal, external and spiritual adjustments), and

(4) To find an enduring connection with the deceased in the midst of embarking on a new life.

### 

### Differentiating between normal reactions and complicated grief symptoms

Grief can be defined as a normal reaction to loss which manifests itself in physical, emotional, cognitive, behavioural and spiritual ways. According to Hall (2014), grievous loss has the capacity to disconnect people from their sense of who they are and often wakes the desire to “make sense” and “find meaning” in their own lives. Neimeyer and Sands (2011) emphasize the reconstruction of meaning as the critical issue of grief.

Most people eventually adapt well to bereavement, and usually regain their psychological equilibrium after some weeks or months of acute mourning, although they frequently will continue missing their loved one for a considerably longer period of time (Bonanno et al., 2002). Referring to previous research Hall (2014) argues that for most people grief intensity is fairly low after a period of about six months, which does not imply that grief is resolved, but rather that it has become better integrated, and no longer stands in the way of ongoing life. Acute grief is a common response to loss, its symptoms should not be pathologised.

Then again, uncompleted bereavement or the failure to find meaning following the loss (especially in terms of “making sense” of the death itself) is associated with complicated grief symptoms. Complicated grief can be considered as a maladaptive form of emotion regulation – which displays a high comorbidity with anxiety, affective disorders and a heightened risk of suicidality (Horowitz et al., 2003). Hence, complicated grief as a subgroup of grief requires professional assistance. According to Hall (2014), the more complicated the grief process, the better the chances of bereavement interventions leading to positive results. Recent research indicates that a specialized complicated grief therapy outperforms a more general psychotherapy when working with bereaved people, and was particularly helpful for those whose losses were traumatic (Shear et al., 2006).

### 

### How to support a grieving person/family?

According to Hall (2014) helpers and caregivers of bereaved people must understand and respect the unique reactions, needs and challenges as individuals and their families cope differently with loss. Helpers should be aware that a classification to a stage theory can lead to the impairment of empathy, where professional helpers fail to recognise and to deal with the needs of bereaved people.

As Znoj (2007) says there is no normal grief, and grief is always dependent on a given culture.

In Mourning the following aspects are helpful (Hall, 2014).

* **Rituals** (for farewell, connecting, yeardays, birthdays etc individual and collective rituals)
* **Balance between negative and positive emotions** (allowance to experience also positive emotions)
* **Remembrance** (fotos, objects, places, talking about the deceased...)

In our own study we found that the following intervention strategies are useful for grieving persons (Mohr, Juen, Siller, Gmeiner 2012).

* Allow for Talking: to be able to talk to somebody who is not emotionally involved (esp. when talking about difficult emotions, being able to tell the whole story)
* Give information and psychoeducation (what to do next, trauma and grief reactions, support systems)
* Be emotionally present and interested
* Activiate social resources
* Provide continuity in support
* Provide warmth and understanding and encourage using rituals in mourning process
* Encourage the individual grieving process and do not force your understanding of grief upon the person
* Encourage and support collective grieving and mutual tolerance of different reactions and needs
* Try to decrease extreme positions of chrif mourner and supporter in grieving family/group
* Encourage distance and recovery as well as positive emotions despite grief

# Reactions and needs of people with mental disabilities in emergencies and disasters

## Where does the information come from?

The idea of the “Trainer Handbook for Trainings with Caregivers and Emergency Personnel” is to improve the situation of people with mental disabilities in emergencies and disasters by catering the training needs of health professionals. In addition, the handbook brings together the expertise of the two occupational groups: caregivers as experts in assisting people with mental disabilities, and emergency personnel as experts in emergency preparedness and response. To elicit both training needs and expertise, a range of methods was used.

Two surveys were conducted in the course of EUNAD-IP: one questionnaire for experts from several European countries of the European Red Cross Network for Psychosocial Support (ENPS), and one for caregivers from German speaking countries. Subject of the surveys were the attention to, as well as the special needs, challenges and resources of people with (mental) disabilities in emergencies and disasters. Moreover, information on the training needs of caregivers and emergency personnel was obtained.

Furthermore, Expert interviews have been conducted in order to get more in depth information about the specific needs and reactions of people with disabilities in emergencies and disasters. These interviews took place during the workshop above in the form of focus group discussions.

In depth interviews were done based on case examples that the experts had experienced themselves. 11 experts came from caregiving organisations, 5 experts came from emergency organisations (see table 1).

A total of 21 Case examples/events were collected.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| ***Type of Expert*** | ***Count*** | ***Age*** | | ***Gender*** | | ***Organisation*** |
|  | ***20-40*** | ***40-60*** | ***female*** | ***male*** |  |
| Caregivers | 6 | 2 | 4 | 3 | 3 | Organisation for people with mental disabilities, home for the elderly |
| Management of disability facilities | 5 |  | 5 | 1 | 4 | Caregiving organisation for children with mental disabilities , Organisation for people with mental disabilities, |
| Emergency personnel | 3 |  | 3 | 2 | 1 | Austrian Red Cross |
| Emergency management | 2 |  | 2 |  | 1 | Austrian Red Cross |

Table . Expert Interviews

As there was very little experience with people with mental disabilities from disaster situations we had to make use of case examples on emergency situations. The results will have to be “translated” into the disaster context.

**Emergencies experienced by caregivers were the following**

* Death of a relative
* Death of a client in a disability facility
* Violence
* Loss of persons of trust
* Medical emergencies

**Emergencies experienced by emergency personnel were**

* Death of a relative
* Death of a caregiver
* Medical emergency
* Delivering a death message
* Supporting through viewing of dead body
* Evacuation
* Rescue

Furthermore, an online questionnaire was sent out to experts from caregiver organisations in Germany and Austria. The participants work with people with physical, mental and/or sensory impairments. Subject of the survey were the attention to, as well as the special needs, challenges and resources of people with (mental) disabilities in emergencies and disasters. Moreover, information on the training needs of caregivers and emergency personnel was obtained.

## Results of ENPS questionnaire

In a “Survey on Challenges and Needs of People with Learning Disabilities in Emergency and Disaster Settings” a total of ten experts from emergency organizations were asked to answer seven open questions regarding their experience with people with learning disabilities in emergency or disaster settings. The participating experts come from ten different mostly EU countries and are members of the European Red Cross/Crescent Network for Psychosocial Support (ENPS). They are all coordinators of the national society of the Red Cross/Crescent in their respective country.

Six of the experts stated they had experience with people with learning disabilities in emergency or disaster settings. They were asked what specific needs and reactions of people with learning disabilities they could remember from their experience, what challenges they had faced, and whether they had experienced knowledge gaps and if yes which. Both groups – those participants with and without experience with mentally disabled people in emergencies and disasters – were asked what kind of training needs they saw for people working in emergency and disaster settings regarding people with learning disabilities. Furthermore, they were asked to share lessons learned, and feedbacks on the topic, as well as other relevant information or comments.

1. **What specific needs and reactions of people with learning disabilities can you remember from your experience?**

The spectrum of answers is quite broad. Basic needs like need for protection, acquaintances, food and the presence of an emotionally warm contact person should be met. One of the participants points out that the specific needs and reactions depend on the type and degree of disability, the educational background and the age of the person.

In order to reach a person with disability, you have to take into account the type of disability and adapt your instructions accordingly. Therefore, instructions should be kept clear and additional necessities like assistance equipment should also be taken into account and become included in preparations. Slow step-by-step training using training aids or models, one-on-one trainings, learning by touching and seeing, but also setting achievable targets for the individual come in handy.

Furthermore, the variety of specific reactions of people with learning disability to emergencies and emergency trainings has to be taken into account. According to the experience of the participants, reactions may vary from complete cooperation to denial. Some may react calm, others may express fear, panic, confusion, stubbornness or may be disoriented. Another reaction to emergency trainings might be contentment that people with disabilities are recognized and considered as actors of their own safety and of the safety of the community.

Another emphasis lays on the support of families of the person with learning disabilities: not only people with learning disabilities need attention but also family members, who often happen to be overwhelmed and tend not to focus enough on their own needs.

1. **Participants without experience with people with disabilities in emergency and disaster settings**

Participants who never faced people with disabilities in emergency and disaster settings were asked what kind of knowledge they would need to feel well prepared for this specific target group. In general, more specific information on age, gender, mental diseases, stigmatization and other target-specific information were requested. Furthermore, participants are interested in how to get information if there are people with learning disabilities in an emergency setting and how to get the message across people with learning disabilities.

1. **What challenges did you face?**

Participants were also asked about the challenges they faced during their work with people with disabilities in emergency and disaster settings. Some of the participants stated that they work in institutions where they have already been obliged to adapt messages and methodologies to the needs of blind people and people with handicaps. According to the results, it is difficult to develop programs tailored to the needs, level of understanding and attention of people with disabilities in critical response situations. Trainings have to be clear and demonstrated in an easy way. It is necessary to have a good time management since the attention of the target group might be shorter. Another problem consists in the training of teams working with this target group. Training teams often face communication issues due to the inability of some participants to read or write. Furthermore, caregivers, helpers and instructors have to master the varying emotions and reactions to those situations. It appears to be hard to cope with heavy and unexpected reactions to emergency settings such as hysteria, the underestimation of danger but also the inability to understand the situation – particularly when people with mental disabilities are affected. It was also reported that it is not easy to provide a calm and controlled environment during evacuation situations. This can prove particularly difficult in case of autism spectrum disorder. Practical issues such as the need for wheelchairs and the need for an adequate medical team also have to be considered.

1. **Did you experience knowledge gaps and if yes which?**

In general, participants agree on the necessity to educate and prepare people with disabilities well for emergency situations in advance. The majority of the participants who already had experienced persons with learning disabilities in emergency and disaster settings did experience knowledge gaps. There is an apparent lack of knowledge regarding the development of pedagogical skills and tools, but also in coping with unexpected reactions in emergency settings. One participant stated to not have experienced knowledge gaps regarding people with disabilities, but recognized difficulties with the preparation of two-tier training programs. Finally, possible knowledge gaps of people with learning disabilities were also mentioned.

1. **What kind of training needs do you see for people working in the emergency and disaster settings regarding people with learning disabilities?**

Basically, it is important to have trainings offering knowledge about the main characteristics (such as physical, mental, behavioral) of different types of disabilities, as well as additional needs and specific reactions that people with learning disabilities might show in disaster settings. Volunteers working with people with learning disabilities and actual support staff could be trained by experts who pass on their experiences, show adequate pedagogical approaches and show how to include people with learning disabilities in disaster preparedness planning. Furthermore, experts could explain how to identify and address the needs of people with learning disabilities and to design and implement specific activities for the target group in different phases of disaster. Another crucial part of training are specific communication methods in emergency and disaster settings. It is also important to take into account the need for additional or special equipment for trainings.

In general, trainings should also try to raise awareness for the topic and include family members who might have gained own experiences. Furthermore, trainings should pay attention to caregivers and families of persons with learning disabilities, who often find themselves in a position where they neglect their own needs. Finally, trainings are a useful tool to raise consciousness about the human rights of people with learning difficulties and raise awareness in general.

1. **What kind of lessons learned, feedbacks can you give on the topic?**

According to some participants, there is a shortage of previous experience in conducting specific activities for people with learning disabilities in crisis situations. Others point out the defective situation of persons with learning disabilities, particularly in developing countries where support is often provided less efficiently. People with learning disabilities face intersectionality. One participant reports positive experiences, stating that the needs of persons with disabilities in emergency or disaster settings are completely included in the Red Cross principles. Another participant highlights the situation of family members and caregivers of people with learning disabilities and how they might neglect their own needs while looking after their disabled friends, family members etc. Finally, the importance of clear, short and simple trainings without any distractions was pointed out as a practical implication.

1. **Other relevant information or comments**

Generally, the participants were highly interested in the project and offered to keep in touch. People with learning disabilities should also be included as experts since they already gained experience in everyday situations and developed different coping strategies. The situation of people with learning disabilities who only have a basic command of the language spoken in the country where they live experience a double impediment to communication. A possible solution might me the use of symbols as a simple and more universal way of communication. Well prepared facilitators who implement educational activities on the topic (learning disabilities in general) to adults but also to children are crucial in order to fight the exclusion of people with disabilities and the neglect of their situation.

*First Aid Award*

One participant mentioned that they had already worked with an expert staff who had been involved with the Paralympics and developed a booklet, a wall chart and a program called “First Aid Award for people with Special Needs and Disabilities”. The award was implemented by Beryl Kelly, a member of the Irish Red Cross, and was already displayed at an ENPS forum. The First Aid Award documents were kindly forwarded to us by the participant.

The participant described the program in detail. Committed Instructors interested in working with people with disabilities and special needs were carefully selected. It was made sure that the instructors got prepared for their highly challenging role and that they had a good understanding of what to expect and how to teach the disabled students. At the beginning of the course the new trainers did some exercises to get an overview of specific problems and to get familiar with different types of disabilities. They experienced them via role playing with people with disabilities participating in the course. The most challenging part was the communication in action and the transmission of knowledge in a short time. The main goals of the training were to get an understanding and to carry out the instructions and complete the task and skills. Participants benefited highly from the training, because they were able to work with people with disabilities and were prepared for unexpected changes of mood and behavior as a reaction to disasters.

## Results of caregiver questionnaire

Another survey was sent to caregivers, all of them members of different organizations for people with disabilities from German-speaking countries, mainly Austria. The participants work with people with physical, mental and/or sensory impairments. 30 persons filled in the questionnaire. Given the topic of the present thesis, only participants stating they had experience working with mentally disabled are included in subsequent data analyses. This holds true for 21 participants. However, two of them aborted the questionnaire after the first questions and are therefore excluded. The answers of the remaining 19 participants (5 male, 14 female; mean age 47.68) are the basis for the evaluation.

The function of the participating experts in each organization varies strongly: management, administration, assistance for people with mental disabilities, leisure activities, sex education, psychological counseling, and basic work. They were asked about their socio-demographic data and professional experience, their experience with people with physical, mental and sensory impairments, and their organizations’ experience with emergencies and disasters. They were asked to gauge the needs, challenges, strengths and weaknesses of people with impairments in emergencies and disasters. Further questions concerned impaired people’s consciousness of emergencies, as well as obstacles for them in emergency and disaster settings. Participants were invited to share their practical experiences and to reflect on supportive as well as challenging factors for their work as caregivers in emergencies and disasters. The survey included both open and closed questions and was developed and carried out by means of the online survey tool “LimeSurvey”. The responses were analyzed with help of IBM SPSS Statistics.

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This survey was dedicated to detect the specific reactions, needs and challenges, as well as strengths and weaknesses of people with disabilities in general, but also mentally disabled people in emergencies and disasters. The expert interviews revealed the importance of acknowledging that each individual reacts to stress differently. Despite these individual processes, some general needs can be described that exist irrespective of any impairment: after an emergency or disaster all individuals seek to re-establish normality by means of the reestablishment of daily structure, to transform losses into gains, and to feel socially connected. The stress reactions and needs of mentally disabled persons are similar to non-disabled persons. Nevertheless, people with disabilities display some specific reactions and needs, as well as strengths and weaknesses described in the following.

**Needs of Disabled in Emergencies**

**Level of Information**

Participants were asked to rate the level of given information to people with all kind of disabilities during emergencies separately (mean= 3,06; SD= 0,70; median= 3). 8 participants reported that information distribution is rather a big challenge and this need is rather not met, additional 4 participants estimated that the need for information distribution is not met, which is very challenging during emergencies. 3 participants stated that information distribution is rather met. None of the participants stated that information distribution was not a problem.

**Psychosocial Support**

Caregivers (mean= 3; SD= 0,65; median= 3) were also asked about the amount of psychosocial support during emergencies. The results are similar to the ones regarding disasters. 3 out 15 participants stated that the need for psychosocial support is not met. 9 out 15 participants reported that there is not enough psychosocial support for people with disabilities in emergencies. 3 of the participants said that psychosocial support is rather met during emergencies. None of the caregivers stated that there are no deficits in psychosocial support.

**Emergency Plans and Numbers, First Aid Training**

Regarding the existence of emergency plans (mean= 2,66; SD= 0,98; median= 3), 3 out 15 participants lamented the lack of emergency plans, 6 participants stated that need for emergency plans rather not met. When it comes to emergency numbers (mean= 2,33; SD= 1,05; median= 2), 2 out of 15 participants state that there are no emergency numbers available. 5 participants said that their need for emergency numbers is rather not met. A slight majority of caregivers (8 out of 15) states that emergency numbers are rather available or available. When it comes to first aid trainings for colleagues (caregivers) and clients 2 of 15 participants state that their need for first aid trainings is not met, 6 report that it is rather not met in their opinion. Also a slight minority (7 out of 15) reported that there is rather no or no shortage in first aid trainings for colleagues (caregivers) and clients (mean= 2,53; SD= 0,92; median= 3).

**Least met needs of disabled in emergencies (among Emergency Plans, Emergency Numbers, First Aid Training, Level of Information Distribution, Psychosocial Support) in Mean Value and Standard Deviation**

**Least Met Needs of Disabled in Emergencies (among Emergency Plans, Emergency Numbers, First Aid Training, Level of Information Distribution, Psychosocial Support) in Absolute Numbers**

**Needs of Disabled in Disasters**

**Level of Information**

According to the participants, information distribution during disasters is challenging as well. 7 out of 15 participants stated that it is very challenging and 5 that it is rather challenging. Only one participant reported that the need for information distribution is fully met (mean=3,2; SD= 0,94, median=3).

**Level of Safety**

15 participants rated the level of safety, such as safe and accessible infrastructure as well as emergency shelters, of people with disabilities in disasters separately. 10 out of 15 stated that the safety is rather a challenge, and 3 more participants even stated that is very challenging (mean=3,1; SD=0,59, median=3).

**Basic Needs**

When participants were asked to rate the fulfillment of basic needs in disasters for all groups of people with disabilities, 3 out 15 reported high deficits and 4 rather high deficits, whereas one participant reported low deficits and 7 rather low deficits (mean=2,6; SD=0,91, median=2).

**Reunification with Family and Friends**

Caregivers were also asked to rate the reunion with family and friends in disasters with regard to people with disabilities, which led to more balanced results (mean=2,3; SD=0,82, median=2). While only 1 out of 15 participants reported that there is no reunion or only a late reunion with family and friends, 6 participants stated it is rather late or does not take place. 2 participants stated that a prompt reunion takes places and 6 that it rather takes place.

**Transportation**

There are further challenges that impede the fulfillment of needs of people with disabilities in emergencies and disasters (mean=3,2; SD=0,67, median=3). A vast majority of caregivers (13 out of 15) rated that the transport of disabled people is often delayed due to insufficient resources. None of the participants stated that transportation during disasters is ensured.

**Supportive Environment and Psychosocial Support**

The vast majority of caregivers (12 out of 15) laments that there is no or not enough supportive environment, such as assistance services in emergency shelters, for disabled people in disasters (mean=3; SD=0,65; median=3). All caregivers report deficits in the supportive environment. Furthermore, a vast majority of participants (13 out 15) stated that not enough psychosocial support is provided for people with all types of disabilities in disasters (mean=3,2; SD=8,6; median=3).

Figure 1. Least Met Needs of Disabled in Disasters (among Level of Information Distribution, Level of Safety, Basic Needs, Reunification with Family and Friends, Transportation, Supportive Environment, Psychosocial Support) in Mean Values.

Figure 2. Least Met Needs of Disabled in Disasters (among Level of Information Distribution, Level of Safety, Basic Needs, Reunification with Family and Friends, Transportation, Supportive Environment, Psychosocial Support) in Absolute Numbers

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**Challenges Impeding the Needs of People with Mental Disabled in Emergencies and Disasters**

In the Survey, caregivers were asked to gauge to which needs of their mentally disabled clients particularly little attention is given in emergencies and disasters. First of all, participants were asked to rate the level of overall fulfillment of their clients’ needs in emergencies and disasters. The vast majority of participants, 18 out of 19 caregivers (94.7%), stated that their clients’ needs are not fully met.

**Satisfaction of All Needs of Mentally Disabled in Emergencies and Disasters**

Figure 3. Do you consider all needs (participation, information, security, reunion with family and friends, and basic needs) as met for mentally disabled in emergencies and disasters?

Then, caregivers were asked to rate the attention given to mentally disabled clients regarding the level of received information, their safety, the degree of fulfillment of their basic needs (such as nutritional needs, shelter, sanitary facilities, medical aid), participation (the possibility to take part in decisions that concern them), as well as the reunification with family and friends.

**Information Distribution**

According to the participants, information distribution during disasters is challenging as well. Regarding the level of information given, 11 out of 19 participants (mean= 0,58) estimated that clients are not provided with sufficient information during emergencies and disasters. 8 participants (mean= 0,42) reported that clients are given enough information.

**Level of Safety**

In total, 8 out of 19 caregivers (mean= 0,42) reported a low level of safety of their mentally disabled clients during emergencies and disasters. However, the slight majority of caregivers, 11 participants (mean= 0,58), reported that their clients’ safety is ensured well enough.

**Basic Needs**

Regarding the fulfillment of basic needs – such as food supplies and other goods – in emergencies and disasters, 14 out of 19 caregivers (mean= 0,74) believed that their clients’ basic needs are fulfilled. Only 5 participants (mean= 0,26) reported that the fulfillment of their clients’ basic needs might be endangered during emergencies and disasters.

**Participation**

Caregivers reported, that people with mental disabilities are not given the possibility to make own decisions and choices in emergencies and disasters. According to the survey, the vast majority of caregivers (16 out of 19 participants, mean= 0,84) reported that their clients’ need for participation is not met. Only 3 participants (mean= 0,16) believed that people with mental disabilities are invited to participate and included in the process of decision-making about themselves during emergencies and disasters.

The lack of participation is exacerbated by the non-inclusion of mentally disabled persons in emergency preparedness and preventive measures. Therefore, they are not only not prepared but have no opportunity to participate in decision-making processes. Participation in preparedness measures – such as the development of adequate information distribution systems, emergency plans, etc. – would improve and ensure the safety of people with mental disabilities. People with mental disabilities should be included in trainings as experts of themselves. This proves particularly valuable as people with mental disabilities cherish being recognized and considered as actors of their own safety and of the safety of the community.

**Reunion with Persons of Trust**

Consequently, caregivers were asked to judge whether their clients are encouraged to reunite with their families and friends in the aftermath of an emergency or disaster. 12 participants out of 19 (mean= 0,63) reported that mentally disabled clients are encouraged to reunite with their families and friends. 7 participants out of 19 (mean= 0,36) reported that mentally disabled are not encouraged to to reunite with their families and friends.

Figure 4. Least Met Needs of People with Mental Disabilities in Disasters and Emergencies

**Summary regarding needs of people with mental disabilities in disasters**

To sum up, the vast majority of caregivers stated that their clients’ needs are not fully met in emergencies and disasters. The greatest deficits can be observed in the estimated level of participation and information. Less acute deficits appear to be the safety of the clients and the reunion with family and friends. It turned out that the fulfillment of basic needs is the need most taken care of.

Challenges impeding the meeting of the needs of mentally disabled are the lack of inclusion in emergency preparedness and preventive measures, deficient information distribution during emergencies and disasters, the lack of information on death and the exclusion from mourning rituals, as well as discontinuity in (in)formal caregivers and living conditions.

Time is an important factor during emergencies and disasters, therefore the emergency staff might be forced to make decisions and react quickly. This makes it more difficult to meet the needs of mentally disabled clients but also to detect and work with the clients’ resources during emergencies and disasters.

**Strengths of People with Mental Disabilities in Emergencies and Disasters**

People with mental disabilities are experts of themselves and should be included in trainings accordingly. In the survey with caregivers, 12 out of 19 participants (63.16%) made a statement concerning the strengths of mentally disabled people in emergencies and disasters. One of those 12 participants (8.33%) pointed out that there is no universal answer to the question. 3 out of 12 participants (25%) believe that mentally disabled people do not have any strengths or resources. One of those 3 participants emphasized the importance of persons of trust. The 9 remaining participants (75%) were able to name and describe strengths. One of them stated that people with mental disabilities “are able to react intuitively in a direction that is good for them” and that they “are more robust than they are often thought to be.” The participant added that “sometimes the way of acting and thinking of mentally disabled appears to be unusual for normal-structured thinkers”, which puts the difficulty in naming strengths of mentally disabled in emergencies and disasters into perspective.

Another participant pointed out that mentally disabled people will possibly not panic that fast and can easily be instructed by others. Furthermore, the ability to patiently await further instructions could also prove beneficial. One participant pointed out that people with mental disabilities have the ability to overcome obstacles and grow in the aftermath of an emergency or disaster as well. Another participant stated that it is easy to stabilize clients quickly and distract their attention if normalcy is reestablished as quickly as possible. One caregiver points out that people with mental disabilities are more mobile compared to physically impaired people and are less dependent on physical accessibility. Further participants stated that mentally disabled people rather tend to act out on their emotions, but are easily influenced and instructed by their persons of trust.

**Weaknesses of People with Mental Disabilities in Emergencies and Disasters**

17 out of 19 participants of the survey with caregivers made a statement concerning the weaknesses of people with mental disabilities in emergencies and disasters. In general, limited cognitive functioning might interfere with their behavior during and in the aftermath of hazardous situations. For example, it might interfere with the ability to detect potential hazardous situations, to set priorities, and inhibit extreme emotional reactions. A client who panics might cause further difficulties and increase the dangerousness of the situation.

Another possible weakness might consist in the misinterpretation or non-adequate evaluation of the situation, leading to inappropriate reactions. Their disability-related weaknesses also influence the crisis intervention and the provision with suiting emergency shelters. Further limitations result from their limited repertoire of self-supporting resources and their limited ability to cope with the incident. Furthermore, limited communication and reading abilities compromise the disclosure of important information, which might hinder the evacuation process and endanger the clients’ safety.

Caregivers also reported that mentally disabled people are even more vulnerable when not prepared for emergency situations and excluded from emergency prevention (lack of trainings). At the same time, they require more information, attention and care as well as more meetings with therapists due to limited cognitive functioning. Furthermore, poor understanding of dangerous situations and necessary emergency measures might elicit extreme reactions, which might interfere with temporarily altered forms of accommodation (e.g. shelters) and caring (e.g. short-term care). They often depend strongly on their known caregiver, their person of trust, or “emergency buddy”, who know them well and know how to communicate with them, how to deal with extreme reactions and are able to calm them down quickly. Thus, the loss of known and trusted caregivers might lead to extreme reactions and a lower capacity to keep calm and deal with the threatening situation. In general, weaknesses and challenges have to be considered and solutions found in order to ensure the safety of mentally disabled people in emergencies and disasters.

## Results of caregiver interviews

As the following tables (2-9) show, stress reactions and needs are the same in mentally disabled as in non-disabled persons, but reactions may be stronger, more nonverbally expressed and with a later onset. Dissociation and regression as well as aggression may occur more often. Dissociation is often not recognized as the differentiation from disability related behaviour is often not easy.

Grief reactions are not as continuous as with non-disabled persons and a lack of understanding endanger recovery, especially when no information is given in order to protect the client.

Regarding coping, strategies using social support seem to be diminished and adaptation to new situations seems more difficult. A regular daily schedule, routines and rituals and a continuity in caregivers seem to be crucial.

Knowing the client, good cooperation and communication between caregivers, emergency personnel and relatives seem to be the most important factors in emergencies.

The following tables illustrate this.

|  |  |
| --- | --- |
| ***Stress response*** | |
| ***Similarities to individuals without disabilities*** | ***Differences to individuals without disabilities*** |
| * same response as individuals without disabilities * no differences concerning emotional responses and needs * individuality of coping mechanisms | * reactions delayed and phasic * reduced ability to verbally communicate emotional responses often leads to higher sensitivity * stress reactions last an extended period of time * people with mental disability tend to use regressive coping strategies * freezing as common reaction * Confusion * Aggression |

Table 2. Caregiver interview results: Stress response

|  |
| --- |
| ***Grief reactions*** |
| * Discontinuous grief with good and bad phases * Withdrawal * Mourning rituals as important coping strategy for people with mental disability (exception autism spectrum disorder) as well as individual differences in the willingness to visit funeral services * Physiological reactions (eczema) * Every individual reacts to stress differently irrespective of the impairment * Return to everyday life is delayed, stepwise coping * Unconventional reaction to grief (laughing) * Aggression, Auto-aggression, self harm * Different death concept * Enhanced need for social contact * In the aftermath of a critical event, small changes are perceived as a disaster * Intense lack of future prospects compared to individuals without disabilities * Need to understand and to process the loss * Regression |

Table 3. Caregiver interview results: grief reactions

|  |  |  |
| --- | --- | --- |
| ***Needs*** | | |
| ***General Needs*** | ***Specific Needs of people with mental disabilities*** | ***Similarities to people without disabilities*** |
| * Reestablishing normality/daily structure * Social connectedness * Transformation from losses to gains | * Difficulties in framing the critical life event * Difficulties in making use of social connectedness * After a loss, people with cognitive disability tend to interpret their environment as threatening, * structure is important * Importance of persons of trust * There are multiform decisions, which put pressure on people with mental disability. Caregivers have to enable the individuals’ regaining control. | * People with mental disability need the same amount of care and attention as other family members * Time and communication as important in transformation process * Participation in the process of dying and berievement helps to understand and transform the matter of death * Mourning rituals as important coping strategy |

Table 4. Caregiver interview results: Needs

|  |  |
| --- | --- |
| ***Interaction*** | |
| ***Interaction with clients*** | ***Interaction with parents/relatives*** |
| * Invite client to talk * Keep daily schedule and routines * Be aware that people who aren’t able to express their needs verbally have the same needs as the ones who can talk * Use approaches that makes use of different senses in order to help individuals understand daily structure * The closer the relationship with the mentally disabled, the greater the possibility to fulfil the needs and individually support the affected * Make use of individualized communication techniques, Adapt communication to the cognitive and verbal level of the client * Clients needs and decisions have priority and have to be respected * Observation and intervention for an extended period of time * Contact external psychosocial health professionals if needed * Give enough time and compassion * Encourage the expression of needs and special concerns * Use rituals: e.g. Planting a tree as mourning ritual and to process the grief but be aware: Mourning rituals and remembrance may be good for some clients but too much emotional involvement may not be good for clients with ASD * Keep continuity of relationships: e.g. need to prepare for moving house after death of relative but keep same caregiver * Appreciation and respect towards people with mental disability is crucial * Positive present moment experience is especially important for people with mental disability * Fulfilment of basic needs more important than psychological intervention esp. in the beginning * Good relationship between relatives and professionals needed * Cooperation between emergency personnel and caregivers is crucial * Emergency personnel needs an overview of existing resources and caregivers | * Raising of awareness as important tool to fulfil the needs of the client * Tense relationship between caregivers and relatives concerning the coping with grief is not good for clients but often experienced * Clients’ needs towards the family members have to be respected * Acceptance of unproductive cooperation with relatives and focusing on the needs of the client * Good cooperation between relatives and caregivers, regular exchange of information on the client’s condition in case of bereavement * Caregivers dilemma concerning themselves as professionals and parents as experts for their children * Raising awareness concerning the matter of openness regarding death as important tool to overcome the avoidance of parents |

Table 5. Caregiver interview results: Interaction

|  |
| --- |
| ***Attitudes and behaviours of relatives and parents*** |
| * Parents often deny their child the possibility to take part in the mourning process * Denial of ability to grief may result in altered behaviour of the client at work * Parents often try to protect their children from grief and understanding * Children with mental disabilities often are seen as incompetent for grief * Parents of children with special needs have the same concerns and worries as other parents * Parents aim to provide support and safety for their children * Parents with mentally disabled children tend to experience worries to a higher degree * Parents often do not communicate the possibility of their own death, thus aggravate the crisis in case of death * Open or hidden appeal of the parents to intensify the care for the affected child |

Table 6. Caregiver interview results: Attitudes and behaviors of relatives and parents

|  |
| --- |
| ***Supportive factors for caregivers*** |
| * Good cooperation with parents, consent of clients and flexibility in time management contribute to an effective work * Parents’ appreciation and interest for the needs of the child are important * Functioning cooperation among family and caregivers diminishes stress * External counselling professionals as relief for caregivers * Death of a client: Importance for caregivers to have their own mourning rituals like for example carry the body and take part in rituals/strong relationship with clients * Knowledge of clients prolonged and discontinuous grieving process * Clear Information dissemination throughout the whole organisation |

Table 7. Caregiver interview results: Supportive factors for caregivers

|  |  |
| --- | --- |
| ***Challenging factors*** | |
| ***Challenging factors for caregivers*** | ***Challenging factors for clients*** |
| * Negative consequences for clients in case of dysfunctional cooperation between family members and caregivers * Attachment behaviour of parents towards their children and resulting conflicts confront the caregivers with their limitations * High amount of responsibility for caregivers who often lack support or knowledge * No briefing or information exchange concerning the clinical picture of the client * No or bad communication between emergency personnel and caregivers * Lack of clear recommendations result in caregiver’s uncertainty how to respond to death towards the client * High workload, no time for special support to bereaved client * Absent support or aftercare by management in the aftermath of emergencies * Specific events: Finding the body, Suicide * Worries of caregivers are dismissed or ignored * Physicians who disregard people with mental disability and manifest themselves negatively towards mentally disabled individuals * Inattentive treatment by internal and external professionals * Lack of training workshops * Guilt feelings and unclear responsibilities * Problems to differentiate between dissociation and mental disability | * Loss of relatives is often accompanied by moving, which may facilitate the development of psychiatric disorders or withdrawal * In emergency situations information dissemination plays an important role especially if there is no awareness concerning the special needs of the individual * There is a lack of ability to understand the conditions and circumstances of the altered environment. Therefore, people with mental disabilities have problems to cope. * The management of the housing facility may assign a new caregiver, which leads to hindered caring possibilities * In disasters, it is important to maintain social networking and contact with persons of trust but this is a special challenge |

Table 8. Caregiver interview results: Challenging factors in emergencies

|  |
| --- |
| ***Emergency response recommendations*** |
| * Persons of trust are rarely spread, established professional networks should be included * Development of nationwide emergency plans in cooperation with housing ad working facilities to raise awareness to structure effectively the emergency response * Importance of emergency plans for housing facilities and families * Involvement of management to enhance transparency in information dissemination and networking behaviour within the organisations * Necessity of tools to determine persons of trust for the single client |

Table 9. Caregiver interview results: emergency response recommendations

## Results of interviews with emergency personnel

Also with emergency personnel we see the importance of a good cooperation and communication between emergency personnel and caregivers/relatives. Furthermore, emergency personnel expresses a need for trainings of specific communication strategies.

Finding emergency shelters and ensuring contact with persons of trust seem to be the biggest challenges in bigger events and disasters. The following table shows this in more detail. Regarding reactions and needs as well as helpful interaction, emergency expert’s narratives do not differ from caregiver’s narratives. The following tables show the results in more detail.

|  |
| --- |
| ***Emergency preparedness recommendations*** |
| * Training in order to gain information about how to communicate and interact with persons with mental disabilities including experts * Include emergency contacts into emergency sheets * Find emergency shelters if no relatives present * Include caregivers or relatives in emergency situation if present * Inform caregivers about necessary procedures and the other way round * Good documentation of all basic information (medication, habits, eating and toilet, contacts, etc.) * Access to emergency sheets in case of emergency |

Table 10. Caregiver interview results: Emergency preparedness recommendations

|  |
| --- |
| ***Experienced acute reactions of mentally disabled persons in emergencies*** |
| * Emotional reactions:   + Insecurity   + Fear because of information deficit about the medical procedure * Behavioural reactions:   + Extreme stress reactions (shock, screaming…)   + Hyperactive and nervous behaviour   + Contraphobic and controversial behaviour: curiosity, Interest, moving towards the source of danger Emergency situation experienced as adventure   + WithdrawaL   + Autoaggression/Aggression (Scratching, Biting) Aggressive reaction depends on the kind of mental disability (ASD)   + Open and positive attitude towards unknown people (emergency workers) (“The good ones”)   + In rare cases rejection   + Persons with dementia: More often fear and rejection |

Table 11. Experienced acute reactions of persons with mental disabilities in emergencies

|  |
| --- |
| ***Experienced helpful interactions with mentally disabled persons in emergencies*** |
| * Praise the patient * Give clear instructions * Give clear messages * Involve the patient into care   + Use simple language   + Use Repetition   + Consider individual needs   + Use small gestures that may give safety: e.g. Hold the hand of the patient, Use closeness to create safety   + Stay with the patient   + Engage on the linguistic, visual, acoustic and cognitive level of patient (simple language)   + Integrate reference person (relatives, caregiver) in care of patient   + Create calm and safe environment   + Create familiar environment   + Consider optimal patient care   + Guarantee privacy   + Build trust   + Death of a relative: Integrate people with dementia into the grieving process of the whole family   + Slow, calm and careful action   + Patient and slow transfer to hospital staff |

Table 12. Experienced helpful interactions with persons with mental disabilities in emergencies

For emergency personnel, a lot of useful information can be found on this website of the University of Hertfordshire: <http://www.intellectualdisability.info/>.

Especially the following guidelines are of great use:

<http://www.intellectualdisability.info/how-to-guides/articles/guidelines-for-managing-the-patient-with-intellectual-disability-in-accident-and-emergency>

# Roleplay and table top exercise instructions

In total, we chose 18 case examples for training. These can be found in the Appendix.

**Roleplay and table top exercise instructions**

You may use the case examples in the Appendix for roleplays and tabletop exercises. You should do this in several steps.

**Roleplay:** you let participants play out the situations by going into the role of each character.

**Table top exercise:** you give out information about the situation and let participants discuss problems that may arise during the situation and how to best solve them.

## Define Objectives

Before starting you should define the objectives

* What topics do you want the exercise to cover?
* How much time do you and your class have to work on it?
* What do you expect of your students: research, reports, presentations?
* Do you want the students role-playing separately or together?
* Do you want to include a challenge or conflict element?

For example you can use the following case example for reflecting on how to best deal with conflicts with relatives in case of emergencies.

The objective here could be to train or discuss good ways of dealing with relatives in ermergency situations.

Example 1 (Accident/Conflict with relatives)

A 43 -year old man with a mental and physical disability fell from the couch during his lunchbreak sleep and had a strongly bleeding head wound. This had not happened before and therefore could not have been prevented. The caregiver informed the supervisor who also worked in the establishment. The supervisor alarmed the emergency doctor and shielded the area off to grant privacy to the client and to protect him and other inhabitants. The doctor sewed the laceration at the establishment, because the caregivers didn’t want the client to go to the hospital alone and because the client would have been too stressed by leaving the facility together with people he did not know. The caregivers signed a form that they took over the decision to leave the client in the facility. The caregivers informed the parents after the event had happened. The parents agreed with the decision of the doctor to leave the client in the facility. The client recovered very quickly but there was a problem with the client’s parents concerning the question of responsibility for the accident. The parents first addressed the higher instance and thereby omitted the caregivers and the facility manager. In addition, one assistant felt extremely guilty because of the incident. The facility manager initiated a clarifying dialogue with the caregivers and the parents, which was very helpful for all persons involved.

## Choose Context and Roles

Decide on a problem related to the chosen topic(s) of study and a setting for the characters. It is a good idea to make the setting realistic, but not necessarily real.

**Define roles and contexts clearly**

In the Case example above you have to define the role of the client as well as his reactions, the role of the caregiver and the manager in the facility, the emergency doctor and a paramedic, as well as the role of both parents.

Prepare cards for each role and give them to the participants. Furthermore you have to define the context of the roleplay (parents on the phone versus parents present in group talk).

In this case you can let participants play two situations

1. the emergency situation itself with the parents on the phone
2. the clarifying group discussion with the parents together with the caregiver and the manager

The same two situations can also be discussed in a table top exercise. You can also do one situation as a roleplay and the second as a table top exercise.

## Give a clear introduction

Engage the students in the scenario by describing the setting and the problem.

* Give information about the characters, the situation, the goals and background information
* Find out how many participants have already done role-playing before and explain how it will work for this exercise.
* Outline your expectations of them and tell the participants what you expect them to learn in this lesson.
* Give them time to go into their roles (by using character cards or by instructing each group of characters separately depending on their role in the situation
* Tell them about the importance to do a roleplay in a constructive manner and give every character the chance to stay in control (no overreactions, no intentional „tricks“ to make the situation especially difficult for the other participants etc.)

Using our case example we have to give all participants an overview of the situation and explain our goal (understanding the situation and needs of caregivers and parents as well as the situation and needs of the client in emergency situations)

In the character cards explain the character his/her background and goals clearly.

**Examples**

Character card for emergency doctor

He has a vast experience in treating patients with mental disabilities, he has been a medical practicioner for 20 years and is also working for a home for the elderly where he has a lot of persons with dementia to deal with every day. He wants to establish a good relationship to the client and is willing to bend the rules if it is for the good of the client. The doctor tries to establish a good communication with both client and caregiver and uses the caregiver as a source for information on the client (does he react as always or is this a new reaction?, …)

(Be aware that it is against the rules to treat a head wound at home wothout going to the hospital-in this case the doctor does all necessary examinations at home and the head wound is very superficial but bleeding profusely. It is the caregivers decision to stay in the facility and the doctor accepts this decision but lets them sign a form).

Character card for the client

The client is confused and does not know what happened, taing a hand to his head he sees blood and panics. When the caregiver comes and tells him everything is going to be ok he calms down. When the doctor comes he is stressed and first does not want to communicate. After a while he tries his favourite approach to new people by pushing him playfully several times.

Character card for the caregiver

The caregiver has been the primary caregiver for this client for several months now. He has several years of experience in the field. He has a very close relationship to the client and wants to protect him. He feels guilty because he has not foreseen that the client might fall from the couch.

## 

## Define problems for table top exercise

Also the problems have to be clearly defined in order to allow for a good discussion.

In the given example you could discuss the following problems

* How to best approach the client as a doctor/paramedic (autism spectrum disorder)
* How to best approach the caregiver as a doctor/paramedic
* How to break the news to the parents on the phone
* How to deal with the parent‘s complaint in a constructive manner
* How to prepare for the clarifying talk with the parents

## 

## Debriefing after roleplay and table top exercise

Do a debriefing for the participants to define what they have learned and to reinforce it. Let them come out of their roles explicitly before starting the debriefing. Let each character talk about his or her experience. Try to highlight the main lessons learned.

After the table top exercises groups present their findings in the plenary.

# Evacuation Exercises and drills

Drills and evacuation exercises in facilities are an excellent way of getting to know each other and preparing for disaster. When doing drills and evacuation exercises in the facility the most important issue is not to frighten inhabitants.

You can find a guide for doing exercises/drills on <http://prepage.eu/wp-content/uploads/2016/07/PrepAGE_Guide_en.pdf>

According to the Marin County Emergency plan for students with special needs by Burke (2010) some basic principles are the following:

* Do regular drills to give the inhabitants the chance to get to know procedures and persons
* Prepare drills together with the affected persons and let them be active and use their own coping strategies (use visualization and do not give too much or frightening information)
* Train the inhabitants in first aid (those who are able to follow) and insert a buddy system
* Make use of innovative educational techniques such as role-playing or the use of audio visual aids
* Hold regular drills so that clients become familiar with the procedures
* Know how to get to all the exits
* Practice using evacuation and assistive devices
* Give clear, concise instructions
* Practice dealing with different circumstances and unforeseen situations, such as blocked paths or exits or buddies that cannot be located.
* Emergency planning for students with special needs should be as individual as the students. Some clients may be at increased risk during an emergency and will need extra assistance or special attention. If possible confer with clients and relatives/parents regarding their preference for emergency situations.
* Assess capabilities, limitations and needs and determine what type of evacuation assistance will be required in an emergency for each client (see PEE)
* Clients with disabilities generally have specific “triggers”—words, images, sounds, etc.-- that signal danger or disruption to their feelings of safety and security. If caregivers miss these cues, clients may escalate their behavior to a point where they completely lose control. It is essential that parents/relatives and caregivers work together to share information about triggers and cues. This is best done on a regular basis,
* Develop an individual/Personal Emergency Evacuation Plan (PEE) for each client
* Develop a preparedness KIT fo each client
* Have an (easily accessible) emergency medical card for each client
* Some clients may not comprehend the nature of the emergency and could become disoriented or confused about the proper way to react:
* Train your staff how to assist those who become upset.
* Check that evacuation routes have directional signs that are easy to follow.
* Practice evacuation route(s) regularly.
* Use simple diagrams or pictures to give non-reading or overstressed clients sufficient information to get to safety.

Especially for persons with ASD who tend to get lost while wandering, getting to know emergency personnel might be of use[[2]](#footnote-2)2

Form partnerships with teachers and law enforcement professionals to help develop a simple curriculum that helps expand skills that will enhance their safety in the community and build personal resilience to risk. Invite a variety of law enforcers to sit among (not stand in front of) clients. Officers can participate in mock interviews, for example, by asking the client what their name is and if they have an ID card. Examples of curriculum could include:

* Recognizing and responding as best they can to law enforcers, their uniforms, badges and vehicles
* Stay with and/or go to police and other uniformed first responders
* Keep an appropriate distance when interacting with a law enforcer
* Avoid making sudden movements
* Carry and safely produce an ID card
* Disclose their autism and/or produce an autism information card
* Tell someone they need help or use the phone to request it

# Framework for developing emergency plans and checklists in facilities for persons wirh mental disabilities

Preparedness means we know what steps need to be taken to facilitate a rapid, coordinated, effective response when an emergency occurs to keep the clients safe. Good cooperation and communication with first responders is essential and facilitates the safe integration of clients with disabilities into emergency procedures.

## Preparedness: What to do before an emergency/disaster happens

(1) Develop emergency cards for each client and make sure that they can be accessed when an emergency happens

According to Kerr et al. (2003) the following characteristics should be documented for each client.

* Reported level of skill (specified in understanding and articulation of words, sentences; the ability to participate in a conversation; the ability to walk without assistance and independent use of hands in self feeding)
* Underlying neurological or genetic disorder
* Psychiatric diagnoses and behavior (problematic behavior may cause difficulties in assessment)
* Non-psychiatric medical disorders (disorders of skin, significant trauma, respiratory disorders, urinary infections, psychoses, autism and depression, schizophrenia, peptic ulceration, cardiac and arterial disease, arthritis, tumors, renal failure, thyroid disorders, diabetes)
* Perceived nutritional needs
* Epileptic seizures
* Current medications
* Vision assessments
* Hearing assessments
* Accumulated burden of needs (based on the severity of intellectual disability and the occurrence and magnitude of comorbid conditions)
* Reference persons and how to reach them

Additionally the authors propose recommendations for an effective treatment of people with intellectual disability

* Regular reexamination to ensure the present diagnosis and adequate care and treatment
* Importance of carer training to access medical advice
* Need of plain English reports
* Consultancy of specialists as well as general practitioners
* Establishment of an interdisciplinary specialist medical team
* Regular reassessment for medical disorders
* Establishment of a database of dependent people and their medical needs

Wong et al. (2000) described the issue of involving individuals with learning disability and individuals with dementia into health care decisions. By simplifying the task or assisting the person with intellectual disability by using graphic means decisions may be possible. Presenting the information in an uninterrupted form, followed by a graphic presentation of constituting parts to limit the verbal demands is recommended.

For persons with ASD an Autism Emergency information handout should be developed, copied, and carried with them at all times[[3]](#footnote-3)3

The handout should cover the following information

* Name of child or adult
* Current photograph and physical description including height, weight, eye and hair color, any scars or other identifying marks
* Names, home, cell and pager phone numbers and addresses of parents, other caregivers and emergency contact persons
* Sensory, medical or dietary issues and requirements
* Inclination for elopement and any atypical behaviors or characteristics that may attract attention
* Favorite attractions and locations where person may be found
* Likes, dislikes - approach and de-escalation techniques
* Methods of communication, if non-verbal sign language, picture boards, written word
* ID wear, jewelry, tags on clothes, printed hand out card
* Map and address guide to nearly properties with water spruces and dangerous locations highlighted
* Blueprint or drawing of home, with bedrooms of individuals highlighted

**For evacuation[[4]](#footnote-4)4**

(1) Establish a buddy system (name a buddy for each client) using the following process

* Give the client the opportunity to select his or her own buddy
* Identify a buddy who is appropriate (e.g. strong enough)
* Designate a backup buddy
* Train for the specific need of the special needs client
* Hold practice sessions to assure that buddies can handle their tasks
* Train the buddies on how to communicate with the students and how to evacuate safely

(2) Medication management

Most clients with special needs have very individualized medication schedules that cannot be interrupted without serious consequences. Medicines or medical devices may not be available in emergency shelters. Make alternative arrangements to meet these needs. Consider how medicines can be stored in an emergency. Heat waves and power outages can affect the potency and integrity of some medications. Include an ice chest and cold packs among the school emergency supplies. If there is a power outage, the ice packs can extend the safe temperature range of medications requiring cold storage until the power is restored.

* If the client is on medication, supply a 72-hour supply in a Ziploc bag with instructions; a refrigerated kit is also advised for medication if needed with instructions.
* Gather all medications before evacuation.
* Transport special medications, supplies and equipment with the special needs client
* Carry contact and medical information for all clients and provide individual medical information on a laminated card with a lanyard to be worn around the neck. Below you can find an example of the Emergency Medical Card.

(3) Communication

* Give clear, succinct verbal instructions.
* Pictorial representations, where appropriate, can provide quick and easily understood instruction to many individuals with cognitive disabilities

(4) Time management

Clients with mental disabilities are likely to respond to any form of stress following a crisis with more extreme reactions. Allow extra time for them than others to make necessary preparations in an emergency.

* Some clients with special needs will need more time to comprehend the emergency.
* The earlier the notification, the better the chances are for a successful evacuation.
* Consider what are the triggers and cues for these clients and anticipate rather than react. Prepare clients for changes in routine. Some clients may need to be more protected or isolated to minimize distractions and sources of agitation during the height of a crisis. Caregiver supervision may need to be more intense for a while.
* Allow time for discussion of the traumatic events in a safe and familiar setting; provide choices in activities to the extent feasible to give these students some sense of control over even a small part of their lives.

1. Preparedness supplies

**Facility Supplies**

* Batteries in different sizes, for adaptive equipment
* Lockdown kit, including portable toilet, privacy screen, toilet paper,
* toilet bowl liners disinfectant, and plastic bag for disposal
* Water pouches for drinking Water for hygiene purposes
* Copies of all clients’ Emergency Information Forms (secured)
* Backup copies of medical prescriptions (secured)
* Hand tools (e.g., screwdriver, wrench, pliers)
* Heavy work gloves
* Whisk broom
* Tarp
* Solar/crank/battery radi
* Cell phone and phone charge
* Flashlight and extra batteries or crank flashlight
* First aid kit
* Small ice chest for refrigerated medications
* Evacuation assistive equipment
* Protein bars (without nuts or nut oil)
* Canned fruit
* Carbohydrate-free foods for meals (e.g. canned meat, nuts, jerky)
* Feminine hygiene supplies
* Household chlorine bleach to kill bacteria or antibacterial soap
* Facial tissues
* Whistle/noisemaker for diabetic clients

**Go Kits (Minimum)**

* Lightweight uncomplicated backpack
* Emergency Information Form
* Medication for up to 36 hours
* Emergency Medical Card, laminated and attached to a lanyard to be worn during an emergency.
* Comfort items
* Paper and pen
* Visualized information

(Burke, 2010)

## How to develop an emergency plan

Emergency checklicts have to be prepared individually for each type of event and each type of facility: this can best be done in a workshop with staff and manager. Bigger facilities or hospitals should nominate a crisis team that develops an emergency plan and manages the emergency together.

There are several steps to be taken in developing an emergency plan

* Choose type of events (use adequate case examples varying in type and complexity)
* Choose type of organisation (home, workplace, care facility or hospital)
* Responsibilities and communication plans (define who is to be informed in which case and who is responsible for what)
* Procedures (develop procedures using case examples; include information on legal requirements, evacuation, medical requirements etc. depending on event type and organisation type)

**Choose type of event and type of facility**

First discuss the main events that may happen or already have happened in your facility. Use the following graph as a framework.

|  |  |  |  |
| --- | --- | --- | --- |
| Event (grouped according to propability) | Moderate Impact | Severe Impact | Critical Impact |
| Medical emergency |  |  |  |
| Accident within facility |  |  |  |
| Accident out of facility |  |  |  |
| Power outage |  |  |  |
| Fire |  |  |  |
| Flooding |  |  |  |
| Etc. |  |  |  |

All events that have severe to critical impact should be considered regardless of their propability.

The following Case examples show how each event needs a lightly different approach. Look at the following examples and then do your own examples according to the list you have developed.

Adapt the examples to your kind of facility (housing facility, working facility, hospital etc.).

Medical emergency in facility

In a working facility for mentally disabled persons a client (46) broke down and was unconscious for a short time. A caregiver immediately alarmed the ambulance and started first aid. When the emergency doctor arrived the patient was able to communicate again. He did not want the doctor to touch him and reacted aggressively.

Accident in facility

In a working facility for mentally disabled persons a client had an accident with a carving knife (he severed an artery in his arm and was bleeding heavily. The caregiver alarmed the ambulance and started first aid according to what the dispatcher told him to do. The co workers became very distressed because of the blood and the fearful crying of the patient.

Swimming Accident

During a swimming lesson of a group of 8 persons with mental disabilities a 49 year old client was found in the water wothout vital signs. Two caregivers took him out if the water and immediately startet CPR. After the emergency doctor arrived the person was declared dead.

Bus accident

A group of 21 persons with mental and physical disabilities and 3 caregivers was on their way to a holiday camp when their bus had an accident. One of the caregivers died. 5 clients were critically injured. These persons were brought into nearby hospitals. The busdriver was also injured. The noninjured group of 16 clients and 2 caregivers was brought to a nearby Red Cross station.

Fire in housing facility for persons with mental and physical disabilities

During the night a fire broke out in a facility for 12 persons with mental and physical disabilities. All inhabiltants could be evacuated with only two minor injuries.

Blackout in facility

Imagine a blackout in your facilty and discuss which clients would be affected first/most? Discuss how long you would be able to sustain without power. Imagine the power outage affecting the whole area and discuss what kind of supports to your facility would be affected first/most (food supply/medical supplies/personnel etc.). Discuss your dependencies and how to best prepare.

Using each case example discuss the following topics and develop a plan

* Responsibilities and communication plans (define who is to be informed when, in which case, and who is responsible for what)

You may do this using your organisations’ structure and communication plans. Here you also have to define external emergency numbers (ambulance, firebrigade, police etc.) and where to put these numbers so that they can be easily accessed when in need.

* Procedures (develop procedures using the case examples; include information on legal requirements, evacuation, medical requirements etc. depending on event type, typology of clients and organisation type)

For the procedures you may need to invite somebody from an emergency organisation (depending on the kind of emergency, paramedics, firefighters or other emergency personnel would be adequate) who supports you with information on emergency and disaster procedures.

You may also use available guidelines for each of the event types. For example:

Emergency Evacuation Planning Guide for people with disabilities, National Fire Protection association, 2016, Chapter 6, <http://www.nfpa.org/public-education/by-topic/people-at-risk/people-with-disabilities>

***“BUILDING AN EVACUATION PLAN FOR A PERSON WITH A COGNITIVE DISABILITY***

*Cognitive impairments prevent a person from using or accessing building features due to an inability to process or understand the information necessary to use the features. Cognitive impairments are caused by a wide range of conditions, but all result in some decreased level of ability to process or understand information or situations.All standard building egress systems require the ability to process and understand information in order to safely evacuate.*

*Possible accommodations for people with cognitive impairments might include the following:*

* *Providing a picture book of drill procedures*
* *Color coding fire doors and exit ways*
* *Implementing a buddy system*
* *Using a job coach for training*

***OCCUPANT NOTIFICATION SYSTEMS***

*No Special Requirements. People with cognitive impairments can hear standard alarms and voice announcements and see visual indicators that warn of danger and the need to evacuate. However, the ability of a person with a cognitive impairment to recognize and understand a fire alarm or other emergency notification systems and what they mean should be verified. If the person does not recognize and understand alarms, then plans for assistance need to be developed.*

***WAY FINDING***

***Is Identification of Which Means of Egress Are Available/Closest Necessary?***

*No Special Requirements. However, the ability of a person with a cognitive impairment to find and use the exits should be verified. If the person is not able to recognize and use them without assistance, then plans for assistance need to be developed.*

*Simple floor plans of the building indicating the location of and routes to usable circulation paths should be available in alternative formats such as single-line,*

***35****high-contrast plans. These plans should be given to visitors when they enter the building so they can find the exits in an emergency.*

*Signs in alternative formats should be posted at the building entrances stating the availability of the floor plans and where to pick them up.*

*Building security personnel, including those staffing the entrances, should be trained in all accessible building evacuation systems and be able to direct anyone to the nearest usable circulation path.*

***Is Identification of the Path(s) to the Means of Egress Necessary?***

*No Special Requirements. However, the ability of a person with a cognitive impairment to find and use the exits should be verified. If the person is not able to recognize and use the exits without assistance, then plans for assistance need to be developed.*

***USE OF THE WAY***

*No Special Requirements. However, the ability of a person with a cognitive impairment to find and use the exits should be verified. If the person is not able to recognize and use the exits without assistance, then plans for assistance need to be developed.*

***IS ASSISTANCE REQUIRED? Who Will Provide the Assistance?***

*Generally, only one person is necessary to assist a person with a cognitive impairment. A practical plan should identify at least two, ideally more, people who are willing and able to provide assistance. Common sense tells us that a specific person may not be available at any given time due to illness, vacation, off-site meetings, and so on. The identification of multiple people who are likely to have different working and traveling schedules provides a much more reliable plan.*

*Specific Person(s) in the Office or the Building*

* *Special training or skills*
* *Known to the person with cognitive impairments*

*Anyone in the Office or the Building*

***What Assistance Will the Person(s) Provide?***

* *Ensuring that the person with the cognitive impairment is aware of the emergency and understands the need to evacuate the building*
* *Guidance to and/or through the means of egress*

***Where Will the Person(s) Start Providing Assistance?***

* *From the current location of the person needing assistance*
* *From a specific, predetermined location  Entry to stairs  Other*

***When Will the Person(s) Provide Assistance?***

* *Always*
* *Only when asked*
* *Other*

***How Will the Person(s) Providing Assistance Be Contacted?***

* *Face to face*
* *Phone*
* *E-Mail"*

(National Fire Protection Association, 2016)

# Tables

[Table 1. Expert Interviews 36](#_Toc501031844)

[Table 2. Caregiver interview results: Stress response 50](#_Toc501031845)

[Table 3. Caregiver interview results: grief reactions 50](#_Toc501031846)

[Table 4. Caregiver interview results: Needs 51](#_Toc501031847)

[Table 5. Caregiver interview results: Interaction 52](#_Toc501031848)

[Table 6. Caregiver interview results: Attitudes and behaviors of relatives and parents 52](#_Toc501031849)

[Table 7. Caregiver interview results: Supportive factors for caregivers 52](#_Toc501031850)

[Table 8. Caregiver interview results: Challenging factors in emergencies 53](#_Toc501031851)

[Table 9. Caregiver interview results: emergency response recommendations 53](#_Toc501031852)

[Table 10. Caregiver interview results: Emergency preparedness recommendations 54](#_Toc501031853)

[Table 11. Experienced acute reactions of persons with mental disabilities in emergencies 54](#_Toc501031854)

[Table 12. Experienced helpful interactions with persons with mental disabilities in emergencies 55](#_Toc501031855)

# Figures

[Figure 1. Least Met Needs of Disabled in Disasters (among Level of Information Distribution, Level of Safety, Basic Needs, Reunification with Family and Friends, Transportation, Supportive Environment, Psychosocial Support) in Mean Values. 44](#_Toc501031870)

[Figure 2. Least Met Needs of Disabled in Disasters (among Level of Information Distribution, Level of Safety, Basic Needs, Reunification with Family and Friends, Transportation, Supportive Environment, Psychosocial Support) in Absolute Numbers 45](#_Toc501031871)

[Figure 3. Do you consider all needs (participation, information, security, reunion with family and friends, and basic needs) as met for mentally disabled in emergencies and disasters? 46](#_Toc501031872)

[Figure 4. Least Met Needs of People with Mental Disabilities in Disasters and Emergencies 48](#_Toc501031873)

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# Case examples

**Case Examples: disability facilities**

Example 1 (Conflict with relatives)

A 43-year-old man with a mental and physical disability fell from the couch during a nap and receives a strongly bleeding head wound. It was the first incident of this nature in the facility, which is why it could not have been prevented. The caregiver on duty informed his supervisor of the establishment immediately. The supervisor alarmed the emergency doctor and shielded the area off to grant privacy to the client and to protect him and other inhabitants. The doctor sewed the laceration on-the-spot, because the caregivers did not want the client to be transported to the hospital alone. They assumed that the transport, the unknown facility and the unfamiliar medical staff might put their injured client under too much stress. Therefore, the caregivers signed a form in which they stated that they refused to let their injured client be transported to the hospital for further medical treatment. The parents of the client agreed with the decision of the caregivers. Even though the client recovered very quickly, his parents were concerned about the question of responsibility for the accident. The parents chose to address their concerns to a higher instance instead of directly turning to the caregivers and the manager of the facility. In addition, one of the assistants blamed himself for the incident. The facility manager arranged a clarifying meeting between the involved caregivers and the parents, which proved very helpful for all persons involved.

Example 2 (Individuality of coping)

A client wanted to visit her parents. In order to get there, a caregiver dropped her off at the train station. Even though the client was familiar with the train schedule, she ended up taking the wrong one this time. In lack of a valid ticket she got asked to leave the train in Bolzano (Italy), which is why she never made it to her parents. The client stayed for two days and two nights at the train station in Italy. The police was alarmed and searched for her Europe-wide. The police found her at the train station, shortly after she was picked up by an assistant of a local caregiving organization. The client never understood the seriousness of the situation. When asked what she had been doing at the train station, the client stated that she got herself something to eat and then waited to be picked up by the caregivers. In order to make sure that nobody took advantage of the client at the train station, the footage of the surveillance cameras got checked. The interviewed expert assumed that the client suppressed the incident mentally since repression is her preferred coping strategy. For example, the client usually cuts people who have passed away out of photos and pretends they have never existed.

Example 3 (Individuality of coping)

A client collapsed and complained of pain in his shoulder. Due to the client’s known low pain sensitivity, the caregiver decided to take him to the hospital for further examination. The doctor diagnosed a broken shoulder and scheduled the client for surgery. Unfortunately, the client collapsed a second time and broke his other shoulder. In the aftermath, the client tried to push his self-esteem by demanding a lot of praise from his caregivers, which was considered as a helpful coping strategy by his psychologist.

Example 4 (Grief reaction)

A client lost his brother in a tractor accident. Two years earlier, he had lost his sister, who died of cancer. He dealt with each of the two losses very differently. The diagnosis of his sister initiated a process in which the client had the chance to prepare himself for his sister’s death. In the case of the sudden death of his brother in contrast, he did not have the opportunity to prepare himself. After the sudden bereavement, the client developed a depression, showed symptoms of highly regressive behavior and was unable to attend work. His caregivers tried to support him without any success. Therefore, they decided to involve a psychiatrist, who prescribed a supporting psychopharmaceutical therapy.

Example 5 (Loss of attachment figures)

A client who suffers from a personality disorder was involved in several thefts within the facility. This time the caregivers decided to inform the police and filed a complaint. Concurrently, the client lost her closest attachment figure, her brother-in-law, and also faced a change of assistance within the facility.

The reaction of the caregivers was so extreme, because they believed that would be the best support for their client. Unfortunately, the client did not get better and developed a depression with psychotic and paranoid episodes, as well as an anxiety disorder. The loss of her brother-in-law elicited increased symptoms. In her paranoid episodes she displayed a lot of aggressive behavior. For example, she was convinced that people on the bus were talking about her, which is why she started to bite them. In situations like this, her main caregiver usually calmed her successfully. However, she was also suicidal, had an addiction and showed aggressive behavior towards other inhabitants. Thus, her caregivers were forced to admit her into psychiatric care a couple of times. The admission proved neither helpful for the caregivers nor for the client, because the psychiatry had to discharge her after a couple of days due to limited capacity. Sometimes they released her with a change in medication, which resulted in confusion on her side. The caregivers decided to involve a psychiatrist, who came into the facility in regular intervals in order to support the client. This not only led to gradual improvement of her symptoms, but also to a more efficient exchange between the caregivers and the psychiatrist.

Example 6 (Loss of attachment figure)

A client was unable to cope with the loss of her mother, because she never received the opportunity to mourn. The client was neither properly informed about her mother’s death nor allowed to attend the funeral or participate in any other mourning rituals. Years later the client still showed clinically relevant symptoms.

Example 7 (Traumatic situation for caregiver)

A mentally disabled man of 30 years committed suicide within the facility. Together with his also mentally disabled girlfriend he lived in a room provided by the organization. The client had a traumatic family history and had repeatedly been admitted to the psychiatry as a teenager. In addition, he was severely addicted to alcohol. Although he had tried alcohol detoxification accompanied by medical treatment several times, he was unable to quit drinking. Despite his daily intake of pharmaceuticals, he continued drinking alcohol. One morning a caregiver got suspicious because the client did not turn off his alarm clock. When the caregiver got into his room to check on him, he found the client lying dead in his bed. The autopsy proved that the client took a pack of Valium and Rohypnol in combination with alcohol.

The caregiver on duty was only a temporary assistant who neither had enough information on the clients, nor enough experience and knowledge in this field. Nevertheless, he reacted quickly and informed the medical emergency service, his colleagues and family members of the client. The girlfriend of the patient had difficulties to cope with the situation. The caregivers were concerned and monitored her closely after the funeral, because she had already tried to commit suicide by taking pills.

Example 8 (Burglary)

A housing facility for mentally disabled persons faced burglary. An inhabitant reported that somebody entered her room at night. The caregiver assumed that the client had suffered from a bad dream until she detected a broken window in the restroom. The caregiver directly informed the manager and the police. The police found no evidence relating to the offender. The caregivers decided to let the inhabitant think that the incident was only a “dream” since they did not want the client to be scared. The caregivers were most worried about the fact that they had not noticed the burglary at all and would not have been able to protect the inhabitants. Thus, they decided to install grids in front of the bathroom windows and close all roller blinds at night to ensure the security of the clients.

Example 9 (Loss of attachment figure)

A client’s aunt was diagnosed with cancer in terminal stage. The aunt of the client played a very important role in her life. She was her closest attachment figure and the client visited her every second weekend at her home. Moreover, it was already known that the client had displayed problems dealing with loss in the past and used to react in an emotional and aggressive way. The caregivers tried to prepare the client for the oncoming death of her aunt by means of intensive conversations with her. Nevertheless, the client displayed emotional outbreaks and aggressive behavior, such as shouting and throwing things. The caregivers considered her outbreaks as “normal” reactions of grieving and tried to support her as well as possible. The caregivers knew that the client already used praying as a coping strategy, which used to help her in difficult situations. Therefore, the caregivers supported the client’s process of mourning by praying together and setting up a box with memories, such as photographs of her aunt and lighted candles. Moreover, they stood by the client at the aunt’s funeral. Surprisingly, shortly after her aunt’s death the client’s sister approached her. She offered the client to visit her one weekend a month, which helped the client to overcome her grief.

Example 10 (Reactions of parents/relatives)

A client lost his father. The client’s mother decided to exclude him from the funeral because she was concerned that her son could not cope with the situation. The client himself was suffering badly because of the exclusion and had problems to implement a daily routine. Furthermore, he displayed noticeable behavioral problems at work.

Example 11 (Understanding the process of dying)

20 years ago a client lost her sister due to cancer. After this traumatic experience, she never visited a cemetery again. One and a half years ago an inhabitant died due to a long disease. The client witnessed the course of the disease of the co-inhabitant and was also present in the moment of death. Since this experience the client started to attend funerals again. Four months ago the client’s father died. Her reaction to his death and her process of grieving seemed to be “normal”.

The caregivers concluded that the accompaniment of the process of disease and death of the inhabitant helped her to understand her own traumatic experience when her sister died.

Example 12 (Loss of attachment figure)

A 60-year-old mentally disabled man lost his closest attachment figure, his mother. The client lived with his mother, who was already over 80 years old. She accompanied him every day to the working facility. One day, the client did not show up at work and his mother did not inform the caregivers about his absence, which was very unusual.

Some of the caregivers worried about their client and drove to his home to make sure that everything was alright. The client opened the door and explained that his mother was still sleeping. The caregivers immediately recognized that the mother was dead and the client had not perceived the seriousness of the situation. Since the client was not able to take care of himself, he had to move to an establishment with assisted living. It was known that the client had problems dealing with small changes and the adaption to them, which is why it was a huge challenge for him to settle at the facility. As a result, the client subsequently crushed from his development level of a four- or five-year-old child to an even lower developmental level.

**Case Examples Emergency Personnel**

Example 1 (Accident: patient with dementia)

An 85-year-old patient with dementia tumbled in the surroundings of her nursing home and suffered a bone fracture of her lower leg. The accident occurred at 4 o'clock in the morning on a weekend. She needed to undergo surgery. After admission to the accident- and emergency department of the hospital, the treating anesthetist was called to carry out a preoperative evaluation of the patient. An anamnestic interview of the patient was not possible because of communication difficulties. Therefore, the anesthetist had to consult the medical history that colleagues from the accident- and emergency department had taken. Existing nursing protocols from the nursing home of the patient were also consulted for the anamnesis. Afterwards the anesthetist carried out the medical examination of the patient. This proved difficult, too, because the patient was primarily non-responsive.

She seemed to be tired, confused and she could only mention her name and place of residence. Further communication about the circumstances of the accident was not possible. Altogether the patient was very restless and tried to get up over and over again. Instructions and explanations from the anesthetist to stop this behavior were unsuccessful. In an attempt to calm down the patient the anesthetist took her hand, whereupon she calmed down immediately. After the preoperative evaluation was finished, the patient was brought to the surgery room. The change from known to unknown surroundings was extremely stressful for the patient, so she became nervous again. This made the anesthesia seem impossible. Constant communication with the patient by the nurse made the anesthesia finally possible and the surgery could be started. To make the process of the operation more comfortable for the patient, a sedative co-drug was administered to her, whereupon she fell into a light twilight sleep. After the surgery, the treatment of the patient was continued in the same mode, including constant communication and touch, as well as lots of patience.

Example 2 (Medical emergency: patient with visual and hearing impairment and dementia – support of relative)

A 70-year-old patient collapsed on account of pneumonia in her house. The patient was limited in her visual and hearing abilities and showed signs of the onset of dementia. The patient´s daughter informed the emergency service and accompanied the emergency doctor and the crew into the room of her mother. At first, the patient was confused about the new situation, so that the daughter had to explain it to her. This worked very well because daughter and mother had developed a special way of communication. With the help of the daughter the emergency doctor could provide medical care to the patient and give her medication via venous access on the forearm. Afterwards, the patient had to be transported to the ambulance. This proved difficult because the staircase was very narrow. Due to the unusual situation, the patient became nervous again and resisted the transport. The emergency crew was unable to calm her down, which is why they needed the assistance of the daughter once again. During the transport and also later in the hospital the daughter remained present, which made the whole procedure easier for the treating emergency doctor.

Example 3 (Accident: mentally and physically disabled adolescent)

A mentally and physically disabled 15-year-old boy tumbled with his wheelchair in the elevator of a facility for disabled people. He was trapped alone in the elevator, because the doors were out of order. It took a total of 1,5 hours to rescue him and get him off the elevator by the in-house technician and the fire brigade. The boy had fallen headlong off the wheelchair. He could not move because his feet were fixed at the wheelchair because of his spastic paralysis. After he had been evacuated from the elevator, he was very nervous and screamed. Also the involved persons were very nervous as they worried he might be seriously injured. When the emergency workers provided medical care to the boy, they found out that he only had a few abrasions and the nervousness of the caregiver team decreased. With coaxing from the caregivers and emergency workers the client calmed down. Altogether, the client was very responsive and it was easy to talk with him. The caregivers used simple sentences to explain what had happened to him, so that he understood the situation. Overall, the whole situation became very exciting for the boy and in the end he experienced it as an adventure. Also the transport to the hospital proved uncomplicated, because the client was used to contact with emergency workers and basically showed a positive attitude towards them.

Example 4 (Death of a relative: patient with dementia)

A father/husband committed suicide in the woods. Together with the police the crisis intervention team (ambulant psychosocial service organized by Austrian Red Cross) told the family about his death. When they arrived at the house, his wife, his daughter and his mother-in-law (who suffered from dementia) were present. His wife and his daughter started to cry. However, the mother-in-law smiled and did not seem to understand the situation. The wife informed the crisis intervention team about the dementia of her mother. Nobody from the family spoke or looked after the mother-in-law who kept smiling. When the husband and children of the daughter arrived, they cried a lot. The crisis intervention worker tried to communicate with the lady suffering from dementia and to integrate her into the families’ grieving process. As a result, the facial expression of the lady changed and she stopped smiling. A member of the crisis intervention team had the impression that the lady had understood something. However, the family did not try to integrate the older lady suffering from dementia into the grieving process during the whole time.

Example 5 (Delivering a death message: person with dementia)

A family asked the crisis intervention team (ambulant psychosocial service organized by the Austrian Red Cross) for support in delivering the death notice of their relative to the grandparents. The grandmother who suffered from dementia came down the stairs and joined her family and the crisis intervention team in the living room. Her husband relies on a wheelchair, which is why he was not able to join his family. The grandmother smiled and appeared to be happy about the visit. The family members told the old lady about the death of her relative. A crisis intervention worker tried to support and improve the communication between the old lady and her relatives. Suddenly, the grandmother stood up and stated that she wanted to go upstairs and retreat into her room. Before doing so, she approached her daughter and hugged her. The daughter experienced her mother’s hug as a very close moment between the two of them, something she had not experienced with her mother since many years. The crisis intervention worker interpreted the hug as a reaction of the old lady to the death notice.

Example 6 (Accident: patient with dementia)

A 70-year-old woman living in a retirement home and suffering from cognitive disorder, collapsed and subsequently suffered a laceration on her head. The caregiver had to make a decision whether the wound needed to be sewed or not. The woman was not only bleeding heavily, she might have suffered a concussion, too. She was left lying on the floor for her own safety. The caregiver first informed trained personnel. A nurse recognized that the patient’s vital parameters were poor and she was not responsive. Consequently, the nurse alarmed the emergency doctor. The caregiver realized that the woman felt threatened by the doctor and the emergency team. Therefore, the caregiver refused to let her client be taken to the hospital. After a few minutes her physical condition stabilized and the doctor decided to treat her in the nursing home.

1. 1 ECHO/SUB/2013/661043 PrepAge enhancing the preparedness of older people in disasters

   2014-2016, <http://prepage.eu/en/> [↑](#footnote-ref-1)
2. 2 <https://www.autismspeaks.org/family-services/community-connections/first-responders> [↑](#footnote-ref-2)
3. 3 https://www.autismspeaks.org/family-services/community-connections/first-responders [↑](#footnote-ref-3)
4. 4 Burke (2010). Emergency plan for students with special needs, Marin County, http://www.marinschools.org/SafeSchools/Documents/EmergencyServices/MCOESpecialNeeds.pdf [↑](#footnote-ref-4)