Manual for the Specifics of Communication and Interaction with People with Mental or Cognitive Disabilities in Emergency/Disaster

Authors: Hedvika Boukalová, Simona Hoskovcová, Štěpán Vymětal, David Čáp

(version: 20.7.2017)

Introduction

This manual is a result of teamwork of service providers from organizations for people with disabilities. They were included in EUNAD IP project as part of expert workshops so as in preparation activities (education, training) for emergency workers in the Czech Republic. This manual reflects outputs of expert literature and very specific experiences from practice. Its main topics are specifics of communication and interaction with people with mental or cognitive disabilities including combined disability. The aim of this manual is to improve emergency management regarding and process of cooperating with this particular vulnerable groups of people.

Recommendation for:

- **Emergency disaster planning**
- **Training and preparation**
- **Crisis situation, communication**
- **Necessary evacuation period**
- **Long term care**

The target group:

The most common mental and cognitive disorders:

- **Mental disability** – preliminary stopped or unfinished mental development, it influences all cognitive components (cognition, memory, speech, but sometimes also locomotion influenced and social interaction).
- **Dementia** – gained reduction or loss of cognitive capacity, slower psychic pace, problems in remembering, maintaining and recalling information, disordered judgment and decision making, problems with planning, worse emotion and self-control, worse adaptability, behaviour disorder, cognitive deficit. Mostly occurs in old age.
- **Autism** – social interaction disorder and limited stereotype repeating activities and interests. Autistic spectrum disorder affects motion, emotion, will, cognitive functioning and speech. It impacts personality and also ability to adapt.
- **Disorder of cognitive functions** – follows other mental disorders (schizophrenia,

Co-financed by the European Commission, Directorate Environment
EUNAD: Grant Agreement No ECHO/SUB/2012/640917
EUNAD-IP: Grant Agreement No ECHO/SUB/2015/7188665/PREP17

mood disorder, neuroticism, use of psychoactive drugs).

In practice there is very often a combination of mentioned disorders including motion disorders or hearing and visual disorders.

Risks of the target group:

- Higher vulnerability – has a strong influence on how persons with cognitive disorder perceive and understand information from the outside world, how they put up with a stress situation/disaster and recover after.
- Worse adaptation to new conditions - especially in sudden unexpected moments, changes!
- Reluctance to be evacuated, distrust to strangers (new people).
- Clients living by themselves are difficult to identify – so are their needs.
- Difficulties in communication, worse instruction understanding.

Specifics of seniors:

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

Co-financed by the European Commission, Directorate Environment
EUNAD: Grant Agreement No ECHO/SUB/2012/640917
EUNAD-IP: Grant Agreement No ECHO/SUB/2015/7188665/PREP17

Emergency plan Recommendations:

- Primary caregiver – should check whether the patients and people with disabilities are prepared for disaster/emergency situation.
- Care coordination – case managers – should be ensuring that the care is complex (can include physical, psychological, social, economic and spiritual part).
- Cooperate with emergency workers including local authorities and organizations to improve emergency preparedness of people with disabilities (planning, evaluating of preparedness and knowledge, raising awareness of needs and sources of people with disabilities).
- Training and technical support of emergency workers to get better in taking people with disabilities into account during emergency planning.
- Develop better communication network for unexpected events for people with disabilities.
- Institutions/service providers which provide services to people with specific needs with permanent or temporary accommodation and care should have emergency help plans at least for first 72 hours.
- In crisis planning include the cooperation with organizations of people with disabilities.
- Create a list of specifics and needs of each person. This list should include also list of medication and dosing (client card in emergency form, i.e. laminated A4 form, portable).
- Prepare medication to cover 14 days.
- It is recommended to create identification bracelet (name + contact of service provider).
- Knowledge of evacuation plan for stuff and clients is essential.
- Transport plans primarily for immobile patients should be well prepared ahead.
- Plan of substitute accommodation/shelter – choosing adequate (similar) institution.
- Cooperate with other organizations for people with disabilities.
- Cooperate with media so that information it is suitable also for this population.

Advantages of engaging community organizations to emergency planning

- Organizations providing daily service for people with disabilities have best awareness how these people can be extremely vulnerable during emergency situations.
- Local organizations may or may not be connected to the state organizations providing

Co-financed by the European Commission, Directorate Environment
EUNAD: Grant Agreement No ECHO/SUB/2012/640917
EUNAD-IP: Grant Agreement No ECHO/SUB/2015/7188665/PREP17

service primarily to certain groups of people.

- These organizations know how to contact i.e. homeless people, low-income people and seniors.
- Engaging them in emergency planning, preparation and training is possible and recommended.
- Community organizations are experts in active searching, giving recommendation, maintaining contact with groups of volunteers, being able to provide special services.
- Language and culture sensitiveness is important.
- Support in availability / accessibility – i.e. for people with limited mobility, people with hearing and visual disabilities.
- Community connectedness helps, using local sources which can support the right reaction of people to emergency situation and efficient recovering.
- Trust in the community – bridge for communication with clients. Clients usually trust their local organization, they are in touch with.

Training and preparation

Cooperation of emergency workers with local organizations:

- Seminars, workshops.
- Trainings (if possible clients should know "their" i.e. firemen, should not be afraid of them) – training of using protective equipment, evacuation.
- "Open doors days" – connecting organizations, public and emergency workers.
- Cooperation is effective just in case it is long term.
- In some cases practical training and preparation in the organisations is not possible due to health state of clients.
- Suggestion and testing of specific ways how to start communication and how to transport people during evacuation.

Suggestions for preparation of the target group:

- Importance of individual plan – includes a basic kit/package of preparedness for emergency.
- Persons with limited mobility should be supported in arranging emergency **transport plans** ahead.
- **Content of kit/package**:
  - ✓ Medication in dosage for 14 days;
  - ✓ List of specific individual needs of each person (name of a client, contact to close person or assistant, actual list of medication and dosage (client card in emergency

Co-financed by the European Commission, Directorate Environment
EUNAD: Grant Agreement No ECHO/SUB/2012/640917
EUNAD-IP: Grant Agreement No ECHO/SUB/2015/7188665/PREP17

form, i.e. laminated A4 form, portable);

- ✓ Identification bracelet (name, date of birth + contact of service provider or assistant);
- ✓ Food and documentation for assistance dog.

Recommendation for Crisis communication

General recommendation:

- Respect of dignity and independence of people with disabilities during emergency.
- Don't treat them like children, talk to them appropriately to their age!
- Stand in client's field of vision, and keep eye contact.
- Speak briefly in short sentences with clear articulation.
- Speak calmly.
- Take into account the fact that despite all the effort some people will not be able to understand.
- To get needed information try to communicate with stuff or assistance person.
- Keep attention on dynamics and emotion transmission in a group of clients. On the other hand evacuation of clients in group may give them feeling of safety.

Communication specifics with seniors with dementia:

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

Communication specifics with mentally disabled people:

- It always depends on the level and strength of the disorder.
- Expect high suggestibility.
- Tendency to be dependent on other people.
- Bad orientation in unknown environment.
- They may react in a "strange way", in their own way (i.e. can react very loudly to very small change).

Co-financed by the European Commission, Directorate Environment
EUNAD: Grant Agreement No ECHO/SUB/2012/640917
EUNAD-IP: Grant Agreement No ECHO/SUB/2015/7188665/PREP17

- Verbal communication is different – they may have trouble using correctly “yes/no”.
- They may ask strange questions and repeat them many times over and over.
- They may talk to themselves.
- At some moments they laugh when other people don’t laugh.
- They use facial expressions less or in their own way.
- They may get into strange body position.
- Very often they don’t respect communication (personal) zone.
- Don’t underestimate them in communication – no child talk, communicate with them like with adults.
- Avoid terminology (using phrases, irony etc.)
- Use illustrative gestures – point at body, at concrete objects etc.
- Verify their understanding.
- If they don’t understand show them what you meant or use different words or sentences.
- Use concrete expression – exact timing: instead of using “we go for a walk in two hours” it is better to say “we go for a walk after the lunch”.
- Speak always just about one topic / one object / one thing.
- Use nonverbal communication + touch + observing the person (to see fear, anxiety).
- Be clear at letting know the person, that we’re finishing conversation or we’re leaving.
- During transport use physical contact (holding hands) till you forward a client to a known person + it is best to involve persons known by clients!
- Calm them down, explain them what is going on.
- Staff and assistance people know clients’ specifics the best.

Communication specifics of people with autism, autistic spectrum disorder:

- Very often they don’t communicate verbally, not always react or react in one word.
- Troubles with correct use of yes/no.
- They don’t ask usual questions – it doesn’t correspondent to age of a person or it is unusual (asking over and over about measures as height, weight, technical questions, time of city transport etc.)
- Asking about the same thing over and over.
- Conversation is not suitable to situation (they don’t respect social context; make no difference in conversation partners).
- Very often they talk to themselves.
- Inadequate laughter with no meaning.
- Stereotypes – repeating same words, sentences, songs, verses etc.
- Verbalism – „verbiage “, accumulation of words, sentences with incorrect using.

Co-financed by the European Commission, Directorate Environment
EUNAD: Grant Agreement No ECHO/SUB/2012/640917
EUNAD-IP: Grant Agreement No ECHO/SUB/2015/7188665/PREP17

- Echolalia – repeating words, sentences, phrases. It may be immediate or postponed.
- Hyperacusis – hypersensitivity to audio impulses, reaction is inadequate (aggression – towards all around, or themselves).
- Overgeneralization of words - i.e. blood is everything what is red.
- Not being able to generalize – "a car" – they can mean only one specific car, toy from their childhood.
- Their talk has mechanical and formal sound.
- They speak about themselves in 3rd person (he/she/it), very small usage of 1st person.
- Trouble in using and understanding irony, abstract expressions.
- Eye contact – problem to establish and to have eye contact, looking "through", not stable in looking at you, looking at object for very long time etc.
- Facial expressions – low or no ability to express and to understand emotional expressions (sadness, happiness.).
- Using of gestures - low or no ability to express or to understand to gesticulation (waving of hand...).
- Inadequate body position or movements (shrugged shoulders, nodding, spinning).
- Communication (personal) zone – not respecting it, either they have too big zone or too narrow.
- Prosodic factors (melodies, rhythm of talk etc.) – voice is too high or too low, monotony, staccato (short talk), legato (prolonged talk).
- Other communication forms – using hand of other person as a tool to get something (putting hand on the door means "open the door").
- They may have very high tolerance of pain (they don't mind their own injury).
- They may have very low tolerance in waiting.
- They may have rage attack (including aggression towards surroundings or towards themselves) while waiting for something or in situation that brings changes in their rituals or reacting to specific impulse (word, context...).

Communication specifics of people with other psychiatric disorders:

- Due to big scale of specifics and needs of people with mental health disorders **best information source** how to take care of them **is staff taking care of them or assistance persons**.

Co-financed by the European Commission, Directorate Environment
EUNAD: Grant Agreement No ECHO/SUB/2012/640917
EUNAD-IP: Grant Agreement No ECHO/SUB/2015/7188665/PREP17

Communication specifics of people with combined handicap – immobile patients

- Each movement is influenced/controlled by other person.
- They may have ability to perceive.
- During transport they are not physically able to cooperate, to help.
- Keep attention to their head stability during transport.
- They are physically more vulnerable – they don't/can't give signals that something is painful for them.
- Stuff and caregivers know their specifics the best.
- You can easily miss or underestimate something in communication – people (i.e. their family) may communicate with you about them "about them without them". Family can ask you: "don't tell him/her that..."

Evacuation

- People with disabilities may need more time to mobilize support, to arrange transport and to find suitable target place to evacuate.
- People with limited mobility should be supported to arrange emergency transport plan in advance.
- Staff providing primary medical care may be interrupted or busy by evacuation process and it may cause troubles in giving necessary care.
- Researches show that most emergency situations happening in nursing homes or hospitals were well managed thanks to flexible staff and other people (friends, families).
- **Shelters in big building** as schools may cause disorientation to people with cognitive disorder, elderly persons. It can cause chaos by noise, higher and quicker activity. Unknown environment, gathering of many people makes problems to autistic people.
- It is necessary to adjust to new environment – it is difficult so it is important to **minimize confusion**.
- **In substitute accommodation/shelter their services must be accessible** – including communication technologies (interpreter, signal equipment, printer, assistance for people with cognitive disorder etc.).
- In case of evacuation of institution for people with disability it is recommended to cooperate with other similar institution where clients can be transported and looked after in similar way.

Co-financed by the European Commission, Directorate Environment
EUNAD: Grant Agreement No ECHO/SUB/2012/640917
EUNAD-IP: Grant Agreement No ECHO/SUB/2015/7188665/PREP17

Aftercare/recovery phase

- Return to usual service functioning and continuity of care.
- Ensure psychological care.
- Risk target group usually obtains **less financial and material help after disaster**. That is why they need more support and guidance.
- **Troubles start with managing official procedures** including demand to fill in forms on PC and to apply to it on-line.
- People with disabilities have bad orientation in new environment. Person with mental / cognitive disorder has problems in directional orientation, numbers. If there is a need to send this person somewhere to office it is always better to go with him / her as a guide. Although this person finds the right office still he/she is afraid to enter and so often leaves with no result or keeps waiting out and lets other people to go in (overtake).
- Orientation in written text is also a problem. We should read the text together with them, explain it, and ensure they understand. We should not just give it to them to fill in.
- They can be afraid of losing social or other benefits.
- Seniors can be ashamed to accept help (can feel it being stigmatizing) or can feel that other people need help more.

Co-financed by the European Commission, Directorate Environment
EUNAD: Grant Agreement No ECHO/SUB/2012/640917
EUNAD-IP: Grant Agreement No ECHO/SUB/2015/7188665/PREP17