ISTANBUL MANUAL "Developing a Disability-Included Disaster Preparedness Program" (AUTHORS: Akundor, C. AKUT)

Istanbul Case Study Manual
Developing a Disability-Included Disaster Preparedness Program

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1. Prologue

From June 2015 to November 2017, Turkish Search and Rescue Association AKUT has realized an innovative field action in Istanbul as a part of the European Disasters in Urban Centers (EDUCEN) Project, an international coordination and support action financed by the European Union’s Horizon 2020 Program. In accordance with the project’s main theme, which is the (possible) contributions of culture to disaster management and disaster risk reduction, AKUT’s public training unit has decided to work on the disability and disaster issue under the direction of the CS leader. Being aware of the specific problems experienced by people with disabilities during disasters, and also, the lack of access to disaster preparedness information for the disabled, AKUT’s training unit has collaborated with seven partner organizations in order to design a new training model.

Not surprisingly, the action has gone beyond a mere adaptation work, pushing the “non-disabled side” to alter its perception of the disability, discover and embrace a modern definition of the phenomenon and recognize the importance of concepts like “diversity” and “inclusivity” as a sound basis for all action in this field. Let’s note that Turkey’s first and largest volunteer search and rescue group has taken important steps in improving its inclusivity and accessibility thanks to the feedback and knowledge gained through EDUCEN case study. While the disability culture has initiated a transformation at AKUT in this regard, the representatives of the disabled community had in their turn the occasion to look at the emergency and disaster-related issues from a new perspective, according to which they could take part in reducing their own vulnerability to disasters, actively assist others in doing so and even take important leadership roles during such incidents. The resulting training model emphasizes the need for addressing mixed audiences through specifically adapted tools, supported by supplementary materials, which are accessible through Internet for all involved groups.

Being based on citizen action and using public training as the main dissemination tool, Istanbul Case Study should be regarded as a cost-effective, replicable model for any similar work with the additional social benefit of including the disabled citizens in the DRR.

The following is an “annotated” account of the EDUCEN Istanbul Case Study, which is also designed to be a “flexible” guideline. It is primarily intended for formal and informal citizen groups (NGOs, citizen initiatives…) who aim to develop and implement their own local action to help disabled community reduce its vulnerability to disasters. Also, the practice derived from Istanbul action is certainly useful for relevant professional groups in the disaster management cycle (planners, managers, responders) who should consider persons with disabilities in all phases of disaster management. Nevertheless, we have to affirm that we did not anticipate any limits in terms of usability for this document: Professionals who belong to medical universe, education professionals and disability professionals would likewise benefit from it.

2. The Rationale: Why Working on Disaster and Disability?

Looking at AKUT’s past, it can hardly be argued that disability had been a priority for Turkey’s largest non-governmental volunteer rescue organization, until recently. Since its foundation in 1996, AKUT has developed -for example- neither a specific operational procedure concerning assistance to people with disabilities during disasters, nor an inclusive membership policy or recruitment effort targeting them. Likewise, the association’s premises, just as its communicative materials remained inaccessible for a large part of the disability spectrum until the issue has been placed recently on the agenda. However, considering this situation as a deliberate omission or discrimination would be an overstatement since members were not insensitive to disability either. In fact, what we observe in AKUT’s first twenty years can be seen as the reflection of a broader scale phenomenon in the society,
which is the lack of awareness of disability: Not only of the needs but also of the capabilities and knowledge of disabled individuals. It would be probably reasonable to admit that the association’s relationship to disability has followed the existing trends in the society.

Another point worth mentioning is that AKUT had -almost- no members having significant disabilities. The presence of active disabled members could perhaps create awareness about the disability issue over the years and even drive the association towards inclusivity. We can no doubt point to different facts explaining this situation but in our eyes, the most interesting one relate to the characteristics of search and rescue activity. The latter is often considered as an “edgework” that requires a high degree of physical ability and strength, other than specialized knowledge. What is seldom affirmed is that those requirements are not relevant to all phases of rescue work as opposite to what is perceived from outside. Not all components of search and rescue operations are performed by people with extreme physical capabilities and technical specialties. In fact, individuals who are far from being competition-level athletes but who are provided with basic knowledge can perform many duties that are vital to operations. Yet the image of rescuer “above the ordinary man” cause reluctance in many people who could join a search and rescue group. During the case study, we have observed that the disabled participants were far from being immune to this exaggerated image of search and rescue volunteers as well.

What is interesting is that while remained “distant” -not to say inaccessible- for people with disabilities for various reasons, AKUT continuously encountered disability in practice, essentially during two cores activities emanating from its official mission. The first of these practice areas was naturally the search and rescue, where some members, including the Istanbul CS leader himself, have observed the additional complexity that disability or chronicle health conditions can bring about in emergency situations, and also observed the need for specific training, equipment and professional support in order to cope with such cases.

Disability in Turkey

Like any country across the globe, the disabled constitute a significantly large “minority” in Turkey, especially if we take into account individuals with chronic diseases. Although the latest available data (12 % of the general population) is from 2002, we have no reason to consider that this figure has decreased. The global estimated average, in a recent figure given by the World Health Organization, supports this proportion: 15 %. Again, according to the 2002 data, people with auditory, speech and visual impairments, orthopaedic and mental disabilities constitute 2.58 % of the general population in Turkey. Consequently, we can assume that Istanbul is home to a “core” disabled group of about 400,000 individuals considering also the increase in population since the last survey. As for the remaining 9.42 % (roughly 1.3 million people), this group is mainly composed of citizens with chronic health problems. Even though citizens with chronic conditions (if not coupled with a certain form of disability) often experience less limitations in life and possess a greater autonomy, this chronic group should be the subject of specific measures since they usually also have special needs to be addressed during and after a catastrophe.

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The second activity where AKUT came into contact with disability has been the disaster awareness and preparedness trainings destined to public. Facing questions by disabled participants or their relatives, the volunteer trainers who reach out tens of thousands citizens every year have increasingly doubted the “universality” of the disaster preparedness content that they were disseminating. Gradually, they have come to recognize that AKUT’s training material seemed to address “healthy” adults only, excluding the less “fit” groups such as elderly, children, people with chronic health conditions or disabilities. Besides, as they have realized, some of these groups had obstacles in getting sound information on disaster risks and disaster preparedness. Few materials existed for people with visual or hearing impairments.

We can argue that the experience gained in these two areas resulted in growing consciousness in the association’s core (most active) group. A limited but meaningful change in the perception of the disability issue prepared the terrain for a dedicated, systematic action on disaster and disability in AKUT. Notably, a visit by a group of graduate students from Harvard Business School (HBS) in 2013 has been the first occasion to tackle the question. Upon the proposal by the Istanbul CS Leader -then the research officer of the association- the visiting students carried out a field study and designed an “awareness campaign on earthquake preparedness for disabled citizens” in Istanbul, in order to complete their graduate program. The seismic risk was focused on as the most important disaster risk the city was exposed to.

Although the developed campaign could been never materialized due to financial reasons, it brought a new insight into the issue by providing an accurate technical description of the conditions on the ground for the disabled in Turkey and the barriers which prevent them from accessing disaster preparedness.

Disaster risks in Istanbul

Istanbul has undergone a significant change in parallel to Turkey’s socio-economic transformation. Like other Turkish urban centres, it has registered very high rates of immigration after the 1960s and plans to impose control and technical criteria to new urban developments have had limited success. The city is still one of the fastest growing ones in the world, on its way to become a mega-polis, with all the associated practical problems that result from this chaotic over-expansion grow steadily. The management of disaster risks is certainly one that rank high in priority among all these issues. Istanbul has been disaster prone throughout its history. Historical records show that seismicity is without doubt the most important hazard. Notably, after a century of no activity, destructive earthquakes in 1999 reminded Istanbul’s dwellers that the risk would remain high in the future. However, other risks such as floods (increased further by human impact on the natural hydrological systems) and landslides should also not be underestimated. In addition to those “natural” hazards, the city is under constant threat from high-risk industrial facilities that are surrounded by residential areas and by the transportation of hazardous material through overcrowded land routes and the Bosphorus strait. Gigantic traffic congestions (usually combined with severe weather) are also increasingly common. Other scenarios can also be mentioned, like a large-scale health or food emergency, of which the potential consequences remained largely not discussed so far. As for the physical assets in Istanbul, their vulnerability to disasters is long recognized. A specific problem is that, despite the so-called “transformation of the urban zones under disaster risk”, action taken by the government (2005), a very large portion of the building stock remains highly vulnerable to earthquakes. This is alarming for a city that almost straddles one of the most active fault lines in the globe, which is expected to generate an M 7.0 or greater earthquake in the next decades.

20 AKUT’s seminar unit has undergone an important renewal in 2009, which increased its performance to an unprecedented level from 2010 onwards. 2012 has been a “record” year in terms of number of reached persons with 112,542 people in total. This figure has remained above 50,000 since then, which is a considerable achievement for a non-profit NGO. More detailed and recent statistics can be obtained from AKUT.

programs. HBS team also proposed a realistic strategy based on practical, measurable goals for AKUT to reach the disabled population. The result was exploitable for all types of major emergencies and catastrophes, not only for the earthquakes. We should note that the many components of the elegant strategy that was elaborated by the HBS team remain useful. Nevertheless, the fact that it was concentrated on “improving the delivery” (how to ensure physical participation of the disabled?) and on the tactics for drawing people with disabilities (what kind of incentives can be used?) to training sessions, was a serious limit for developing a comprehensive action.

In other words, although the HBS team seems did not fail in recognizing disabled people’s capabilities, it identified them as “passive clients”. Also, the HBS report seemed to indicate mostly people with orthopedic conditions when referring to disability and is not based on an encompassing definition of the disability. Moreover, the question of validity of tools was barely mentioned, implying that the HBS team has taken the existing training and dissemination material’s “universality” for granted, both in terms of form and content.

What is interesting is almost two years after this collaboration’s results, our reflection on what we considered as its “shortfalls” constituted a starting point when we have been contacted for the EDUCEN Project. From June to August 2014, we have worked on the design of the Istanbul Case Study. The HBS experience in combination with AKUT’s previous experience on disability has helped us in formulating our priorities and structuring our base assumptions during the writing of the proposal. Without explicitly referring to it, we also have taken into consideration the recommendations that were relevant for us in the Hyogo Framework for Action. The resulting assumptions were as follows:

- Citizen participation is key to substantial reduction of disaster losses. Citizens can and should take active roles in the relevant activities of the disaster management cycle such as risk reduction, preparedness and response. This principle applies to disabled citizens who are most aware of their own specific needs (but also capabilities) and who can participate to many disaster-related process provided they get the necessary support.
- Many of the tasks in incorporating the disabled in the disaster management, such as adapting the physical environment, are public policy issues that require political will, legal basis, leadership of the public sector and often, large public funds. However, there are many opportunities for non-governmental actors for making a significant impact in this area, even with limited means.
- Public education and awareness raising is a cost-effective way of reducing the vulnerability and increasing the resilience of a community including its disabled members, on the condition that the programs are adapted to their needs and allow their participation. The number of existing actions on this question are very limited in Turkey.

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22 Hyogo Framework for Action is the participants’ joint declaration that came after the World Conference for Disaster Reduction that was held in Kobe, Japan (January 2005). It may be considered as a “generic plan” that is supposed to be implemented by signatories from 2005 to 2015 in order to reduce disaster losses. Although the Hyogo Framework fails in mentioning people with disabilities, it underlines several points that were directly relevant to EDUCEN Istanbul Case Study at the time we were drafting it. Notably, it emphasizes the necessity to take vulnerable groups into account as well as the culture (par. 13, art. e); use of knowledge, education and innovation (par. 18); the importance of community participation (par. 16, art. h); the importance of providing information on disaster risks and protection options (par. 19, art. j); and urges governments to promote community-based training initiatives, considering the role of volunteers (par. 18, art. l), while ensuring equal access to appropriate training and educational opportunities for women and vulnerable constituencies (par. 18, art. m).

23 We could locate only three relevant works during our preliminary research.
It is of urgent priority to provide the disabled communities of Istanbul with the much-needed information since this “megapole” of more than 14 million dwellers is expecting a major earthquake in the next decades.

A specialized NGO such as AKUT can elaborate a disaster preparedness training program that would encompass the disabled audiences, in collaboration with other citizen groups focused on disability. In such a design, AKUT would bring the “disaster knowledge”, which would be harmonized with the “disability knowledge” brought by its partners; in order to produce a model that could be replicated elsewhere in the World by vulnerable groups experiencing similar problems vis-à-vis catastrophes.

As it was integrated in the EDUCEN proposal, Istanbul Case Study was a hastily designed field action, which was principally limited to the production of a disability adapted disaster training program and its physical and digital dissemination through “side-products”, such as printed, audio and visual material. It was indeed more “inclusive” in comparison with the HBS campaign, in the sense that it relied on the disabled participants for adapting AKUT’s existing training materials. However, as we clearly see it almost 3 years later, there was no mention of further roles that could be played by the disabled, who were once again reduced to a silent audience. On the other hand, there was emphasis on the training sessions as socialization and cultural exchange opportunities for the disabled participants, although it was unclear if the sessions would be “mixed” or the participants with disabilities would be trained in dedicated, separate trainings. Yet, Istanbul Case Study had green light when the proposal was accepted by the EU – REA in November 2014, which set the project’s starting date to 1 May 2015 (later became 1 June).

Upon the reception of the news, we have started to work on the case study design again. Two international events, although different in terms of size, to which we have participated in the pre-start period of EDUCEN have been important opportunities to meet members and representatives of various disability organizations and networks working on “disability inclusive disaster risk reduction” (DiDRR). The first one was the U.N. World Disaster Risk Reduction Congress (WDRRC) that was held in Sendai, Japan (March 2015). Sendai became the first WDRRC where the disability was given significant emphasis, as illustrated by its final declaration text. Our networking efforts in Sendai resulted in securing an invitation to a second important meeting, which was organized by the European Council Major Hazards Agreement (EUR-OPA) secretariat’s relevant workgroup in Brussels (May 2015).

These two events not only allowed us building a comparative perspective on the issue of disability and disaster, but also establishing contacts with some of the most renowned experts of the area and finally, to collect feedback about the Istanbul action which was about to start. Meeting disabled participants with years of disaster-related experience allowed us to broaden our scope and define the guiding principles that will shape the Istanbul action in the coming months. For example, defining disability was an important point in our work.

As we have studied the history of disability and the contemporary perspectives on the phenomenon, it became clear that the Istanbul Case Study had to be built on a “social” definition of disability and not a “medical” one. We have realized that obsolete definitions, which identify the disability with physical or/and cognitive deficiencies, still dominate perceptions as well as legal texts and even public policies in many countries. These medical perspectives of disability convert the latter to a “welfare” or “charity” issue and fail in recognizing the disabled individuals’ abilities. Such a perspective would be incompatible especially for our case since our goal was to help the disabled persons using their own potential against disaster risks. In this respect, we have adopted a vision based on the UN Convention on the Rights of the Persons with Disabilities (2007), which states that “the disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders
their full and effective participation in society on an equal basis with others”\textsuperscript{24}. In other words, “impairment” was indeed a reality but it became “disability” when it met an unfavorable social and physical environment for most of the cases. Such a view on disability is closely linked to human rights. In fact, the (relatively) recent right-based approach to disability is mostly an emphasis of the fact that persons with disabilities should also enjoy these fundamental rights. We have concluded that the principles of “equality” and “non-discrimination” alone were sufficient to tackle the disability and disaster issue. Since the people with disabilities “should enjoy their inherent right to life on an equal basis with others” and their “physical and mental integrity of persons with disabilities” must be protected again, on an equal basis\textsuperscript{25}, they also must enjoy support that is “as good as that enjoyed by the general population during emergencies and disasters”.\textsuperscript{26} In other words, protection against disaster risks and provision of support after disasters is a non-alienable right for the disabled citizens as well.\textsuperscript{27} Naturally, this right includes the right to information on disaster risks and preparedness, which corresponded well to Istanbul Case Study’s aim.

As a part of this rights-basis perspective, we have adopted a series of principles and concepts that are necessary to address - in our eyes- any disability-related issue, not only for ethical reasons but for practical ones as well. This would also signify that the case study was tacitly attributed another function, if we can name it as such: To demonstrate that these principles, often perceived as difficult and “costly” to apply, were far from being so and needed more will than material resources to be put into application. Therefore, EDUCEN Istanbul Case Study has adopted diversity, inclusiveness, and accessibility as key principles within a capacity-based approach. To put it in a more detailed way, we would therefore:

- Consider disability as a part of human diversity and not a personal tragedy, focusing on disabled people’s capacities, and concentrate on how they can contribute to Istanbul Case Study;
- Ensure the necessary adjustments in the physical environment and if necessary, the social arrangements in order to make the action (and information) accessible to them, which is a prerequisite for inclusion,
- Include as much as possible the disabled persons in the action so they could take up their role as active, equal citizens; defying prejudices and stereotypes.

As we have realized later, we could grasp the meaning of these terms only after we had started to cooperate with our disabled partners, when we encountered disability knowledge and culture. Still, our “theoretical build” has met no opposition on behalf of the disabled partners and remained unchanged throughout the case study, providing us guidance when we were in need of it.

\textsuperscript{24} UN Convention on the Rights of Persons with Disabilities (2007), article (e), preamble section.
\textsuperscript{25} Ibid., articles 10 and 17.
\textsuperscript{26} ALEXANDER David and SAGRAMOLA Silvio, Major Hazards and People With Disabilities, European and Mediterranean Major Hazards Agreement (EUR-OPA), Council of Europe, Strasbourg, July 2014, p.11.
\textsuperscript{27} Notably, the Convention of 2007 included a dedicated article (Article 11) for this issue, urging states to take “all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.”
3. Networking for partnership

While building the theoretical argumentation for the case study, we have also worked for developing a strategy and an action plan in order to reach our aim. The initial strategy we had submitted in the project proposal consisted on producing multiple versions of AKUT’s existing public disaster preparation material, each version being adapted for a specific disability group. According to this scheme, disabled partners’ feedback about the present training content would be collected through focus-group meetings, interviews and questionnaires; to be integrated in the content. The same feedback, together with some technical knowledge, would help AKUT to create the adopted versions to be used afterwards. Having gained a better understanding of the disability phenomenon, we had noticed that this crude strategy that gave AKUT the “lead role” in the action needed to be altered to be genuinely inclusive. Nevertheless, it was adequate as a starting point, especially when looking for shareholders but we first had to make a decisive choice about which disability groups to work with.

Although our initial idea had been to cooperate with shareholders representing a maximum variety from the disability spectrum, the preliminary study we have conducted and our exchanges with different experts have made us realize that it would be realistic to narrow our focus down as much as possible. Our financial means, human resources being very limited and timespan being very short for
addressing almost all types of disability, we have decided to establish some precise limits for the action. But we also knew that the selection had to be carefully justified so it would not have signified “exclusion” for those who were not selected. The most difficult issue was whether we had the potential for addressing persons with mental disabilities.

After much discussion, we have decided to consider people with mental disabilities in a next stage, for the following reasons: Our interviews with medical professionals and caretakers have showed us that we would be able to address only a very limited portion of the existing mental disability groups with significant efficiency. Our conclusion was that it would be more realistic to focus on these groups, in parallel with the families and care professionals they were depending on, in a dedicated project that would be realized in cooperation with a network of specialists, for AKUT having absolutely not the knowledge and expertise on working with having mental disabilities. The decision was indeed a difficult one to make, and the technical argument was not the only one that has influenced it. In fact, we have also faced a powerful ethical dilemma during this stage, which was the question of informed consent. To obtain the participants’ consent about the activity of which they are going to be a part is an absolute ethical and legal condition, also a requirement by the European Commission, but a valid consent can only be given by a person who has legal autonomy, a delicate issue when it comes to persons with cognitive impairments. Our consultation with a legal specialist further justified our reticence on this issue, helping us understand this autonomy/consent issue alone would require dedicated preparation (which may ensure a legal basis, but would not guarantee an ethical solution) which would be beyond the Istanbul Case Study’s limited means.

As for the people with physical disabilities, we have decided to consider the groups, which could potentially endure the biggest hardships during and after a disaster: Persons with impaired sight, persons with hearing impairments and people with reduced mobility. Note that we also excluded the minors from the case study, as their participation was -both legally and ethically- subject to specific rules and conditions, such as the parental consent. That was in fact a further point in defining the scope of the action, which we now considered as a “pilot” work that was supposed to demonstrate the feasibility and the potential of the “Istanbul model” to be built. The model would then set an example for larger and technically more sophisticated projects, such as one destined to people with mental disabilities.

Let’s affirm that the selection issue has also made us realize that we had hardly questioned the meaning of the term “disabled” so far and had reduced the extreme variety of possible physical and cognitive human conditions in a vague, broad category.

We had less hesitation with regard to the legal category of potential stakeholders: We have considered the Istanbul Case Study essentially as a local “grassroots” action, with minimum involvement of governmental organizations since our aim was to produce a model that could be replicated anywhere in the World by citizen groups who wish to address similar problems. This would mean an action of which the design and the implementation would be well within the capacity of - virtually- of any organized citizen group, without resorting to public resources (which may not be available depending on the country anyway) and having to handle bureaucracy. Naturally, we turned our eye to existing disability civil society organizations in Istanbul, with the intention of giving the priority with groups having a legal status (association or foundation) in order to ensure -as much as possible- their continuity.

Consequently, we have obtained from the Ministry of Interior the relevant datasets on disability organizations in Istanbul (the action being a “city” action) which we have processed according to two criteria, the first one being representation (how large is the membership base?) and the second one being continuity (how old is the organization?) which we have considered as indicators of stability and
durability. The following step was to prepare a detailed information note on EDUCEN Project and the Istanbul case study, contact the ones that are the most prolific in terms of activity and public visibility, and to conduct a preliminary interview with respondents. During these first contacts, our interlocutors sometimes referred us to other potentials shareholders or contributors as well, which helped in enlarging our network. Among the 11 organizations we have contacted, six have shown interest in the case study.

- İED İşitme Engelliler ve Aileleri (People With Auditory Disabilities and Their Families) Association
- Altı Nokta Körler Derneği İstanbul Şubesi (Six Black Dots Blinds’ Association Istanbul Branch)
- Engelsiz Erişim Derneği (Access Wihout Barriers) Association
- TSD Türkiye Sakatlar Derneği (The Handicapped Association of Turkey)
- TOFD Türkiye Omurilik Felçlileri Derneği (The Spinal Cord Paralytics Association of Turkey)
- SEBEDER Sesli Betimleme Derneği (Association for Vocal Description)

Thus we had obtained the support of six organizations, one representing people with visual impairments, one representing persons with partial hearing impairments, two others representing people with reduced mobility. A couple of months later, Türkiye Sakatlar Derneği (The Handicappeds’ Association of Turkey) has become unable to participate to the action but Türkiye İşitme Engelliler Derneği (Association of People with Hearing Impairment of Turkey) joined the action, representing -mostly- people with total hearing impairment.

As for the Engelsiz Erişim Derneği and SEBEDER Sesli Betimleme Derneği, their “status” as “specialists” within Istanbul Case Study has been a bit different than the one above. In fact the first one was founded (mostly by people with visual impairments) in order to address accessibility issues while the second one was founded in order to make audio-visual products accessible for people with hearing impairments and visual impairments. Let’s note that the latter was based in Ankara, which constituted a “necessary” exception to the geographical limits we have deliberated for the case study (Istanbul Metropolitan Municipality’s Jurisdiction), since its expertise in audio-visual accessibility has been an invaluable contribution to our work.

Following verbal approval by these organizations’ representatives we have prepared a bilateral cooperation protocol. We took similar “model” documents that were available online when we have drafted this document. We have also benefited from two volunteer lawyers’ reviewing and corrections. Such a document was necessary in order to prove that the objectives, the scope and the ethics of the action, as well as the rights and the duties of the cooperating parties and individuals, have been well understood by both sides. It has also clarified the issue of intellectual property rights with respect to the materials used during the case study and the eventual case study outputs. We strongly believe that the protocol contributed to

Building a Cooperative Network

Our experience in general with respect to partnership building is that flexibility is the key for organizing a cooperative action, which becomes possible only to the extent that the action’s goals meet potential partners’ agendas. Genuine cooperation is based on an egalitarian relationship and not on a top-down approach. This naturally involves a certain level of bargain between two organizations with different aims, capabilities and needs and flexibility is necessary to reconcile mutual demands, including the design of the activities and the calendar. It is also necessary to admit from the beginning that not all groups will show the same level of interest to the disaster preparedness theme, despite its importance or usefulness. Our observation is that larger organizations with a primary mission of advocacy or lobbying may be less suitable for such an action for many reasons, including internal bureaucracy. Small-scale NGOs however, can be more flexible, open to innovative actions and more agile in terms of decision making.
building trust between AKUT and its shareholders by defining the action’s structure in writing, making it more transparent and the CS team more accountable; besides reducing the possibility of having misunderstandings and disputes. It also brought a sense of conventional obligation (with no economical liabilities, of course), which could be useful in ensuring the continuity of the action. We should likewise add that the protocol has also caused some delay in the case study program, since the shareholders were obligated to have it approved by their board before the signature, which may take considerably long time.\(^\text{28}\)

4. A Sound Ethical Base

EDUCEN being an EU Horizon 2020 Project, all the case studies including Istanbul had to comply with EU and national legislation, regulations but also with the ethical rules in the country where they would be carried out. This has implied seeking approval of the relevant local institution responsible from ethical issues. The conformity at the EU level was already under careful oversight of the project’s ethics advisor so have started to collect information about the existing rules at the local level. Indeed, there was a regulation on this topic according to which the Scientific and Technological Research Council (TÜBİTAK) had delegated ethics screening task to selected universities, including Koç University to which we have later sent our application.

Our second step has been to confirm that our work in Istanbul actually needed a compliance check at the local level. In fact, ethics screening in Turkey concerned only research actions, which was not EDUCEN’s official status. The latter is a coordination and support to action (CSA) project which, by definition did not (and should not) cover the research itself but the coordination and networking of projects, programs and policies. It may include, however, a very limited level of research activity that is necessary for the action’s implementation. Notably, some activities we had projected for the Istanbul Case Study could be considered as qualitative research, as in the case of the face-to-face interviews we had planned. Again, other activities like focus group meetings could also lead the way to “probing” about participants’ private life and experiences. Lastly, the collection and protection of personal data like names, addresses, phone numbers, was also an ethical consideration. Thus, EDUCEN Istanbul Case Study would effectively need a screening.

The screening process is relatively long because firstly, it requires a careful preparation, secondly the relevant committee may not be available for reviewing at the moment of submission and thirdly, the review itself takes time. In our case, the duration between the time we started preparing the submission and received the approval was as much as two months. In coordination with project’s ethics advisor, we have reviewed our plan for the case study and the methods and activities to be used, mainly by taking use of the support documents from EDUCEN consortium, as well as the extensive information provided by the Canada Government’s Panel on Research Ethics\(^\text{29}\). In this way, we have build an ethics scheme to answer all the questions of the Koç University’s Committee on

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\(^{28}\) Let us note that the length of the administrative processes prevented us from cooperating also with the Istanbul Metropolitan Municipality’s Disability Services Department within the short timeframe of the project, despite efforts from both side.

\(^{29}\) http://www.pre.ethics.gc.ca. The main document we have considered as a guideline is Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans by Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada (Ottawa, December 2014).
Human Research and elaborated the relevant material (consent forms for the participants and the list of the interview questions).

Ethical screening process may seem like a formality but in our opinion it should be seen as a critical element of any similar fieldwork, even the latter does not involve “research”. Whatever the importance of its goals or the benefits of its outcomes, such an action should also respect for human dignity and, in short, be “sensitive to the inherent worth of all human beings and the respect and consideration that they are due”. A clearly defined ethics approach that is manifested through written documents is the primary step for ensuring this condition. The next step is to seek for compliance, during which a competent, independent third party institution would confirm (or deny) the soundness of the approach. The last requirement is naturally the constant respect of the ethics scheme during and after (with respect to data protection, for example) the action.

In our view, creating and maintaining sound ethics procedures contribute to trust building among shareholders as well, by making them aware of the fact that the action they are about to join or support is subject to strict rules that would reduce -if not prevent- the risk of being exposed to any conduct degrading human worth or any breach of what they might consider as intimate or sensible. It should also be clear that the ethics scheme does not merely regulate the relationship between the leading organization (AKUT, in our case) and the other shareholders. It equally creates obligations for the shareholders towards each other.

5. Ethics of Cooperation

Even for a field action with a limited research component, submission to ethics reviewing requires a careful preparation. The submission document has to answer in detail quite a few questions about the aim and the rationale of the action, its expected outcomes and possible contributions to our existing knowledge, the selection, recruitment and inclusion of the participants, the measures to be taken in order to protect them from harm, their intended role in the action, the methods to be used for data collection and preservation, as well as for ensuring privacy and confidentiality... In fact, these questions seek to understand if the following principles have been taken into account in the design of the action:

- **Voluntariness**: The organizers and the participants should not be bounded by a dependency relationship and the potential participants shall fell no form of constraint or pressure during recruitment. The recruitment process should be transparent.
- **Informed consent**: The participants should be clearly informed about the goals and the nature of the action; of the identity of its organizers and sponsors; of its risks and benefits; on how the collected data will be used; what will be the outcomes and how these results will be disseminated. They should also be given the contact information of a third-party institution, which they would contact regarding possible ethical issues. The person has to have autonomous decision capacity (which explain why it becomes more complicated to work with minors and people with mental disability) and the consent should be given voluntarily, and should be maintained through the process: The participants have to know that they can withdraw it any time and require also the withdrawal of their data. It is also crucial that the consent is documented.
- **Privacy**: All participants shall have control over their personal information (and whatever they might consider as intimate), free from intrusion or interference by others.
- **Confidentiality**: All information entrusted by the participants shall be protected from unauthorized access, use, disclosure or modification. The necessary technical and procedural
measures shall be taken. The participants shall be informed about how their data is protected.

It is important to note that submission for ethics review should take place before the recruitment of the participants or data collection (except for preliminary activities). Clearly, the participants’ consent should also be obtained before the action starts. In the EDUCEN Istanbul Case Study, we did not have any issues with documenting it despite the fact that we worked with participants with impaired sight and with hearing impairments, for whom documents with Latin script could be partially or totally inaccessible. Let us underline that people with the mentioned disabilities have legally right to sign any documents by themselves in Turkey. Yet, as the main issue here is to obtain informed consent, and not only ensure legal compliance, we sent the consent form long to our shareholder associations long before the focus-group meetings, giving them time to have it read (and translated if necessary) by persons of trust in case they prefer to do so. Again, the consent form was read aloud before the start of the focus-group meetings (simultaneously translated by a certified translator in the case of people with total hearing loss), before signature by the participants.

The consent can be documented through other instruments such as audio or video recordings. However, it is always preferable to ask what is the participant’s own preference about it, since they can also be sensible about their right to manifest their autonomy. Also, a good practice is to use the consent for all individuals participating to the activities, including the lead organization’s staff (AKUT’s) or support persons such as sign-language translators and ensure their commitment to ethical requirements.

Another important point to note is that the right to privacy and confidentiality extends to “volatile” material as well. Voice records, still images or video recordings should also be considered as personal data and be treated as such. In practice, the consent form should inform the participants about the use of these data collection modalities and explicitly ask for their permission, including future use of the data. For example, Istanbul Case Study’s consent form has a clearly separated area where the potential participant has to indicate if he/she agrees or opposes to audio or visual recording, knowing that these can be later used for dissemination or ensuring visibility (for example in the press or social media announcements). Note that the consent form also explicitly states that the participants shall abstain from taking pictures or doing image recordings of any kind without other participants’ permission. The use of digital media and digital social networks is ubiquitous today but it should also be regulated if necessary, as in the case of our action. Both for preventing possible violations of personal rights and for complying with EU visibility rules, AKUT had been given the management of all public relations activities by the cooperation protocol. This fact has also been stated in the consent forms, in which participants were asked to consult with the CS management before doing any public relations work.

6. Organization of the Case Study Activities

Inspiring from the EDUCEN Project’s “learning loops” concept, we have planned Istanbul Case Study mainly as a “feedback loop” during which disabled and non-disabled participants would meet in order to review AKUT’s disaster preparedness material. “Updating the material” was no doubt a main goal in the action but the idea was that the material would also serve a catalyst for reflection and learning beyond what was in its content and help AKUT providing a platform for exchange between disaster volunteers and disabled citizens who have different ideas of their own about disaster and disability.
As we have noted before, the “instrument” we have chosen for building our feedback loop has been the focus group meeting, which is relatively facile to organize and monitor with limited resources. In case additional information could be needed on a specific issue, we could obtain it through semi-directive interviews or questionnaires, but we have preferred keep these options as “last resorts” in order to maintain the Istanbul Case Study as a field action and not to transform it into a research project; the objective being to develop an action feasible for other groups in the World with absolutely no research capabilities (we have realized only one interview with a visually impaired participant who had a major emergency situation experience in the past). In total, six focus group meetings have been conducted from April to August 2016 (to which we could add our meeting with Association for Vocal Description in Ankara in June).

The goal here was to organize focus group meetings with each disability group until we reach a joint understanding of what to eliminate, add, modify and besides, what to “invent” in order to develop a disability-included public disaster awareness training. Naturally, this involves working on both the content and the form, but also on the principles and guidelines underlying the training. Consequently we had not set any limit on how many iterations would be needed to reach a consensus, but as we have predicted, one ore two meeting with each disability group have sufficed: Two meetings with participants with visual impairments, two meetings with participants with partial hearing impairments, one meeting with participants with total hearing impairment and one meeting with participants with reduced mobility.

The focus groups meetings have been held in AKUT’s headquarters except two meetings. AKUT building is situated in a business district in Istanbul, to which access by subway is easy. However, the route from the metro exit to the building is barely accessible for a participant with reduced mobility, especially for a wheelchair user. Yet the real difficulty for a person with reduced mobility starts at the entrance of AKUT headquarters, which is in fact a two-storey building with a small backyard... Neither the entrance gate, nor the leveled garden, nor the interior spaces are disability-adapted. Consequently, AKUT team has been deployed to Türkiye Omurilik Felçliler Derneği’s own premises (The Spinal Cord Paralytics Association of Turkey) for the focus group meeting. The meeting with Türkiye İşitme Engelliler Derneği (Association of People with Hearing Impairment of Turkey) has been held also at this association’s location, which was in the same district with AKUT’s. In the second case, it was simply on our shareholders’ preference to realize the event in their own social space. In general, AKUT as the organizing partner has remained flexible as to the meeting schedule and venue. It is interesting to note also that the idea of meeting at AKUT headquarters has a certain attraction for the participants due to AKUT’s mission and prestige.

The shareholder associations have internally announced the meetings and invited (also incited) the members who were interested to participate. In the case of visually impaired group, we also recruited one “independent” participant who had been informed about the study through Internet and contacted us to volunteer. A second visually impaired participant also joined the study through his own contacts in AKUT. An important point is that the participants may want to come accompanied by another person without giving prior notice. In that case, if the companion’s presence was requested by the participant during the meeting, he or she also had to be asked to sign the content form and be given the same briefing about the study.

We had obtained the participants contact information prior to meetings (usually about a week before) in order to get prepared in terms of support. Four to six volunteers from AKUT’s “public training unit” have been present during the meetings that have been held at AKUT’s premises. Their contribution has proved extremely valuable not only from the conceptual side of the work but also from logistics perspective for they have taken care, for example, of participants arrival to AKUT building from the subway station and ensured their safe return the same way.
The “logistics” of the meetings itself takes much more time and effort than expected and should be carefully planned before, including the catering. The number of participants being around 11 for each meeting (min.8-max.13), we tried to include at least 2 AKUT supports staff for every 4 participant. We have had one support staff for every 3 participants in the case of people with visual disabilities who may need more guidance in a physical space they are familiar with. Thus the case study leader and the trainer (head of the public training unit as the most experienced trainer) could focus on their tasks: The first one has focused on taking minutes and moderating the discussions, while the second delivered the training. Also both have observed the progress of the meeting for a later evaluation and exchange.

Focus group meeting with participants with partial hearing impairment
After initial gathering in accordance with the time schedule, each focus group meeting has started with a reminder on the EDUCEN and the Istanbul Case Study, what was expected from these activities and how they would progress. In case it was their first iteration, the participants were also informed about the ethics framework and asked to sign the content forms; following which the review of AKUT’s disaster preparedness training has started. The main training material was a digital slide-show composed of 120 slides, which contained a small section on AKUT Association’s mission and history, then general information section on the disaster concept and existing disaster trends in Turkey, followed by three sections on earthquake, fire and flood. Although the fire is usually not considered as a catastrophe (large urban or wilderness fires excepted) it has taken an important place in the training as the secondary effect of most disasters (especially of the earthquakes) and as a potential disaster catalyst.

As conceived, the idea was to expose participants to the training as it had been delivered for the last five years (and even before, considering AKUT’s previous training material which was similar) and discuss what could be done in order to transform it into a disability-included and disability-adapted program. Note that the expected transformation would also affect all other public preparedness material like booklets and brochures. Since the presentation had been prepared for non-disabled audiences, the visuals had to be described orally as much as possible for each slide in case of the participants with visual disabilities. As for the participants with partial auditory disabilities, it has become necessary to advance with a slower pace and repeat information or replay audio-visuals from time to time. In the case of the participants with a total auditory disability, the training had to be delivered with simultaneous sign-language translation. Note that in, the training duration has differed compared to usual timing. As a result, we had to two organized second iterations with the relative groups, by dividing the seminar in two parts.
The focus group meetings have been held in a convivial atmosphere to facilitate dialogue and exchange. The participants were urged to intervene at any time. Audio recording proved to be inefficient due to the length of the activity, thus we have relied on notes taken by hand for preparing the minutes. We should note that some most interesting ideas came out during coffee breaks as well. In accordance with the ethics framework, participants’ permission has been asked before taking any live or still image. Following the meetings, minutes have been transcribed within two weeks and sent to all participants via e-mail. The idea was to leave sufficient time for reflection in case they would give additional feedback.

Our meeting with SEBEDER Sesli Betimleme Derneği (Association for Vocal Description) in Ankara worth also mentioning, although it was not a focus group meeting but a technical study visit. This encounter has given the AKUT team (case study leader, head of the public training unit, head of the information technologies unit) an occasion to grasp the concept of accessibility in the context of audio-visual production. We have discussed the role and the extent of the accessibility in the EDUCEN Istanbul Case Study and shared some of our observations so far with Sesli Betimleme Derneği’s administration. In addition, all the staff of the SEBEDER have received AKUT’s disaster preparedness training, which helped them familiarize with the disaster terminology and with the material they would be working on in a very near future.

As we will see in detail in the next section, EDUCEN Istanbul Case Study has almost transformed AKUT’s public training materials and the way the “disaster seminars” will be organized and held in the future by giving birth to a disability-adapted public material both in terms of form and content (usability limited currently to persons with hearing impairments; impairments sight and persons with reduced mobility). Using the presentation and the derived support materials will allow AKUT to reach disabled and non-disabled populations together. On the other hand, newly created “trainers’ training” materials in adapted forms will allow AKUT to recruit volunteer trainers with visual or auditory impairments. Lastly, a “disaster sign-language lexicon” for responders will help the latter improving their communication with people with hearing impairments (and therefore the effectiveness) of the response.

As of the first week of December 2016, the seminar presentation was under rework by SEBEDER for accessibility. The resulting product will also serve for the making of the others, which are expected to be ready for “test-runs” in February and for routine use in March 2017 (February for the lexicon). In a way, EDUCEN Istanbul Case Study itself may be considered as only the first iteration of a “learning loop” will never close, in the sense that new inputs by disabled participants will keep bring improvements to the public trainings and dissemination activities.
Rearrangement of AKUT’s Public Disaster Training Material

<table>
<thead>
<tr>
<th>CORE MATERIAL</th>
<th>PUBLIC TRAINING MATERIAL</th>
<th>OTHER DISSEM. MATERIALS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base Presentation*</td>
<td>Presentation*</td>
<td>Booklet</td>
</tr>
<tr>
<td>Trainer’s Narrative</td>
<td>3D tools (tactile maps, sample gas vanes, sample fuses etc.)</td>
<td>Sign Language “Booklet”</td>
</tr>
<tr>
<td>Trainer’s Guides (ethics, values, training techniques)</td>
<td></td>
<td>Audio “Booklet”</td>
</tr>
<tr>
<td>* now available in disability-adapted forms</td>
<td></td>
<td>Flyers and Posters</td>
</tr>
</tbody>
</table>

Focus group meeting with participants with reduced mobility
Focus group meeting with participants with sight impairment

7. Learning Outcomes

EDUCEN Istanbul Case Study has given birth to two distinguishable but intertwined types of learning outcomes. The first type is rather “generic”, applicable in our eyes to all disability-related actions at all levels, in the private or public sector, whether it is commercial product development or policy-making. The second type of outcomes is more specific and related to the case study. We also decided to add, as an annex, a “disability etiquette” guide that may help future users in confidently interacting with people with disabilities.

8. On the Principles: The “inner transformation”

One of the important conclusions we have reached is that inclusiveness is the key to significant results when realizing a disability-related action. Yet, inclusiveness is more than applying a set of predetermined rules in a mechanical way. In fact, we have come to believe that genuine inclusiveness in our attitude can only be possible by a genuine transformation on our perceptions towards disability. But such a change may require more efforts than one might imagine, especially if he/she was constantly exposed to a disability concept emphasizing “impairment, inability and dependency”. Still, as we have mentioned in earlier chapters of this manual, studying some contemporary resources about disability is likely to open up new perspectives for the “non-disabled” person. Encounter and interaction also play an important role in realizing the potential of the people with disabilities,
provided that the intellectual and physical barriers have been lifted to make a dialogue among equals possible.

It is certainly true that disabled persons endure more hardships than the rest of the population in many respects. However, disability is not a constant state of suffering either, as frequently affirmed by people with disabilities themselves. It is a very wide spectrum of physical and mental conditions, which are all part of the human variety, having different impacts on individuals’ lives. Despite its negative effects, which the society tends to focus on, disability becomes rarely equal to unproductivity and unhappiness (if equality of opportunity is ensured). It may also lead to experiences that the “able-bodied” people may never acquire. It is thus important to recognize the specificity of disability experience, and the value of the “life-knowledge” of people with disabilities as well. And if the recognition of people with disabilities’ capacity and knowledge is a first level in ensuring inclusivity, the second level is to guarantee that people with disabilities, as equal citizens, can take other active roles -should they prefer- than giving guidance or feedback. In our view, participation to decision making, for example, may be considered as an indicator of a high level of inclusiveness.

As for the case of EDUCEN Istanbul Case Study, we have tried to emphasize its collective aspect and make it as inclusive as possible with the help of our disabled partners. It would be hard to say that all phases of the case study have the same level of inclusiveness, such as in the preliminary stages and general design stage of the action. Nevertheless, partner organizations’ and participants’ contributions, remarks and preferences have influenced the following stages, from the organization of focus meetings to the production of the material outcomes. It is important to understand that “working for the disabled, with the disabled”, with all its challenges like inclusiveness, requires an important learning effort. We believe our first experience has rather been a satisfying one for all the shareholders but we are also aware that we still have much to improve, among other things, the physical accessibility conditions at AKUT’s premises. Surprisingly, our disabled partners were less concerned about the limits of accessibility at AKUT premises than we were, accepting that adapting the physical environment could be hard for NGO with limited means. EDUCEN experience has been an opportunity to place this issue on AKUT’s agenda, just as it has initiated a discussion on the membership policy and procedure, which have to be adapted to become disability-inclusive. In this regard, it would be appropriate to say that the Istanbul Case Study’s effects will probably extend beyond the limits designed by us.

9. On Disaster, Disability and Inclusive Disaster Preparedness Training

The following is a series of conclusions we have drawn from our observations and not the results of a systematic research, which would be out of the scope of the action. We strongly believe, however, that they can provide guidance in many disaster and disability-related situations.

- The disabled people are not more or less interested in receiving disaster preparedness information than the rest of the population. When compared to other life issues like employment or health, preparing for emergencies and disasters may not be the priority of a person with disability. Besides, a disabled person’s perception of the disasters is not disconnected from his society’s perception of the disasters and follows the existing trend (awareness, sensitivity, negligence, ignorance...) As a consequence; different types of incentives may be used to capture his/her interest.
- Not every disabled individual will need assistance during and after disasters, depending on the disability type, they can keep their autonomy just like the rest of the population, provided
that they benefit from the same level of information and material support. Again, they alone are those who know best what type of assistance they would need during and after such an event.

- It is important to ask to people with disabilities themselves what they would endure and what kind of problems they would be subjected to, during emergencies and disasters. What is considered as safe for the majority of the population may be extremely dangerous for some types of disability, as in the case of audible fire alarms which become completely useless for people with total hearing impairment if not backed by visual signals and vibration mechanisms (placed in beds, at night, for example). Another interesting example is the quasi-emergency situation caused by sudden, heavy snowfall, for people with total vision loss. The latter may experience great difficulties of orientation due to reduced echo levels from the ground and the temporary change in surface topology.

- Regarding disaster preparedness, it is vital to recognize the potential of the disabled people and not deprive them of any information provided to the general population. Our discussion on fire extinguishers with our partners with sight impairment has been an important learning moment for AKUT in this respect. In a nutshell, we have insisted on the critical importance of sight when using a fire extinguisher while some participants affirmed it was possible to point the device accurately solely by sensing the heat through their skin. We have then argued that the misuse of an extinguisher could be even more dangerous than not using it, as it would cause the fire victim to waste his/her valuable escape time. In our opinion, escape was a more efficient strategy for someone with total sight impairment in case of fire. This discussion has ended by a disabled participant’s argument on “right to information,” which we have admitted without hesitation: “A person without sight may not use a fire extinguisher as efficient as someone who can see, but he/she still has the right to know how the extinguisher is used. Once he/she possesses the information, he/she can only decide to use it or not. Besides, he/she can always guide someone else who has sight but who does not know how to use it.”

- People with disabilities themselves, who will be the “end users”, should also decide the way the information will be disseminated during the trainings and after. In our case, both the participants with sight impairment and the participants with total hearing impairment have expressed their desire to benefit from “digital resources” rather than printed ones. Their preference is explained by simple reality on the field: Both groups have access to IT tools such as computers and smartphones, as well as to Internet. Many of them are avid users of IT technologies, through which sharing the information is faster and less costly. An audio book (with audio descriptions of the visuals) is much efficient for most blind than a voluminous Braille print, just as a sign-language video book is preferable to a printed text for most sign-language users for whom our texts are difficult to grasp.

- It is interesting to note that our efforts to make AKUT’s “Community Disaster Awareness” presentation (the core material in trainings) disability-adapted have also made it easier to follow and recall for the general population (simplification of the texts, better and bigger visuals, better dubbing in video clips...). This clearly showed us the value of the “universal design” approach of which we have given the definition above. It is also definitely an advantage when designing an inclusive training, where disabled and non-disabled persons will be trained together. AKUT has adopted this approach of “mixed audience” upon suggestion by one of participants (with disability), our previous approach being producing a separate training module for each type of disability, which would literally isolate the participants with disabilities. “Mixed” trainings, on the other hand, will create an occasion for social interaction, as well as for learning especially in the sense that the non-disabled population needs to be informed about the needs but also the capabilities of the disabled participants with respect to disasters. As we have noticed during the focus group meetings and later, accessibility tools may slow down the training (as in the case of audio description), which would make it hard to
follow it for the non-disabled audience. Nevertheless people with disabilities are aware of the problem and ready to compromise provided that detailed information will be available later.

- Physical accessibility (and in many cases, transportation to training space) will likely to continue to be an important issue for the future training activities. But we hope that a disability-included training will motivate many people with disabilities to participate despite physical accessibility problems. People with disabilities are aware that total accessibility for all disability groups is an extremely hard-to-reach goal and often ready to cope with the situation provided that a minimum level of accessibility has been ensured. Yet, cooperating with other actors such as local governments, educational institutions and private actors who can offer accessibility solutions is always possible and even worth a dedicated field action.

- Disability cultures can increase the efficiency of disaster preparedness and response. It is possible to distinguish a group identity and the traits of a sub-culture in a specific disability group. If a distinct “cultural” pattern is considered as, for example, enhancing resilience, it could be integrated into disaster preparedness. One such observation we have made during EDUCEN Istanbul Case Study is the networking capability of people with hearing impairments. Thanks to contemporary technology, the latter propagate information among them much faster than one may imagine, even on the national level, which can be extremely useful in emergency situations. As for people with sight impairments, a clear tendency we have observed was to refuse external assistance and protect their autonomy as much as possible. This attitude of self-reliance is clearly opposite to what is suggested in many disaster preparedness material we have studied, in which people with sight impairments are depicted as dependent to a “support network” they should have create for disasters and similar situations. To quote one of our blind participants: “Why should I wait for some buddy who might never show up instead doing whatever necessary to protect myself?”
Annex I

The “Disability Etiquette”

Good manners for interacting with persons with disabilities are not different from the rules for appropriate behavior in the society. The reality is that the people with disabilities expect only equal treatment in that matter just as they do in other areas of the social life. Unfortunately, most “non-disabled” people lack basic knowledge on how to interact with a person with disability, consequently preferring to show either an indifferent - even rude- attitude or an exaggerated attention; thus a breach in etiquette either way.

The lack of knowledge on that matter often prevents many individuals from interacting with people with disabilities. As the Istanbul Case Study has shown to AKUT volunteers, people with disabilities are ready to give guidance on that matter. Nevertheless it is preferable to know a set of principles in advance in order to keep a natural and relaxed attitude. On the other hand, disability is a large spectrum, thus the following set of rules should not be considered as a “one size fits all” formula. Note that the following rules apply not only to “cooperation projects” like the Istanbul Case Study but also to all possible setups of social life, including disaster response!

- Do not make assumptions about a person with disability. Keep in mind that you are interacting with an (most of the time) independent adult who has his autonomy and privacy. Do not offer assistance unless requested.
- If your help is requested and you are not sure what is the best way to assist someone with a disability, do not hesitate for asking how to do.
- Be careful with your contact: In certain cases, you may unbalance a person while trying to assist her/him. Remember that physical contact depends on the contacted person’s authorization. That includes his assistive devices (cane, wheelchair or any kind of prosthesis).
- Remember to address a person with disability directly and not through someone who accompanies her/him, including a sign-language translator, just as you do with other people.
- People with disabilities have no mission like talking to you about their disability and experience, or about disability in general. If you want to break the ice, prefer your usual small talk topics.
- It is more appropriate to talk about a “person with disability” than a “disabled” or “handicapped”. Often, people with disabilities would affirm not being offended by terms like “blind” or “deaf” but it is preferable to focus on the “person” and not on his impairment.

And some tips with respect to the three disability groups we have worked with. In case you work with people with vision problems:
- A person with total or partial vision loss can very well orient herself/himself and move around and not in the need of help most times. Yet you should not hesitate to offer assistance in case you realize that he is in immediate danger.
- Always clearly identify yourself (and your function if necessary) when you encounter a person with vision loss and introduce her/him to other people around if you are in a group. Face her/him when addressing her/him. Do not talk loud unless the setting is noisy.
- It may be very useful to offer a tour of the house or the facility to a person with a significant sight loss if it is his first visit. Ensure that he feels comfortable to ask for it again in his following visits. You may also help her/him be seated. Always offer your arm; do not take his.
- Keep describing the environment and the obstacles around when walking together. Be precise when giving guidance, talk in meters.
- Be specific when giving a warning. “Be careful!” is not as useful as “Stop!”.
• A guide dog is not a “pet” but a “worker” who has to keep concentrate on its task. Do not touch it.
• You may also be helpful by reading signs, labels and documents in case these are not accessible.

For people with total hearing loss:
• Know that a sign language is a real language with its own grammar and vocabulary and not a translation of a spoken language. It is important to learn at least some courtesy words and most useful terms in sign language even if you cannot learn it to a certain level of fluency.
• For transmitting complex information, a certified sign-language translator is a must.
• Make sure you obtained the deaf person’s attention before start talking. Always look at her/him, not to the translator and remember your face expressions and gestures are part of your speech. Do not obscure your face (and lips) by your hand or other objects. You do not need to speak loud.
• Do not decide in the name of a deaf person because you cannot communicate with her/him. Thanks to the current technologies, he can reach to sign-language interpreter through video-call.

For people with a partial hearing loss (and using a cochlear implant or hearing device), the good practice is not very different. We could however add the following:
• Always speak clearly and rephrase your sentence in case the person does not understand it (mostly because he is unfamiliar with a term or expression you have used).
• A person with partial hearing loss may also require using sign language or writing depending on the situation. Respect his preference.
• In case you have difficulty of understanding the speech of a person who has total or partial hearing loss, be sincere and let her/him know. Do not pretend understanding as a “courtesy”.

People with reduced mobility are not a homogeneous group either so it is hard to draft a set of all-encompassing rules. However, it would be good to remember the following:
• An assistive device such as a walker, cane or wheelchair is part of the “private space” of its user, do not touch or try to manipulate it.
• In the case of a wheelchair user, it is appropriate to address her/him from his eye level so he would not to strain his neck. On the other hand, it is especially impolite to lean over her/him in order to, for example, talk to someone else.
• Do not push or try maneuvering someone’s wheelchair unless you are requested to do so, and you are told how to do it. Always ask before offering help otherwise you can cause an accident.
• Keep all passages and accessibility ramps open and free of obstructions all the time. If necessary, temporarily rearrange the furniture to create space for wheelchair or other mobility-device users.
• Pay attention to people’s reach limits and rearrange objects in the room if necessary in order to make them accessible.
Annex II

The transformation of the training material

The following pages illustrate an example of how the Community Disaster Awareness presentation of AKUT has been modified since 2011. The sample slide is the one where recommended personal-protective action during an earthquake (indoors) is explained. Note that the tips given have been also changed in time, to become “lay down, cover, hold” but the graphic simplification is remarkable as well. EDUCEN Istanbul Case Study has played an important role in pushing the simplification further, which resulted in not only a disability-adapted but also “universal” presentation that is easy to follow and recall for everyone.

Prior to October 2011
From October 2011 to January 2012

January 2012 to February 2013/a
January 2012 to February 2013

From February 2013 to March 2014
From March 2014 to October 2016

After October 2016 (Non-accessible EDUCEN Version)
After October 2016 (Accessible EDUCEN Version with integrated sign-language translation; also subtitles have been added to video clips)