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SPECIFIC ACTION PROTOCOL

ATHENA BEGIN: 856613 - EUROPEAN CORPORATIONS AGAINST DOMESTIC VIOLENCE TOWARDS PEOPLE WITH INTELLECTUAL DISABILITIES

WP2: DATA COLLECTION ON PROFESSIONALS NEEDS AND DEVELOPMENT OF MATERIAL FOR IMPROVEMENT OF COMPETENCES

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social cooperative activities for vulnerable groups

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1) Introduction.

The present Specific Action Guidelines is one of the outputs of the “ATHENA BEGIN” project. The project aims to offer resources and tools to professionals who assist people with intellectual disabilities victims of gender-based violence (hereafter named as GBV), namely domestic violence, and empower the victims themselves to improve their quality of life by developing their skills and personal abilities. This arises the need to identify hidden realities, to tackle them professionally and effectively, and to minimize any secondary victimization that victims/survivors may suffer during the process.

To achieve these goals, there has been a commitment to develop content to train professionals involved in the care of victims of GBV, to develop training programme(s) for prevention and guidelines for different actions. Women and men with intellectual disabilities, professionals (healthcare, psychologists, social workers, jurists, police agents, caregivers) and others (policy makers and general public) are the direct and indirect beneficiaries from the project.

It is expected that these training materials improve the competences of professionals for the protection and support of people with intellectual disabilities.

The Specific Action Guidelines in particular is an example of one of those materials. It is the product of a thorough analysis obtained from the extraction of quantitative and qualitative data previously reported and made available by each partner country (Portugal, Spain and Greece), concerning professionals and informal caregivers of people with intellectual disabilities that seek to effectively support this vulnerable group.

With these Specific Action Guidelines, the expected attainment is to make known the limitations encountered by these professionals and informal caregivers towards this vulnerable group by (1) bringing public awareness to them and by (2) presenting improvement opportunities for the gaps detected in this field of work.

For that purpose, the document has been organized in three major dimensions: recommendations, action guidelines and action areas on attention to women with disabilities, victims of GBV and domestic violence.

2) Glossary/Definitions

For the purpose of these action guidelines, the definitions below should be considered:

Gender-based violence: According to the European Institute for Gender Equality, Gender-based violence shall mean a 'phenomenon deeply rooted in gender inequality, and continues to be one of the most notable human rights violations within all societies. Gender-based violence is violence directed against a person because of their gender. Both women and men experience gender-based violence but the majority of victims are women and girls.'[1]

Domestic violence: According to Article 3b of the Istanbul Convention, domestic violence 'shall mean all acts of physical, sexual, psychological or economic violence that occur within the family or domestic unit or between former or current spouses or partners, whether or not the perpetrator shares or has shared the same residence with the victim.'[2]

People with intellectual disabilities: any natural person, regardless gender or age who have 'significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development'[3] (as provided by the World Health Organization).

Child/Young person: any natural person under 18 years of age.

Informal caregivers: According to John Hopkins Medicine, informal caregiver shall mean any person who 'gives care to family or friends usually without payment. A caregiver gives care, generally in the home environment, for an aging parent, spouse, other relative, or unrelated person, or for an ill, or disabled person. These tasks may include transportation, grocery shopping,

[1] Definition retrieved from EIGE's official website, available at: https://eige.europa.eu/gender-based-violence/what-is-gender-based-violence
[2] Definition retrieved from Istanbul Convention text, available at: https://rm.coe.int/168008482e
[3] Definition retrieved from World Health Organization glossary/definition, available at: https://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability

housework, preparing meals. Also giving assistance with getting dressed, getting out of bed, helping with eating, and incontinence.'[4]

Formal/professional caregivers: all formally educated and trained professionals who work in support structures, such as health and social care services, and are paid for the care that they provide for people with intellectual disability. The term also includes independent professionals, not linked to institutions, but who, likewise, are paid for the provision of care.

Victim/Survivors: shall mean any natural person with intellectual disabilities who is subjected to gender-based violence and domestic violence.

3) Aim and Purpose

The Specific Action Guidelines aims to raise the attention of key-actors namely professionals, agencies, policy-makers and politicians to the main gaps and urgent measures that should be taken in order to ensure that victims of GBV and domestic violence with intellectual disabilities have their rights preserved when contacting formal structures of support. To this end, the present guidelines represent an effort to provide adequate support for victims with ID and to build more suitable professional and institutional responses. These guidelines should be considered in conjunction with official documents, which at national and international levels have regulated the matter. The main relevant documents at international level are (non exhaustive list):

- The Council of Europe Convention on preventing and combating violence against women and domestic violence (Istanbul Convention);
- The United Nations Convention on the Rights of Persons with Disabilities;
- Directive 2012/29/EU of the European Parliament and of the Council which establishes the minimum standards on the rights, support and protection of victims of crime.

The Specific Action Guidelines encourages key-actors to develop cooperation and effective measures to tackle GBV and domestic violence against people with intellectual disabilities and to provide support for its victims. In the same way,

[4] Definition retrieved from John Hopkins Medicine official website, available at: https://www.hopkinsmedicine.org/health/caregiving/being-a-caregiver

encourages the specific training of professionals involved in assisting these people in order to become able to identify the abuse and victimization, as well as to recognize risk factors and act appropriately considering the specific vulnerabilities of this group.

4) Principles

This Specific Action Guidelines has the key function to inform and prepare professionals and agencies to develop responses for victims and address the specific training needs. The key actors involved in this response shall safeguard the following principles:

Intersectionality as a starting point for intervention - Meaning that each person has to be treated considering their individuality, subjectivity, contextual and social characteristics without any prejudice to promote substantive equality by providing adequate support in each particular case.

Victim-centered approach - Meaning that institutions can never instrumentalize victims and should prioritize all their specific needs and rights. Victims' interests have to orient intervention.

Multi-agency approach - Meaning that vulnerable groups have specific and multiple needs. To address them adequately, professionals and agencies from different specializations must work collaboratively to meet their needs within a reasonable time.

Awareness and specific training needs - Meaning that all professionals responsible for providing support to victims with intellectual disabilities should be aware of the specificities of this vulnerable group and have specific training on this matter. Agencies have the duty to train their professionals in this regard adequately.

5) Recommendations on attention to people with intellectual disabilities, victims of GBV and domestic violence.

Gender-based violence (GBV) encompasses several forms of abuse which affect women and girls disproportionately such as rape, sexual exploitation, sexual

harassment, genital mutilation and domestic violence. GBV against women is a pervasive form of human rights violation, affecting 1 in 3 women worldwide (WHO, 2013). The everyday risk is especially experienced by women with disabilities, since evidence shows that abuse is more frequent against this vulnerable group (FRA, 2014; Dunkle, Van Der Heijden, Stern, & Chirwa, 2018). In this regard, it is essential to mention that women with intellectual disabilities are equally exposed to the same forms of violence than women without identified disabilities. However, the "additional vulnerability factor" (as referred by Nosek, Foley, Hughes, & Howland, 2001, p. 186) creates some particular forms of violence which only affect women with disabilities, since that is intrinsically related to their limitations and healthcare needs (Walter-Brice, Cox, Priest, & Thompson, 2012).

The aforementioned research confirms that those professionals ought to address this group considering their vulnerabilities and challenges. Upon such reality, recommendations can be taken into account to better meet this group's needs and their professionals'.

The work carried out throughout the ATHENA BEGIN project so far has brought light into the glitches experienced by professionals, be those caregivers (formal and informal), psychologists, elements of the medical and police bodies, or other indirect parties; and by victims. Moreover, the focus has now been set on how these glitches can be transformed into improvement opportunities or recommendations to this field of work seeking to mitigate further repercussions upon victims and professionals.

Recommendations ought to be considered in two different modules: (a) professionals, whereas one can include formal and informal caregivers, bodies from the police force, psychologists, and other entities/individuals whom partake in the direct and/or indirect contact with victims of domestic violence with intellectual disability. This module is more training oriented. In a more small segment, module (b) whereas victims of domestic violence with intellectual disability are to be concluded. This module is more intervention oriented.

(a) Professional oriented.

In regards to professional oriented recommendations, adequate training has been significantly highlighted and reckoned by professionals themselves. They are the first in line to identify that, indeed, they lack the training to cope with a wide range of challenges brought by vulnerable populations such as people with intellectual

disabilities, especially in cases of gender-based violence, more particularly, domestic violence. In this framework, training insufficiencies have been detected in different contexts. Regardless of their line of work (health care, police force, law, or other), training ought to be implemented early on in the academic life, enduring throughout their professional career, as long as the appointed professional is set to have contact with people with intellectual disabilities.

The need for proper monitoring starts early on, when soon-to-be parents are informed that their child carries some level of disability. Training in this area would enable parents to receive some guidance in terms of what can be expected throughout the parenthood journey, preventing them from experiencing feelings of helplessness and despair. Professionals ought to be trained to provide information on the existing degrees of disability, furthermore, on what these degrees actually signify in terms of behavior and cognitive abilities throughout the child's stages of growth. Adolescence, for instance, can be a more challenging stage, moreover, if one considers a person with intellectual disability, as it awakens parents to a wide range of possibilities to which they (and professionals) lack preparation for. In regards to sexuality, for example, training is absent. Even worst is the fact that people with intellectual disabilities are somewhat seen as asexual beings, so much that, when they manifest sexual behaviors and interests, these tend to be disregarded. Training in this area of knowledge would help parents offer proper guidance to children with intellectual disabilities on what is acceptable and what is not in regards to intimate contact, more importantly, working on a more preventive level.

The lack of training in the framework of the existing degrees of disability and respective repercussions is also experienced by professionals from other lines of work, such as police forces and caregivers (formal and informal) who have testified their inability to understand to what extent their message is being fully received by its receptor.

The main difference between the population with and without intellectual disabilities in the expression of mental health problems lies in the greater use of behaviour as a method of expression of psychiatric symptoms by individuals with intellectual disabilities. The concept of "behavioural equivalent" refers to the expression of psychiatric symptoms through behaviour. The greater expression of "behavioural equivalents" among individuals with intellectual disabilities is undoubtedly due to their communication problems. This communicational posture may

present itself as a barrier in terms of risk assessment and it is imperative to find mechanisms to overcome it.

Adequate instruments would also be necessary in this sense, nevertheless, the inadequacy of instruments for risk assessment is another experienced reality. The current instruments were thought out to people without intellectual disabilities hence the reason why professionals, failing to find better resources to assist this group, are left with a limited number of instruments to which they can resort to but none of them adequate for the assessment of conditions amongst people with intellectual disabilities. The condition of the recipient is disregarded (intellectual disability), the condition in need of assessment is prioritized (violence). The development of instruments thought out for people with intellectual disabilities, allied with the improvement of better communication skills, ought to be seen as a priority since it represents (1) the quantitative gateway to the client's condition and (2) a primary tool towards the identification of signs amongst children, adolescents and adults. Nonetheless, a holistic approach is not to be disregarded. In fact, it is quite the opposite. A holistic approach is highly recommended as it would allow a more comprehensive understanding of the events.

The aforementioned training essentials are thought to exponentiate upon the development of multidisciplinary teams and consolidation of existing networks. An open channel with solid communication procedures exchanged would have to exist amongst the different working cells (health care, medical institutions, police stations, psychology offices, and others), working towards the increase of both recovery and prevention stages and, consequently, assuring higher levels of protection towards victims of GBV, moreover, domestic violence, with intellectual disabilities. To standardize the exchange of information and *modus operandi* between the different working cells, a specific protocol of responses would be of key significance. A common protocol of responses for cases of GBV – domestic violence – towards people with intellectual disabilities that takes into account the ethical principles of the client and walks towards the deconstruction of ingrained stereotypes, prejudiced approaches.

This set of recommended training skills could help shed some light and helpful guidance towards the ease of human and emotional burdens carried out by professionals who work with this vulnerable group, consequently shutting the doors that leads to emotional exhaustion and burnout.

(b) Victim oriented.

Victim oriented recommendations endorsed a more personalized intervention.

From the professional standpoint, people with intellectual disabilities experience the ongoing disregard of their speech. This reality finds its foundation in the belief that disability is often associated with the impossibility to provide a reliable testimony. In cases of domestic violence, where victims with intellectual disabilities are involved, this posture is even more noticeable. At this stage, the recommendation is that, just as with people without disabilities, professionals are able to detach from the disability factor without failing to offer a proper intervention from the voice validating standpoint.

In cases where the victims are somehow prevented or incapable of providing a speech, the recommendation was that these victims ought to have - or to be provided with - a voice facilitator. A voice facilitator can be a trained professional or an informal caregiver (family member or similar) who will give voice to the victim with intellectual disability, while defending their rights and taking their interests at heart.

Also noticeable was the fact that people with intellectual disabilities are often approached with childlike attitudes, be them from relatives or from professionals (such as police officers when they are collecting an intellectually disabled victim's testimony). This kind of posture feeds stereotypical behaviors and indoctrinates beliefs that prevent people with intellectual disabilities from enduring a full life experience. A voice facilitator can embody a key role in tearing down these childlike attitudes and enabling the victim with intellectual disability to have her/his experience as well as her/his testimony validated. The recommendation is that services of all lines of work are *equipped* with such a person in order to:

(1) bring awareness to the person with intellectual disability that she/he was a victim of violence (in some cases, when people with intellectual disabilities are victims of domestic violence, they are not conscious of it, not of their victim status);

(2) bridge the existing communicational gap that prevents victims of domestic violence with intellectual disabilities from having their voice heard.

Professionals are recommended to foster a relationship of trust and an environment of security, not only for the victim, but also, for the respective families. This happens because both victims of domestic violence with intellectual disabilities and their families have reported experiencing feelings of judgement and prejudice from bodies that were meant to offer an environment of understanding. The aforementioned

conditions are even more fruitful when the acquainted professional is able to set in motion his/her active listening skills.

Deterioration of the inequalities experienced by the victim and encouragement of the professional to opt for a common approach is the main goal.

6) Proposed model of joint protocol for agency providers and key-actors

In order to provide practical orientations and guidelines regarding victim assistance and professionals needs, the Specific Action Guidelines elaborated under the scope of Project ATHENA, encourages agency providers and key-actors to establish protocols with minimum standards for intervention with this specific vulnerable group to avoid secondary victimization and to ensure their safety and rights. In the same way, investing in capacity building can be a key for a more victim-centered approach and effectiveness of the intervention.

In this way, the Specific Action Guidelines provided a set of recommendations oriented both for the victims needs as well as for professional needs. Such recommendations should be turned in practice through protocols for action between agencies at country-level taking special attention to the geographical scope of this commitment, since victims with intellectual disabilities have the right to be assisted in the same standards of quality whenever they live. Geographical location can not be a barrier for finding help. Protocols should include a broadly scope of agencies, in a way to create an effective multi-agency approach towards the responses for people with intellectual disabilities. The multi-agency approach is a mandatory principle considering that in this specific group, the disabilities can require the assistance of professionals from different expertise and the networking and partnership across sectors can increase the quality of services provided. It is also important to consider that Academic Authorities and Universities could be interesting partners to be involved in the protocol since professionals refer to the lack of academic specific training as a barrier to better performance when dealing with intellectual disabilities.

Considering all recommendations and topics mentioned, the Specific Action Guidelines proposes a model of joint protocol for agency providers and key-actors, including specific roles and responsibilities for each signatory partner.

- **Joint protocol (scope, roles and responsibilities)**

I - Scope: All signatory parties are committed to applying jointened and coordinated efforts to offer the appropriate support for people with intellectual disabilities who are victims of gender-based violence and domestic violence. In the same way, partners are committed to invest resources in capacity building to tackle the main gaps in professional's training needs. The proposed protocol applies to all signatory parties and produces immediate effects. The protocol encompasses specific measures that should be implemented regardless of prejudice in all structures involved. The signatory parties are committed to making available all the resources and technical means necessary to carry out the proposed measures.

II - Roles and responsibilities:

(a) Victim oriented measures: The signatory parties shall be committed with a victim-centered approach. All the necessary means should be applied to ensure victims safety and rights, as well as their family members, namely children. The signatory parties shall be aware that effective measures includes, among other measures:

- Victims' rights to understand and be understood by professionals and all necessary means should be applied to ensure effective communication;
- Provide adapted and accessible structures/facilities for victims and their families;
- Specific instruments for risk assessment for people intellectual disabilities should be developed and applied by the signatory parties;
- Safety-plan should be established in articulation with police forces and informal caregivers;
- A relationship of trust with the victims and informal caregivers is crucial, this way, all the communications and the support should be provided by the same professionals during all the intervention.

(b) Professional oriented measures: The signatory parties shall be committed with capacity building. All the means should be applied to

ensure that all professionals who deal with people with intellectual disabilities victims of gender-based violence and domestic violence have the adequate training to recognize victimizations and to provide support for such vulnerable groups. The signatory parties shall be aware that effective measures includes, among other measures:

- Planning and executing training sessions with professionals involved in support for victims with intellectual disabilities, namely those who work in the first line responses;
- Monitoring the intervention and ensure that a multi-agency approach in implemented when needed;
- Implement efforts to monitor and prevent work overload, namely using appropriate work schedules to avoid burn out;
- Provide psychological support for professionals when needed;
- Invest in general resources and facilities to enable better working conditions.

7) Clues for Intervention - additional and practical insights for professionals

European Strategy for the Rights of Persons with Disabilities 2021-2030 has outlined four main axes for development across Member States: accessibility; independent life; job; including education. All countries that have signed the United Nations Convention on the Rights of Persons with Disabilities have committed to reducing existing barriers and dangers that withdraw people from their rights and freedom. Article 8º of the United Nations Convention on the Rights of Persons with Disabilities calls for greater awareness with the aim of promoting respect for the rights and dignity of people with intellectual disabilities, eliminating prejudice against them, valuing their skills and competences. In order to give effectiveness to this objective, educational measures must be taken, with targeted training in the education system, raising awareness with campaigns and media coverage.

Likewise, article 21º emphasizes that people with intellectual disabilities / multi-disabilities must have access to technologies using adequate communication and receive information in accessible formats and in a timely manner and at no additional cost. Both organizations and the media should be encouraged to provide information in a way that makes it accessible to all.The American Psychological Association (2015) and the American Association for Intellectual Disabilities and Development (2018)

recognizing gaps in training professionals developed a set of guidelines/recommendations for professionals, namely:

- Fundamental knowledge and awareness.
- Understand that intellectual disability is not just the person with disabilities but their interaction with multiple factors that influence their expressions, recommend a multiple perspective approach to risk factors that incorporates associated risk factors, allowing a variety of identity perspectives of the intellectual disability.
- Understand that people with intellectual disabilities and guidelines are distinct constructs, but interrelated if the risk is identified through specific support strategies to prevent, mitigate or mitigate that risk improving the functioning and well-being of the person with Intellectual Disabilities.
- Be aware of how attitudes and knowledge about intellectual disability affect the quality of care that professionals provide to people with disabilities and their families.
- Incorporating a justice perspective in the field of intellectual disability can influence the development of policies and practices to improve laws and human rights.

(a) Stigma, discrimination and barriers to care

- Recognize how stigma, prejudice, discrimination and violence affect the health and well-being of people with intellectual disabilities;
- Recognize the influence of institutional barriers in the lives of people with intellectual disabilities and help the development of affirmative contexts;
- Understand that it is necessary to promote social change to reduce the negative effects of stigma on the health and well-being of people with intellectual disabilities

(b) Development of a satisfying life

- Understand the differences in the development and needs of children and adolescents, as well as knowing that not all young people have equal adaptive and intellectual functioning
- Understand the specific challenges of resilience experiences that adults, elderly people with intellectual disabilities can develop, with support in the dimensions of their human functioning.

(c) Evaluation, therapy and intervention.

- Use the concept of human functioning as a measurable indicator of health.
- Recognize that people with intellectual disabilities are more likely to have positive experiences in their lives when they are properly supported.
- Understand how parenting and family formation of people with intellectual disabilities are variable.
- Recognize the potential benefits of interdisciplinary approaches when providing support to people with intellectual disabilities and working in collaboration with other care providers.

(d) Research, education and training

- Respect the well-being and rights of participants with intellectual disabilities in investigations and present results accurately to avoid misuse or misrepresentation of these
- Prepare other professionals for specific interventions with people with intellectual disabilities.

(e) Addressing the gaps in National Laws

Spain, Greece and Portugal and other European countries have created plans and programs to combat domestic and gender-based violence, however it appears that very little has been done in relation to people with intellectual disabilities. Therefore, more effective action plans or measures must be adopted to improve the

protection of women, children and men with disabilities. It is crucial that Governments develop specific laws and policies to protect people with intellectual disabilities.

(f) Cooperation between state institutions and non-governmental organizations

It is intended to change the fundamental political paradigm with a self-determined perspective on life for people with disabilities. However, violence against women with disabilities has increased and reveal that work, activism and political advocacy for women with disabilities has not been enough to defend these women.

- Tackle gender-based violence and domestic violence, eliminating taboos, creating support networks, and taking into account specific gender aspects - these are the objectives of the focus area Domestic violence among people with disabilities.
- Empowering Individuals and their Families
- Promote the transversal and integrated vision of the various active agents on the issue of Domestic Violence and gender-based violence
- Creation of a Facilitator who supports and accompanies the victim with intellectual disability.
- Specific shelter houses for people/women with intellectual disabilities.

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